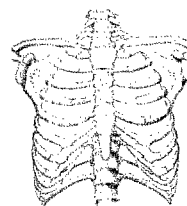
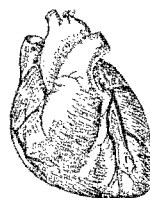
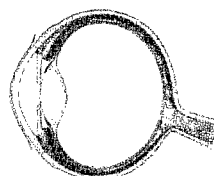


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Handbook of

# Human Tissue Sources



A National Resource  
of Human Tissue Samples

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Elisa Eiseman  
Susanne B. Haga

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## PREFACE

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One aspect of the recent and rapid advances in biological and medical research is that human tissue is being used in an increasing variety of new ways. Now that techniques exist to extract DNA from minuscule archival samples, including frozen blood or tissue samples and even paraffin-embedded tissue blocks, genetic tests could potentially be performed on virtually any size stored tissue sample. These technological advances, which have been so instrumental in recent biomedical discoveries, have also raised several legal, ethical, and societal issues, including concerns about privacy and informed consent.

To assist in their examination of the issues associated with the use of stored tissue samples, the National Bioethics Advisory Commission (NBAC) requested information about the magnitude of the existing archives of tissues in the United States from the Science and Technology Policy Institute at RAND. The commissioned report represented the first inventory of stored tissue sample repositories in the United States. The report provided information about major tissue storage facilities and information about several aspects of stored tissue samples, such as how many tissue samples exist in the United States, where they are, who has access to them, and for what purposes they are used. This handbook is an extension of the NBAC-commissioned report and represents a comprehensive inventory of stored human biological materials in the United States. The handbook is the first of its kind and should be extremely useful to scientific researchers throughout the world.

Originally created by Congress in 1991 as the Critical Technologies Institute and renamed in 1998, the Science and Technology Policy Institute is a federally funded research and development center sponsored by the National Science Foundation and managed by RAND. The institute's mission is to help improve public policy by conducting objective, independent research and analysis on policy issues that involve science and technology. To this end, the institute

- Supports the Office of Science and Technology Policy and other Executive Branch agencies, offices, and councils

- Helps science and technology decisionmakers understand the likely consequences of their decisions and choose among alternative policies
- Helps improve understanding in both the public and private sectors of the ways in which science and technology can better serve national objectives.

Science and Technology Policy Institute research focuses on problems of science and technology policy that involve multiple agencies. In carrying out its mission, the institute consults broadly with representatives from private industry, institutions of higher education, and other nonprofit institutions.

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## SUMMARY

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In the United States, human tissues have been stored for more than 100 years. Some institutions in the United States have archived specimens of human tissues that are more than 100 years old. Historically, these stored tissue samples have been used by the biomedical community for educational and research purposes. More recently, stored tissues have played a major role in the understanding and treatment of such diseases as cancer, HIV/AIDS, and heart disease. However, the use and storage of human tissues raises several legal, ethical, and societal issues. Furthermore, as recent and rapid advances in biological and medical research have made it possible to analyze DNA from almost any minuscule sample of human tissue, concerns about privacy and informed consent have been raised. Complicating these issues is the paucity of information addressing tissue acquisition, use, and storage.

To date, no central database captures information about stored tissue samples. Therefore, the National Bioethics Advisory Commission (NBAC) initially requested information about stored tissue samples in the United States for its report on research involving human biological materials to obtain a better understanding of the magnitude of existing archives. This handbook is an extension of that report, and its purpose is to collect for the first time, in a single document, information about tissue storage in the United States. It also provides information about several aspects of stored tissue samples, such as how many tissue samples exist in the United States, where they are, who has access to them, and for what purposes they are used. The completion of this handbook coincides with the recent release of NBAC's final report, "Research Involving Human Biological Materials: Ethical Issues and Policy Guidance." (NABC, 1999.)

A conservative estimate from the tissue collections described in this book is that more than 307 million tissue specimens from more than 178 million cases are stored in the United States, accumulating at a rate of more than 20 million per year. These tissue collections vary considerably, ranging from formal repositories to the informal storage of blood or tissue specimens in a researcher's

freezer. Archives of human tissue range in size from fewer than 200 to more than 92 million specimens.

The two largest tissue repositories in the world, the National Pathology Repository and the DNA Specimen Repository for Remains Identification, are housed within a single institution, the Armed Forces Institute of Pathology (AFIP). These two repositories alone store more than 94 million specimens. The tissue repositories supported by the NIH are not as large as those at AFIP, but the NIH is probably the largest funder of extramural tissue repositories, supplying more than \$53 million in fiscal year 1996. Finally, the pathology departments at graduate medical education (GME) teaching institutions collectively constitute the largest and oldest stores of tissue samples in the United States with some specimens more than a century old.

The vast majority of tissues were originally collected for diagnostic or therapeutic reasons. Three sources, the AFIP National Pathology Repository, GME teaching institution pathology departments, and newborn screening laboratories, represent more than 265.5 million diagnostic and therapeutic specimens from more than 176 million cases. Tissues collected for diagnostic or therapeutic reasons can sometimes be used for research, educational, and quality-control purposes, but the vast majority are not.

Several repositories have been established specifically for research. In addition, several very large longitudinal studies collect and bank samples from their study participants. Likewise, a fair amount of research simultaneously creates tissue collections or contributes to tissue banks. Collectively, these tissue collections contain more than 2.3 million specimens. Because these tissues are collected specifically for research purposes, it is not surprising that the use of these tissues has resulted in numerous research publications.

Other than for diagnostic and therapeutic purposes or for use in research, tissues are collected and stored for a variety of reasons. Blood banks collect approximately 12 million units of blood a year, but only about 20,000 to 40,000 units are stored at any one time. Also, most of the blood collected is used for transfusions, and very little is used for such other purposes as research and quality control. Organ banks do not collect the same volume of tissue that blood banks do but are very similar in the respect that most of the organs and tissues collected are used for transplants, and very little is available for research. Forensic DNA banks collect and store tissues for use in criminal investigations. The DoD DNA Specimen Repository and some commercial DNA banks store DNA samples for remains identification. Sperm, ovum, and embryo banks store specimens for anonymous donation or for later use by the individual storing the material. Umbilical cord blood banks also store blood for anonymous donation and later use by families banking their newborn's cord blood.

Many valuable specimens and data resources exist from a variety of sources, but no centralized database allows researchers to obtain access to and information about them. This RAND handbook brings together information about several sources of stored tissue samples in the United States. It represents the first time that this information has been assembled in a single publication and the first time the magnitude of the archives of stored tissues has been assessed. This handbook may serve as a reference for researchers to identify potential tissue resources. It may also serve as a basis for developing a national database. This handbook will be a valuable resource for researchers who require tissue samples for studies in genetics, cancer, immunology, physiology, and cell biology, among other disciplines. In addition, this handbook will be useful to policymakers, physicians, and other health-care professionals.



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## ABBREVIATIONS

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ACTG	AIDS Clinical Trials Group
ADA	American Diabetes Association
AFDIL	Armed Forces DNA Identification Laboratory
AFIP	Armed Forces Institute of Pathology
AIDS	Acquired Immune Deficiency Syndrome
ALL	Acute lymphoblastic leukemia
AMB	AIDS Malignancy Bank
AM-CTC	AIDS-Malignancy Clinical Trials Consortium
AML	Acute myelogenous leukemia
ARC	Alzheimer's Research Center
ARNC	Army-Navy Serum Repository
ART	Assisted reproductive technology
ASCO	American Society of Clinical Oncology
BBDR	Benign Breast Disease Registry
BTR	Breast Tissue Repository
CALGB	Cancer and Leukemia Group B
CAP	College of American Pathologists
CBCTR	Cooperative Breast Cancer Tissue Resource
CCCBB	Chicago Community Cord Blood Bank
CCG	Children's Cancer Group
CCOP	Community Clinical Oncology Program
CDC	Centers for Disease Control and Prevention
cDNA	Complementary DNA (deoxyribonucleic acid)

CFRBCS	Cooperative Family Registry for Breast Cancer Studies
CGOP	Cooperative Group Outreach Program
CHR	Center for Health Research
CHTN	Cooperative Human Tissue Network
CJD	Creutzfeldt-Jakob disease
CLIA	Clinical Laboratory Improvement Amendments
CLSS	Central Laboratory Services Section
CME	Continuing Medical Education
CMV	Cytomegalovirus
CNS	Central nervous system
CNSC	Central Nervous System Consortium
CODIS	Combined DNA Index System
CPP	Collaborative Perinatal Project
CRISP	Computer Retrieval of Information on Scientific Projects
CTI	Critical Technologies Institute
DIEP	Diabetes in Early Pregnancy Study
DISC	Diet Intervention Study in Children
DNA	Deoxyribonucleic acid
DoD	Department of Defense
EBV	Epstein-Barr virus
ECOG	Eastern Cooperative Oncology Group
EPA	Environmental Protection Agency
EST	Expressed Sequence Tag
FASEB	Federation of American Societies for Experimental Biology
FBI	Federal Bureau of Investigation
FDA	Food and Drug Administration
GIVF	Genetics and IVF Institute
GME	Graduate medical education
GOG	Gynecologic Oncology Group
GVHD	Graft versus host disease

H&E	Hematoxylin and Eosin
HBDI	Human Biological Data Interchange
HD	Hodgkin's disease
HHANES	Hispanic Health and Nutrition Examination Surveys
HIV	Human Immunodeficiency Virus
HIVNET	HIV Network for Prevention Trials
HNPCC	Hereditary Nonpolyposis Colorectal Cancer
IRB	Institutional Review Board
IRS	Intergroup Rhabdomyosarcoma Study
MACS	Multicenter AIDS Cohort Study
MBC	Maryland Brain Center
MGH	Massachusetts General Hospital
MRFIT	Multiple Risk Factor Intervention Trial
MSSM	Mount Sinai School of Medicine
MTS	Mid-America Transplant Services
NBAC	National Bioethics Advisory Commission
NBSB	National Biomonitoring Specimen Bank
NCHS	National Center for Health Statistics
NCI	National Cancer Institute
NEOB	New England Organ Bank
NHANES	National Health and Nutrition Examination Surveys
NHATS	National Human Adipose Tissue Survey
NHES	National Health Examination Surveys
NHL	Non-Hodgkin's lymphoma
NHLBI	National Heart, Lung, and Blood Institute
NHMP	National Human Monitoring Program
NIA	National Institute on Aging
NIAID	National Institute of Allergy and Infectious Disease
NICHD	National Institute of Child Health and Human Development

NIDDK	National Institutes of Diabetes and Digestive and Kidney Diseases
NIGMS	National Institute of General Medical Sciences
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Diseases and Stroke
NIST	National Institute of Standards and Technology
NNRSB	National Neurological Research Specimen Bank
NPF	National Psoriasis Foundation
NPTB	National Psoriasis Tissue Bank
NSABP	National Surgical Adjuvant Breast and Bowel Project
NWTSG	National Wilms Tumor Study Group
NYBC	New York Blood Center
OCT	Optimum cutting temperature
OSU	Ohio State University
PCBs	Polychlorinated biphenyls
PCI	Pittsburgh Cancer Center
PCNA	Proliferating cell nuclear antigen
PCO	Pathology Coordinating Office
PCOS	Polycystic ovary syndrome
POG	Pediatrics Oncology Group
PPH	Primary pulmonary hypertension
PPT	Polyp prevention trial
PSA	Prostate-specific antigen
R&D	Research and development
RMMSC	Rocky Mountain Multiple Sclerosis Center
RTOG	Radiation Therapy Oncology Group
SCOR	Specialized Centers of Research
SEER	Surveillance, Epidemiology, and End Results Program
SHSF	Split hand/split foot

SPORE	Specialized Program of Research Excellence
SWOG	Southwest Oncology Group
TPSR	Tissue Procurement Shared Resource
TRP	Translational Research Program
UAREP	Universities Associated for Research and Education in Pathology
UCCC	University of Colorado Cancer Center
UCSF	The University of California at San Francisco
UMCC	University of Michigan Cancer Center
UNOS	United Network for Organ Sharing
UPMC	University of Pittsburgh Medical Center
VA	Department of Veterans Affairs
VAMC	Veterans Affairs Medical Center
WHI	Women's Health Initiative
WIHS	Women's Interagency HIV Study
WITS	Women and Infants Transmission Study

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Chapter One  
**INTRODUCTION**

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Human tissues have been stored for a long time. Some institutions in the United States have archived specimens of human tissues that are more than 100 years old. Historically, these stored tissue samples have been used by the biomedical community for educational and research purposes. More recently, stored tissues have played a major role in the understanding and treatment of such diseases as cancer, HIV/AIDS, and heart disease. However, the use and storage of human tissues raise several legal, ethical, and societal issues. Furthermore, as recent and rapid advances in biological and medical research made it possible to analyze DNA from almost any minuscule sample of human tissue, concerns about privacy and informed consent have been raised. Complicating these issues is the paucity of information addressing tissue acquisition, use, and storage.

Once removed, human tissue may serve many beneficial purposes. The most familiar and widespread use of human tissue is in the diagnosis and treatment of illness. Another common use of human tissue is for quality-control purposes in diagnostic and pathologic laboratories. Human tissue is also used for medical and biological research and for medical education and training. Other uses of human tissue include identification, such as in paternity testing, cases of abduction or soldiers missing in action, and forensic purposes in crime cases when biological evidence is available for comparison.

The most common source of tissue is from patients following diagnostic or therapeutic procedures. Tissue specimens may also be taken during autopsies performed to establish the cause of death. In addition, volunteers may donate blood or other tissue for transplantation or research, organs for transplantation, or their bodies for anatomical studies after death. Each specimen of human tissue can be stored in multiple forms, such as slides, paraffin blocks, formalin-fixed, frozen, tissue culture, or extracted DNA.



## HISTORICAL PERSPECTIVE

The development of the use of human biological materials for research has been a slow process. Early Egyptians did not study the deceased human body for an explanation of disease and death, though some organs were removed for preservation. The Greeks and Indians cremated their dead without prior examination. The Romans, Chinese, and Muslims all held various taboos and beliefs against opening the body for examination, and thus, no study of human organs or tissues occurred in these societies. Human dissections were also not permitted in Europe during the Middle Ages.

The first real dissections for medical study of disease were carried out around 300 B.C. by Alexandrian physicians Herophilus and Erasistratus. In the late second century A.D., the Greek physician Galen was the first known person to correlate a patient's symptoms with what was found upon an internal examination of the "affected part of the deceased." Greek medicine was essentially the beginning of human medical study based on scientific investigations and observations. Medicine before the Greek advances was almost entirely confined to religious beliefs and rituals. Disease was considered a result of divine interference and human sin, and the maladies of those unlucky individuals were "treated" with spells and prayers.

During the Renaissance, the artists rather than the anatomists were intent on rendering an accurate picture of the human body. Leonardo da Vinci performed dissections and extensive analysis on the human body during the late 1400s and early 1500s. The study of human organs and tissues began to take hold in the nineteenth century. Early biologists viewed their work as a study of the organism. The German pathologist Rudolf Virchow introduced the cellular doctrine, which viewed changes in cells as the basis of the understanding of disease, through his work in pathology and autopsy. In 1838, Theodor Schwann and Matthias Schleiden announced their cell theory that postulated cells as the basic unit of all living tissues.

In 1912, scientists performed an experiment that demonstrated that cells could be kept alive indefinitely if proper conditions were maintained. The advent of transplantation surgery in the mid-twentieth century spurred organ donor programs and organ banks as the technology advanced for specific organs. It was found that without a blood supply, organs would deteriorate rapidly, although cooling could slow the deterioration process somewhat. Blood cells, spermatozoa, and certain other dissociated tissue cells were found to survive subzero freezing indefinitely. Special preserving fluids were shown to prevent cell destruction by ice crystals, but, unfortunately, these fluids have damaging effects if introduced into whole organs. Long-term storage and banking of organs seems unlikely in the near future, because preservation techniques for

heart, liver, and lung have not been extensively studied (the kidney can be preserved up to 72 hours).

Several historical examples have demonstrated the value of archived tissue samples. For example, research in tracking viruses and studies tracing the pathology of a particular disease have been extremely beneficial to medical research (NBAC, 1999). A recent case involved the rediscovery of slides stored by Alois Alzheimer and the confirmation of his original diagnosis by histological and genetic analysis (Graeber et al., 1997; 1998). Slides of the first brain known to have Alzheimer's disease were stored in 1906, and a paper was published in 1907 describing the disease. The search for the brain of patient Auguste D. began when her original hospital file was found in 1996 at an institute at the University of Frankfurt. In 1998, more than 250 slides of Auguste's brain were found in a basement at the University of Munich, where Alois Alzheimer worked at the time of her death. The reexamination of the slides clarified the definitive pathologic diagnosis of Alzheimer's disease.

### **TYPES OF TISSUE/ORGAN BANKS**

Tissue collections vary considerably, ranging from formal repositories to the informal storage of blood or tissue specimens in a researcher's freezer. The form in which the tissue is stored can also vary widely, including solid organs, sections of organs, histology slides, cells, and DNA. Large collections include archived pathology samples, autopsy material, and tissue biopsies from diagnostic tests. These tissue samples are stored at military facilities, the National Institutes of Health and its sponsored facilities, other federal agencies, state collection agencies (e.g., state forensic DNA banks and newborn screening laboratories), diagnostic pathology and cytology laboratories, university- and hospital-based research laboratories, commercial enterprises, and nonprofit organizations.

### **USES OF TISSUE/ORGAN BANKS FOR BIOMEDICAL RESEARCH**

A common use of stored tissues was to correlate changes in structure or appearance of a tissue with a diagnosis of a particular disease. Pathology exams were performed broadly with what could be seen by the naked eye and eventually with the light microscope. As the understanding of science advanced, tissue analysis was reduced to a smaller scale. Molecular biology and genetics research has minimized the need for viably stored tissue. Frozen tissue, paraffin blocks, or formalin-fixed tissue is sufficient for the study of protein and gene expression and genetic mutations. Research of tissue samples has evolved toward a much smaller scale, where once a large portion of an organ may have been required for study, a single slice or a million cells is now more than suffi-

cient to answer a researcher's question. Thus, a single freezer could store a lifetime of research samples on a particular tissue or disease.

Different areas of research that routinely use tissue samples include studies of gene or protein expression, initial analysis of tissues affected by a newly discovered viral or bacterial pathogen, studies of changes in genetic sequences over time or in different populations, genetic linkage studies in normal and affected populations to narrow the location of the mutant gene, and analysis of cell structure in affected and normal tissue. The older a tissue bank is, the more valuable it may be to ascertain changes over time as environmental or societal shifts occur. The need to achieve statistical significance requires large sample numbers, and thus researchers may need to use tissue samples from a number of different banks. The ongoing need for tissue samples in research calls for a handbook, such as this, to facilitate the process of finding particular tissues for research. Both public and private entities use tissue samples for both academic and commercial enterprises. The savings in time and money of avoiding collection of tissues for each new research study is invaluable to the researcher in an environment where both are scarce.

## **AN INVENTORY OF TISSUE SOURCES IN THE UNITED STATES**

To date, no central database captures information about stored tissue samples. To obtain a better understanding of the magnitude of existing archives, the National Bioethics Advisory Commission (NBAC) initially requested information from RAND about stored tissue samples in the United States. The purpose of the report was to collect for the first time in a single document information about tissue storage in the United States. Although it was not meant to be a comprehensive inventory, the report identified the major sources of stored tissue. This handbook is an extension of the NBAC commissioned report and is meant to serve as an inventory resource of stored tissue samples in the United States. The abundance of such samples in the United States is essentially useless to scientific investigators unless they are aware of its existence and its availability. The report as well as this handbook attempts to provide information about several aspects of stored tissue samples by addressing the following questions:

1. Where are tissues stored? (e.g., repositories, pathology laboratories, blood banks)
2. How many tissue samples are stored at each institution?
3. Who are the sources of stored tissue samples? (e.g., patients, volunteers)
4. Why were the tissue samples originally collected? (e.g., diagnostic purposes, research)

5. For what purposes have the stored tissues been used? (e.g., cancer research, gene mapping)
6. Who has access to the samples? (e.g., researchers, insurers, employers)
7. How are the tissue samples stored (e.g., paraffin blocks, slides, frozen tissue) and for how long? (e.g., months, years, indefinitely)
8. What identifying information is kept with the tissues? (e.g., patient's name or medical record number).

We intend this handbook to serve the research community as a comprehensive reference source of tissue banks in the United States and to facilitate the distribution of tissues for individual research projects.



## DEFINITIONS

Several terms are used in this handbook that need further definition:

*Human tissue* is defined as including everything from subcellular structures like DNA, to cells, tissue (bone, muscle, connective tissue, and skin), organs (e.g., liver, bladder, heart, kidney), blood, gametes (sperm and ova), embryos, fetal tissue, and waste (urine, feces, sweat, hair and nail clippings, shed epithelial cells, placenta).

This handbook attempts to count both the number of *cases* from which stored tissues are derived as well as the number of *specimens* generated from each case. For example, when a patient enters the hospital for a biopsy, the resulting tissue is accessioned in the pathology department as a single case. However, that single biopsy may generate several specimens, including a number of slides, paraffin blocks, and frozen specimens. When portions of specimens are distributed to researchers, the researcher is receiving a *sample* of that specimen. For example, a specimen of frozen brain tissue from a case of Alzheimer's disease may provide a number of researchers with samples for use in genetic linkage studies.

The term *DNA bank* refers to a facility that stores extracted DNA, transformed cell lines, frozen blood or tissue, or biological samples for future DNA analysis. Specimens are usually stored with some form of individual identification for later retrieval. *DNA databanks* are repositories of genetic information obtained from the analysis of DNA samples, sometimes referred to as *DNA profiles*. The genetic information is usually stored in computerized form with individual identifiers.

*Graduate medical education (GME) programs* are the primary means of medical education beyond the four-year medical school training received by all physicians. GME programs are usually referred to as residency

programs and are based in hospitals or other health-care institutions, some of which do and some of which do not have formal relationships with medical schools. *GME teaching institutions* include medical schools; U.S. armed forces hospitals; Veterans Affairs medical centers; the Public Health Service; state, county, and city hospitals; nonprofit institutions; and health maintenance organizations.

## DATA COLLECTION

For this handbook, collections of stored tissue samples were identified through several sources: a literature review of papers about tissue banks and DNA banks; searches of the worldwide web; searches of RAND's RaDiUS database and NIH's CRISP database to identify federally funded sources of stored tissue; and personal communications and consultation with experts. Several papers served as valuable sources of information on DNA banks and DNA databanks, including forensic DNA banks and the Department of Defense DNA Specimen Repository for Remains Identification. Information contained in numerous Internet Web sites for several tissue banks, organ banks, umbilical cord blood banks, sperm and embryo banks, and longitudinal studies was also used. Relevant Web sites appear in Appendix I and Appendix J of this report. RAND's RaDiUS database provided information about government, university, nonprofit, and commercially based tissue repositories. Finally, a substantial amount of information was obtained through personal communications with knowledgeable sources in the field, including pathologists, relevant people at several tissue banks, and experts who have published papers on the subject of stored tissue samples.

### RaDiUS

RAND's Research and Development in the United States (RaDiUS) database is a comprehensive, real-time accounting of federal research and development (R&D) activities and spending. RaDiUS allows users to see the total R&D investment by all federal agencies, to compare the level of R&D investment in specific areas of science and technology across all federal agencies, or to examine the details of research investments within a specific agency. RaDiUS was searched using proximity and wildcard searches for combinations of different search terms, including "tissue(s)," "bank(s)," "repository(ies)," "blood," "DNA," and "cell(s)."

## ESTIMATE OF CASES ACCESSIONED AT GRADUATE MEDICAL EDUCATION TEACHING INSTITUTIONS

Two techniques were used to estimate the total number of cases accessioned per year at all GME institutions and the number of tissues stored at each institution. The first estimate used information found in the American Medical Association's Graduate Medical Education Directory 1997-1998 about residency programs in pathology at GME institutions (American Medical Association, 1997). However, not all pathology specialties yielded information. Therefore, a second estimate was made from information obtained from several chairs of pathology departments attending the Universities Associated for Research and Education in Pathology (UAREP) conference hosted by the Federation of American Societies for Experimental Biology (FASEB).

An analysis was performed (see Figure 2.1) to estimate the total number of cases accessioned per year at all GME teaching institutions in the pathology spe-

RAND MR954-2.1

$$\begin{aligned}
 & i = \text{state (e.g., New York, Massachusetts, Virginia)} \\
 & j = \text{specialty (e.g., anatomic, forensic, pediatric)} \\
 & k = \text{procedure (e.g., autopsy, surgical pathology, cytology)} \\
 & \alpha = \text{duration of the program in years} \\
 \\
 & X_{ij} = \text{number of programs by state } i \text{ and specialty } j \\
 & Y_{ij} = \text{number of residents by state } i \text{ and specialty } j \\
 & Z_j = \sum_i X_{ij} = \text{total number of programs by specialty} \\
 & W_j = \sum_i Y_{ij} = \text{total number of residents by specialty} \\
 & S_{jk} = \frac{\text{number of tissue samples examined by specialty } j, \text{ procedure } k \text{ per resident}}{\text{duration of program in years } \alpha} = \text{number of tissue samples examined by specialty } j, \text{ procedure } k \text{ per year per resident} \\
 & T_{jk} = W_j * S_{jk} = \text{total number of samples required for all residents to see by specialty } j \text{ and procedure } k \text{ per year} \\
 & U_j = \sum_k T_{jk} = \text{total number of samples required for all residents to see by specialty } j \text{ per year} \\
 & V = \sum_j U_j = \text{total number samples per year}
 \end{aligned}$$

Figure 2.1- Mathematical Model for Cases Accessioned at GME Teaching Institutions



cialties of anatomic and clinical pathology, dermatopathology, forensic pathology, neuropathology, and pediatric pathology. This calculation was based on the number of GME pathology programs in each specialty ( $Z_j$ ); the number of resident positions open in these programs for the academic year ( $W_j$ ); the recommended number of cases per program to meet the training requirements of the residents ( $T_{jk}$ ); and the duration of the program in years ( $\alpha$ ). A mathematical model showing the calculations used is shown below. An estimate of the number of cases and specimens accessioned in cytopathology and hematology programs was obtained by averaging the number of cases and specimens reported on various GME teaching institutions' Internet Web sites.

Chairs of pathology departments attending the UAREP meeting were asked several questions about the pathology departments at their institutions. Information from 10 pathology chairs was obtained about the size of their institution, the number of cases accessioned per year, the age of the oldest tissues archived, how long the tissue samples are stored, what identifying information is kept with the tissues, and who has access to the samples. This information was used to calculate ranges and averages of hospital size and number of cases accessioned.

## ORGANIZATION OF HANDBOOK

This book is organized into sections based on the type of institution where the tissue is stored. Chapter Three describes large tissue banks, repositories, and core facilities, including those that are federally funded, those at research universities and academic medical centers, and commercial and nonprofit entities. Chapter Four describes tumor registries and the types of data and information they collect. Chapter Five describes longitudinal studies and research projects that simultaneously create tissue collections. Chapter Six describes human tissue specimens collected through hospital pathology departments—the oldest and largest source of human tissues in the United States. The remaining three chapters describe state screening laboratories and forensic DNA banks, cryopreservation facilities and storage banks, and private and public umbilical cord blood banks, respectively. Detailed appendixes list addresses (D, F, H, and I) and Web sites (J) of all tissue banks described in the handbook, as well as many more too numerous to describe individually. We intend this handbook to serve the research community as a comprehensive reference source of tissue banks in the United States and to facilitate the distribution of tissues for individual research projects.

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**LARGE TISSUE BANKS, REPOSITORIES,  
AND CORE FACILITIES**

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Large tissue banks and repositories exist in almost every sector of the scientific and medical communities, including the military, the federal government, universities and academic medical centers, commercial enterprises, and nonprofit organizations. In addition, several universities have established core tissue banking facilities to support both their own research and collaborations with other universities. These large tissue banks, repositories, and core facilities are major sources of human tissue for biomedical research.

**MILITARY FACILITIES**

The military maintains two of the largest tissue repositories in the world. The National Pathology Repository and the Department of Defense (DoD) DNA Specimen Repository for Remains Identification are housed within the Armed Forces Institute of Pathology (AFIP). The AFIP is responsible for maintaining a central laboratory of pathology for consultation and diagnosis of pathologic tissue for DoD, other federal agencies, and civilian pathologists. The AFIP also conducts research in pathology, trains enlisted personnel in histopathology and related techniques, and offers more than 50 pathology education courses for medical, dental, and veterinary personnel.

**National Pathology Repository**

The National Pathology Repository, located at the AFIP, is the largest and most comprehensive collection of pathology material in the world. Since 1917, the Pathology Repository has collected more than 2.5 million cases comprising more than 50 million microscopic slides, 30 million paraffin tissue blocks, 12 million preserved wet tissue specimens, and associated written records. The Pathology Repository accessioned approximately 50,000 cases annually, with 53,384 cases accessioned in fiscal year (FY) 1996, and 51,908 in 1997. In addition, approximately 40,000 cytology cases are sent for primary diagnosis annu-

ally but are not accessioned (only cytology cases sent for second opinions are accessioned). During 1993, approximately 10,000 of the cases were cancers and 8,000 were benign neoplasms, with the balance representing the entire spectrum of human disease. Material is stored permanently unless a specific request comes from the contributor or other authorized individual to return or release the material.

The AFIP accepts cases from all Army, Navy, and Air Force medical facilities and investigative agencies. The AFIP also serves as the central laboratory of pathology for the DoD and certain other federal agencies, such as the Public Health Service and the Justice Department. In addition, the AFIP serves as a Veterans Affairs Special Reference Laboratory for Pathology and maintains a special registry of former prisoners of war. Civilian and foreign contributions are accepted from pathologists (or clinicians functioning as pathologists) through the Civilian Consultation program. Cases represent both sexes, all races/ethnicities, and all ages and come from contributors worldwide.

Cases are sent to the AFIP for a variety of reasons. The majority of cases are submitted to the AFIP because the contributor wants a second opinion regarding the diagnosis. Some are forwarded as part of established peer-review and quality-assurance programs. DoD regulations require some military cases to be forwarded, such as forensic cases and cases subject to litigation. Other cases are submitted because they are rare and could be used by the AFIP in their research and education missions. In addition, cases have been submitted over the years for specific purposes, such as to study particular diseases or to answer current and future research questions (for example, sera from Gulf War veterans).

All submitted case material is coded by pathological diagnosis and is identified by an AFIP accession number. The source name, Social Security number, date of birth, age, sex, and race are stored if provided by the contributing pathologist. Any medical history provided is stored in the case folder and on an optical disk imaging system. The source address is not routinely provided or stored but is obtained on occasion for follow-up studies. Likewise, the original consent remains a matter between the patient and the clinician and is not routinely provided to AFIP by the contributing pathologist. The submitting pathologist's name and address and the source's surgical identification numbers are also stored.

All research protocols using Pathology Repository stored material or data are reviewed by the AFIP's Institutional Review Board (IRB). Research involving patient follow-up, and thus requiring identifying information, is reviewed at a full meeting of the IRB prior to approval. Other than for research involving follow-up, original sources of material are not notified. If an unexpected dis-

ease or abnormality is discovered, the contributing pathologist is notified, then it is up to the pathologist to contact the patient. Otherwise, current AFIP policy requires that material be made anonymous before release to outside investigators.

The main functions of the Pathology Repository are consultation, education, and research in pathology. The Pathology Repository also loans pathologic material to assist in patient treatment, for research, or for litigation. Requests for loan of material or provision of data for research purposes require submission and approval of a research protocol. Requests from individuals or organizations other than the original contributor must be accompanied by a properly executed authorization signed by the patient or designated representative. Pathologic specimens stored at the Pathology Repository can be used to study unusual tumors or as part of a public health surveillance system to study emerging infectious diseases or trends in disease progression. For example, samples in the repository have been used to identify and date tissues harboring genomic material of the Human Immunodeficiency Virus (HIV) obtained before the availability of HIV testing and before the worldwide spread of the HIV infection.

### **DoD DNA Specimen Repository for Remains Identification**

The DoD DNA Specimen Repository for Remains Identification is the world's largest DNA bank. As of September 1999, the DNA Repository has received more than 2.8 million DNA specimens. Specimens come into the DNA Repository at a rate of 10,000 per day, and the tally (database) is updated every seven seconds. It is estimated that by 2001 the DNA Repository will contain approximately 3.5 million samples. All DNA specimens will be maintained for 50 years before being destroyed. However, donors may request that their specimens be destroyed following the conclusion of their military service obligation or other applicable relationship to DoD.

Since June 1992, DoD has required all military inductees, and all active-duty and reserve personnel to provide blood and saliva samples for its DNA Specimen Repository at the time of enlistment, reenlistment, annual physical, or preparation for operational deployment (McEwen, 1997). The DNA Repository also contains samples from civilians and foreign nationals who work with the U.S. military in arenas of conflict. Three DNA specimens are collected from each person: a bloodstain card (stored in a pouch in the service member's medical record), a second bloodstain card, and a buccal swab (stored at the DNA Specimen Repository). The blood is placed on special cards with the service member's Social Security number, date of birth, and branch of service designated on the front side of the card and a fingerprint, a bar code, and signa-

ture attesting to the validity of the sample on the reverse. The bloodstain card stored at the DNA Repository is placed in a vacuum-sealed bag and frozen at  $-20^{\circ}\text{C}$ . The buccal swab is fixed in isopropanol and stored at room temperature. DNA will be extracted from the specimens in the repository only when it is needed for remains identification.

The DNA Repository, along with the Armed Forces DNA Identification Laboratory (AFDIL), make up the DoD DNA Registry. The purpose of the DNA Registry is to identify the remains of soldiers killed in combat or missing in action. High-velocity weapons often destroy any chances of using fingerprints or dental records, but DNA can almost always be used to identify remains. Most times the armed forces can identify the dead based on rosters, but DNA identification provides closure for the family and biological proof of death required by life insurance companies. The military's policy ensures that specimens can be used only for remains identification and routine quality control, except for cases subpoenaed for the investigation or prosecution of a felony. The specimens cannot be used without consent for any other purpose, such as paternity suits or genetic testing. In addition, the specimens are considered confidential medical information, and military regulations and federal law exist to cover any privacy concerns.

## **NATIONAL INSTITUTES OF HEALTH**

The National Institutes of Health (NIH), founded in 1930, consists of 24 separate Institutes, Centers, and Divisions. NIH is the principal health research agency of the federal government. It is one of the eight health agencies of the Public Health Service, which is part of the U.S. Department of Health and Human Services. The mission of NIH is to protect and improve human health. To accomplish its mission, NIH conducts and supports basic, applied, and clinical health services research aimed at understanding the processes underlying human health and acquiring new knowledge to help prevent, diagnose, and treat human diseases and disabilities. In 1999, the NIH budget was more than \$15.65 billion. The extramural program, which accounts for approximately 80–85 percent of NIH's total budget, awards grants to researchers at universities, medical schools, hospitals, small businesses, and research institutions across the country, while the intramural program, which represents approximately 11 percent of the budget, supports research and training of scientists at NIH. NIH is probably the single highest funder of extramural tissue and data resources for basic, applied, and clinical research. Some of the institutes at NIH that support tissue banks include the National Cancer Institute, the National Institute of Allergy and Infectious Disease, the National Heart, Lung, and Blood Institute, the National Institute of Mental Health, the National Institute on Aging, the

National Institute of Environmental Health Sciences, and the National Institute of Diabetes and Digestive and Kidney Diseases.

### **National Cancer Institute**

The National Cancer Institute (NCI), the largest of NIH's biomedical research institutes and centers, has coordinated the U.S. government's cancer research program since 1937. Through both its extramural and intramural programs, the NCI supports research on all aspects of cancer prevention, detection, diagnosis, and treatment. In addition, the NCI supports several tissue and data resources for cancer research, including the NCI Cooperative Human Tissue Network, the NCI Clinical Trials Cooperative Group Human Tissue Resources, the NCI Cooperative Breast Cancer Tissue Resource, the NCI Breast Cancer Specimen and Data Information System, the NCI Cooperative Family Registry for Breast Cancer Studies and NCI Cooperative Family Registry for Colorectal Cancer Studies, and the NCI AIDS Malignancy Bank.

The NCI supports a great number of other tissue banks and collection systems. Among the many NCI-funded tissue collections are breast and prostate cancer and HIV/AIDS. These tissue collections may vary in their specific objectives and goals, but, overall, the tissues are collected for the advancement of knowledge and development of clinical applications in a particular field.

**NCI Cooperative Human Tissue Network.** The Cooperative Human Tissue Network (CHTN), supported by the NCI since 1987, provides biomedical researchers access to fresh surgical or biopsy specimens of normal, benign, pre-cancerous, and cancerous human tissues. The CHTN is a tissue collection system and not a tissue bank. Only very rare specimens that are difficult to obtain are stored to anticipate future requests. Except for a collection of frozen tissue from rare pediatric tumors, banked specimens are generally not stored for more than one year. Normally, the specimens are obtained prospectively to fill specific researcher requests. Five member institutions coordinate the collection and distribution of tissues across the United States and Canada.<sup>1</sup> Tissues are provided by the CHTN only for research purposes and cannot be sold or used for commercial purposes. The intent of the CHTN is to encourage research using human tissue for the good of the public rather than for private gain.

During the first nine years of its operation, the CHTN supplied more than 100,000 specimens to approximately 600 investigators. CHTN tissues have been used widely in cancer research for both basic and developmental studies,

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<sup>1</sup>The five regional divisions are the Eastern Division, the Midwestern Division, the Southern Division, the Western Division, and the Pediatric Division, which provides samples of childhood tumors nationwide through the Children's Cancer Study Group.

including molecular biology, immunology, and genetics. Researchers have used these tissues to study mutations of protooncogenes in human tumors and the role of growth factors in cancer and to isolate new cancer genes. More than 2,000 publications have resulted from studies using CHTN tissues.

The CHTN obtains tissues from routine surgical resections and autopsies. Tissues from both adult and pediatric patients represent all organ systems, as well as blood and other body fluids. Specimens are collected according to the individual investigator's protocol and may be preserved as fresh, fixed or frozen, slides, or paraffin blocks. The CHTN was designed for basic research studies not requiring clinical follow-up information. Each specimen is given a unique identifier, and a link is maintained by the parent institution for quality-control purposes. Only minimal demographic data is provided with each specimen. Other information routinely provided with the specimen includes pathology reports and histological characterization.

Participating CHTN institutions include the University of Alabama at Birmingham, University of Pennsylvania Medical Center, the Ohio State University Medical Center, Case Western Reserve University, and Children's Hospital of Columbus.

**NCI Clinical Trials Cooperative Group Human Tissue Resources.** The NCI Clinical Trials Cooperative Group (CTCG) is a program of national networks that conduct large-scale, multi-institutional clinical trials supported by the Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis. The primary goal of CTCG is the definitive evaluation of clinical treatment programs. Currently, the groups conduct approximately 400 clinical trials, evaluating approximately 20,000 patients a year. The large amount of patient data collected annually through these trials and the large-scale collection of biologic specimens with clinical and outcome data provide researchers with a rich resource of specimens for correlative studies. The network member groups that maintain tissue banks are briefly described below.

*Pediatric Oncology Group.* The Pediatric Oncology Group (POG), established in 1980, is a consortium of 39 full member institutions, 48 affiliate, 12 consortia, and 9 CCOP institutions. This consortium has pooled its patient resources and scientific expertise to study the natural history of childhood cancer, develop and compare effective therapeutic regimens, and investigate the toxicity and efficacy of new anticancer agents in the treatment of childhood cancer. Many of the members are funded through the NCI. Since 1980, nearly 50,000 children have been enrolled in pediatric cancer research studies. Several tissue banks have been established to provide qualified investigators with tissue and cells for studies focused on childhood cancers. For example, the Acute Lymphoblastic Leukemia (ALL) Cell Bank (Stanford University, California) has collected thou-

sands of frozen cell suspensions from bone marrow extractions from ALL patients. The cell bank collects and stores approximately 600 new samples each year. Other POG-maintained tissue banks are listed below:

Pediatric Oncology Group—Hodgkin's Disease Cell Bank (*Wake Forest University, North Carolina*)

Pediatric Oncology Group—Germ Cell Tumor Bank (*University of Alabama, Birmingham, Alabama*)

Pediatric Oncology Group—Lymphoid Relapse Cell Bank (*MCSD Medical Center, California*)

Pediatric Oncology Group—Neuroblastoma Tumor Bank (*Children's Memorial Hospital, Illinois*)

Pediatric Oncology Group—NHL Cell Bank (*University of Massachusetts Medical School, Massachusetts*)

Pediatric Oncology Group—Hepatoblastoma Biology Study and Tissue Bank (*University of Texas Southwestern Medical Center, Texas*)

Pediatric Oncology Group—AML Cell Bank (*St. Jude Children's Research Hospital, Tennessee*)

Pediatric Oncology Group—CNS Tumor Bank (*Duke University, North Carolina*)

Pediatric Oncology Group—Sarcoma Cell Bank (*Dana-Farber Cancer Institute, Massachusetts*)

*Gynecologic Oncology Group Tissue Bank.* The Gynecologic Oncology Group (GOG) Tissue Bank, supported by the NCI, provides malignant, benign, and normal ovarian and cervical tissue from almost 3,200 patients for molecular biology studies of gynecologic tumors. The specimens are stored as snap-frozen specimens, formalin-fixed sections, OCT embedded primary tumors, touch imprint slides, and patient serum collected prior to surgery. Currently, specimens are stored dating back five years. Each case is given a unique identifier, and a link is kept at the GOG Tissue Bank. The link provides a one-way flow of information for research purposes. Clinical information is provided with each case and may include patient age and race in addition to the institutional pathology and operative reports.

Specimens obtained from patients in clinical trials at approximately 76 participating institutions are stored centrally at the Children's Hospital Research Foundation in Columbus, Ohio. The GOG Tissue Bank is ideal for clinical correlative studies to identify those factors that place patients with ovarian carcinoma at high risk for treatment failure independent of such traditional vari-



ables as stage, grade and cell type. A total of 52 projects, focusing mainly on the molecular genetics underlying gynecologic malignancies, have utilized this resource.

*Intergroup Rhabdomyosarcoma Tissue Bank.* The Intergroup Rhabdomyosarcoma Study (IRS) was initiated in 1972 and is a collaborative multidisciplinary study carried out by the Children's Cancer Group (CCG) and the POG. The IRS was designed to answer therapeutic, clinical, and laboratory questions about rhabdomyosarcoma. Eligible patients in CCG and POG institutions are enrolled in IRS protocols. Four major study protocols have taken place, and between 600 and 1,000 patients have been enrolled in each protocol. Tissue samples from patients in many of these protocols have been collected and stored in the Intergroup Rhabdomyosarcoma Tissue Bank for future study.

*Cancer and Leukemia Group B.* The Cancer and Leukemia Group B (CALGB) was founded in 1955 and is a national clinical research group sponsored by the NCI. CALGB consists of 31 university medical centers, more than 185 community hospitals, and more than 3,000 physicians. CALGB seeks to conduct clinical research studies aimed at reducing the morbidity and mortality from cancer, to relate the biological characteristics of cancer to clinical outcomes, and to develop new strategies for the early detection and prevention of cancer. CALGB research focuses on six diseases: leukemia, lymphoma, breast cancer, lung cancer, gastrointestinal malignancies, and prostate cancer.

The CALGB maintains a leukemia tissue bank at the Arthur G. James Cancer Hospital and Research Institute in Columbus, Ohio. Tissue specimens from study participants are collected from newly diagnosed patients with acute or chronic leukemia or myelodysplastic syndrome who are entered into a CALGB protocol for previously untreated patients. The specimens are archived for future investigations. Bone marrow, blood, and buccal swabs are collected from patients. Requests for tissue will be reviewed for scientific merit, strength of the analytical techniques, and track record of the investigator, among other criteria.

*Children's Cancer Group.* The Children's Cancer Group (CCG) was founded in 1955 and is a national cooperative research organization devoted to the development of new treatments and cures for childhood cancers. CCG conducts research on the biology of these cancers, their etiology, and long-term follow-up of cured patients into adult life. In 1990, the National Childhood Cancer Foundation was established as the fiscal agent of CCG. More than 2,500 pediatric cancer specialists are CCG members at more than 115 pediatric medical centers in the United States, Canada, and Australia. CCG's main priority is to facilitate the transition of new biological findings into clinical trials for treatments of childhood cancer.

Tissue specimens are collected from study participants and stored for future investigations. The CCG maintains a solid tumor tissue bank, an AML tissue bank, and an ALL tissue bank.

*National Wilms Tumor Study Group.* The National Wilms Tumor Study Group (NWTSG) was established in 1969, and POG and CCG member institutions participate as part of their study groups. The NWTSG seeks to increase the survival rate of children with Wilms tumor and other renal tumors, to study the long-term outcome of children who have been treated successfully for Wilms tumor, to identify adverse effects of treatment for Wilms tumor, to conduct epidemiological and biological studies of Wilms tumor, and to disseminate information regarding successful treatment strategies of Wilms tumor.

More than 100 pediatric oncology treatment centers are involved in NWTSG therapeutic studies. Approximately 440 patients are enrolled annually into NWTSG studies. A tissue bank is maintained for tissue specimens collected from NWTSG study participants for future research.

*Radiation Therapy Oncology Group.* The Radiation Therapy Oncology Group (RTOG), established in 1968, has received funding from the NCI since 1971. RTOG is a national cooperative cancer study group that conducts multicenter clinical trials that integrate surgical, radiotherapeutic, and chemotherapeutic treatments. Since its inception, the RTOG has activated 271 protocols and accrued almost 56,000 patients in its cooperative group studies. Close to 300 radiation oncology departments in North America are members of the RTOG, which has its headquarters at the American College of Radiology in Philadelphia, Pennsylvania. In 1996, RTOG created the Translational Research Program (TRP), which coordinates RTOG's basic science committees, including the Tumor Repository.

In 1993, a frozen tumor tissue repository was established at Fox Chase Cancer Center to provide access to frozen tissue for use in correlative and translational studies. The frozen tumor repository collects 3–5 frozen tissue fragments per case from phase III protocols of cervical, lung, head and neck, esophageal, and anal cancers. Currently, the frozen tumor repository contains more than 290 specimens from approximately 70 different tumors (cases). About two-thirds of the specimens are from cervical cancer, and the next most abundant specimens are from head and neck tumors.

Because of technological advances allowing the analysis of tumor markers in paraffinized tissue removed from tumors, the RTOG began archiving paraffin blocks and tissues from all RTOG phase III trials in 1995. Phase III protocols for cancer of the prostate, bladder, lung, head and neck, esophagus, and malignant glioma were modified to contain a request for blocks or unstained slides on each patient. The patient consent form was modified to allow tissues to be

stored and used for future research. These tissues are used for population-based studies but not for patient-related issues. Investigators performing research on RTOG specimens lack access to clinical information that might allow patient identification or linkage to treatment and demographics. A central processing site for all blocks and unstained slides was established in February 1996 and funded by the NCI in November 1996. The fixed tissue repository was moved to Latter-Day Saints Hospital in March 1997. Currently, the RTOG has approximately 4,400 cases stored at a central repository in Salt Lake City, Utah, and is accruing about 1,500 cases per year.

*Eastern Cooperative Oncology Group.* The Eastern Cooperative Oncology Group (ECOG), established in 1955, is supported by the NCI. ECOG is an international organization with more than 365 university and community-based hospitals and practices and more than 5,000 participating scientists and health-care professionals, including physicians, statisticians, nurses, clinical research associates, and pharmacists. ECOG's primary functions include conducting clinical trials that compare new therapeutic approaches to standard therapies, assessing dose and toxicity levels, and determining response rates of experimental therapies. In addition to clinical trials, ECOG conducts studies in cancer control and prevention and performs translational research. ECOG's overall goal is to improve the care of patients with cancer.

Tissue banking is an integral part of the laboratory science effort of ECOG. ECOG maintains four tissue banking facilities, a solid tumor tissue bank, a myeloma tissue bank, a leukemia cell bank, and an immunologic tumor repository. In January 1997, ECOG moved the solid tumor tissue bank and disbursement facility from the ECOG Operations Office in Boston, Massachusetts, to the Pathology Coordinating Office (PCO) in Evanston, Illinois. The new facility consists of 750 square feet of space—a 500-square-foot laboratory, a specially designed 250-square-foot walk-in cold room for storage of paraffin-embedded tissue blocks and slides, and a  $-80^{\circ}\text{C}$  freezer for storage of bone marrow and DNA. The ECOG-PCO is responsible for acquisition, storage, data entry, tissue processing, and quality assurance of solid tumors and lymphomas. The ECOG-PCO stores both retrospective, archived fixed tissues (blocks and slides) and prospectively collected tissues (blocks, slides, frozen tissues, etc.). Tissue samples will never be discarded from the bank, and great efforts will be made to maintain at least a portion of all samples indefinitely. Tissues will be returned to their home institutions for storage if the ECOG-PCO bank ever closes. In 1995, the solid tumor bank contained 3,000 paraffin-embedded blocks and 15,000 slides with an estimated accrual rate of 3,000 blocks per year. The ECOG-PCO bank also stores specimens for three other Cancer Cooperative Groups—the Southwest Oncology Group (SWOG), the Cancer and Leukemia Group B (CALGB), and the Radiation Therapy Oncology Group (RTOG).

*Southwest Oncology Group.* The Southwest Oncology Group (SWOG) was first organized as a pediatric oncology group in 1956 but has evolved into an adult multidisease, multimodality, clinical research organization. SWOG is primarily funded by the NCI and includes 34 full member institutions; 26 Community Clinical Oncology Programs (CCOP) institutions, including seven minority-based CCOPs; 23 urologic cancer outreach programs; 25 high-priority program members; and a network of approximately 1,000 Cooperative Group Outreach Programs (CGOPs) investigators at 291 affiliate hospitals. Approximately 3,500 oncologists are members of SWOG and actively participate in the enrollment of patients to oncology protocols. Participants in SWOG study protocols are in excess of 8,000 per year. Tissue samples collected from participants are stored in the SWOG National Tissue Repository for future use by approved investigators in the field of oncology. For example, the Intergroup Breast Tissue Bank has more than 4,000 breast tissue specimens and estimates that more than 8,000 additional specimens from nine study protocols will be collected.

*National Surgical Adjuvant Breast and Bowel Project.* The National Surgical Adjuvant Breast and Bowel Project (NSABP) was established in 1971 and is primarily supported by the NCI. The NSABP is a cooperative group that conducts clinical trials in breast and colorectal cancer research. Currently, almost 300 participating medical centers in the United States and more than 6,000 physicians, nurses, and other medical professionals conduct NSABP research. In 1997, NSABP treatment trial members enrolled more than 3,000 breast and colorectal patients in seven treatment trials. The NSABP has collected malignant breast tissue samples from 10,000 patients enrolled in NSABP trials. These specimens are available for confirmatory studies for potential therapeutic response variables and limited nongenetic studies.

**NCI Breast Cancer Specimen and Data Information System.** The NCI has developed a national information database of breast cancer resources to help investigators studying breast cancer identify sources of biological specimens for use in their research. The NCI Breast Cancer Specimen and Data Information System contains information about 14 breast tissue banks. This database does not represent an exhaustive national listing of all facilities holding breast cancer tissue. However, by centralizing information on biological specimens, this database promotes access to breast tissue specimens and facilitates collaboration among basic, clinical and epidemiologic researchers. Table 3.1 summarizes the information contained in the NCI Breast Cancer Specimen and Data Information System.

Cumulatively, the 14 breast tissue banks in the NCI database contain more than 130,000 cases of breast cancer-related specimens and data, with banks ranging in size from 48 cases to approximately 101,000 cases (see Table 3.1). Three of

Table 3.1  
 NCI Breast Cancer Specimen and Data Information System

Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations	Consent
Baylor SPOR—Familial Breast Cancer Registry and Gene Bank Alkek N550, MS 600 One Baylor Plaza Houston, TX 77030 Ph. 713-798-1600 Fax: 713-198-1642	6 frozen and 42 paraffin-embedded malignant breast cancer specimens Blood or blood products Frozen and paraffin-embedded malignant tissue	Demographic Clinical Outcome	Proposals reviewed and approved by Baylor SPOR Executive Committee, and collaboration is required	Specific patient consent form for research use of breast cancer-related specimens
Baylor SPOR—National Breast Cancer Tissue Resource Alkek N550, MS 600 One Baylor Plaza Houston, TX 77030 Ph. 713-798-1600 Fax: 713-198-1642	151,320 biopsy specimens from about 101,000 cases of breast cancer Frozen malignant tissue	Demographic Clinical Outcome	Proposals reviewed and approved by Baylor SPOR Executive Committee, and collaboration is required	Standard hospital consent
Dana Farber Cancer Institute 44 Binney St. Boston, MA 02115 Ph. 617-632-5189 Fax: 617-632-5189	225 invasive breast cancer cases aged 32 and under Cell lines Genomic DNA Plasma Viable frozen cells	Demographic Clinical Other	Outside advisory committee prioritizes requests for specimens and risk factor data; no identifying information provided. Tissue samples are available for detection of p53, BRCA1, and additional inherited breast cancer susceptibility genes and studies of gene-environmental interactions Costs associated with generating and delivering all specimens requested	Not applicable since data provided is unidentified

Table 3.1- continued

Resource	Number of Specimens/Tissue Type(s)	Other Data	Limitations	Consent
Duke University Box 3873 Duke University Medical Center Durham, NC 27710	>1,400 blood and tissue samples in inventory (50 fresh and 100 frozen tissues per year) Blood or blood products Fresh and frozen malignant, benign, and normal tissue	Demographic Clinical Outcome	Use by Duke researchers is high and has priority, otherwise collaboration is required	Standard hospital consent
Georgetown University Medical Center and Lombardi Cancer Center and SPORE 3900 Reservoir Rd., N.W. Washington, D.C. 20007 Ph. 202-687-2904 Fax: 202-687-8935	~200 cases per year of paraffin- embedded tissue since the mid- 1970s (each case has from 3-30 tissue blocks) Blood or blood products Frozen and paraffin-embedded malignant, benign, and normal tissue	Demographic Clinical Outcome	Use of some samples restricted for use by Lombardi Cancer Center investigators, otherwise collaboration is required	Standard hospital consent
National Cancer Institute of Canada—Manitoba Breast Tumor Bank 100 Olivia St. Winnipeg Manitoba R3E 0V9 Canada Ph. 204-787-1446 Fax: 204-783-6875	Malignant: >2,000 frozen and >2,000 paraffin-embedded Normal: 100 frozen and 100 paraffin-embedded	Demographic Clinical Other	Acknowledgment of bank in publication required Use of material restricted to studies proposed Data limited to information requested at outset of study Fees restricted to cost recovery only	Standard hospital consent

Table 3.1- continued

Resource	Number of Specimens/ Type(s) Tissue	Other Data	Limitations	Consent
National Surgical Adjuvant Breast and Bowel Project (NSABP) 320 East North Ave. Pittsburgh, PA 15212 Ph. 412-359-5013 Fax: 412-359-8685	10,000 specimens of malignant tissue from breast cancer patients enrolled in NSABP clinical trials Paraffin-embedded malignant tissue	Demographic Clinical Outcome	Available only for confirmatory studies for potential therapeutic response variables; use limited to nongenetic studies only, otherwise collaboration is required	Old tissue banks have no research-related consent. Newer protocols have consent regarding research
NCI Cooperative Breast Cancer Tissue Resource (CBCTR) Information Management Systems, Inc. 12501 Prosperity Drive, Suite 200 Silver Spring, MD 20904 Ph. 301-680-9770 Fax: 301-680-8304	8,289 primary breast cancer tissues Formalin-fixed, paraffin-embedded primary breast cancer tissues	Demographic Clinical Outcome Other	Must document IRB approval for use of human subjects; scientific merit will be determined by Research Evaluation Panel Charge for preparation of section and shipping costs	Standard hospital consent
NCI Cooperative Human Tissue Network (CHTN) (See Web site for contact information of division most relevant to research)	Specimens collected to meet researcher requests; only rare specimens banked to meet future requests Neoplastic and associated normal tissue, blood, and body fluids from routine resections and autopsies	Demographic Clinical Outcome	Cannot be used to produce commercial products. Must have evidence of IRB approval, and nominal processing fee for each specimen and shipping and handling fees	Standard hospital consent

Table 3.1- continued

Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations	Consent
NCI Surveillance, Epidemiology, and End Results Program (SEER) 6130 Executive Blvd., Room 343J Rockville, MD 20892 Ph. 301-496-8510 Fax: 301-496-9949	Not applicable; this is a source of breast cancer-related data, not actual specimens. Database contains information on 1.7 million cancers diagnosed between 1973 and 1991; ~12,000 new cases per year	Demographic Clinical Outcome	Must not make primary data available to anyone who has not signed a confidentiality statement	Not applicable—data are unidentified and collected under state regulations
New York University Medical Center Tisch Hospital, NYU Medical Center 560 First Ave., TH466 New York, NY 10016 Ph. 212-263-8826 Fax: 212-263-7916	300 malignant samples 500 benign and precancerous samples (10 slides per case) 500 serum and blood samples Blood or blood products Frozen and paraffin-embedded malignant, benign, and normal tissue	Demographic Clinical	Fees will be levied	Standard hospital consent
North Central Cancer Treatment Group Research Base at Mayo Clinic Mayo Clinic 200 First St., S.W. Rochester, MN 55905 Ph. 507-284-4849 Fax: 507-284-1803	800 specimens from breast cancer patients entered in clinical trials over the past 10 years Paraffin-embedded malignant tissue	Demographic Clinical Outcome	Peer reviewed, scientifically meritorious uses only, and collaboration is required	Specific patient consent form is signed



Table 3.1- continued

Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations	Consent
University of Michigan Breast Cell/Tissue Bank Data and Data Base Dept. of Radiation Oncology University of Michigan Medical School 1331 East Ann St. Ann Arbor, MI 48109 Ph. 313-647-1008 Fax: 313-763-1581	Malignant: 5-10 fresh/month, >100 frozen, several hundred paraffin-embedded Normal: 1-2 fresh/month, ~20 frozen, >100 paraffin-embedded Fresh, frozen, and paraffin-embedded normal and malignant tissue Blood or blood products Cells and cell lines	Demographic Clinical Outcome	None specified	Standard hospital consent
University of Pennsylvania 1009 BRBI, 422 Currie Blvd. University of Pennsylvania Philadelphia, PA 19104 Ph. 215-898-0247 Fax: 215-662-7617	Frozen: 200 malignant, 30 benign, and 100 normal Paraffin-embedded: >1,000 malignant, >1,000 normal >500 lymphoblastoid cell lines Fresh, frozen, and paraffin-embedded normal, benign and malignant tissue Blood or blood products Lymphoblastoid cell lines	Demographic Clinical Outcome	Results reported back for inclusion in University of Pennsylvania database, and collaboration is required	Standard hospital consent for tumor tissue. Specific patient consent for immortalized cells

the 14 banks accrue as many as 200 new cases per year. A specimen from a single case can generate several samples. For example, a specimen from a single case might be split into 3–30 paraffin-embedded blocks, 10 slides, or matched frozen and paraffin-embedded tissue blocks (i.e., one frozen and one paraffin-embedded sample from the same case). Conservatively, a total of approximately 240,000 samples are included in the repositories listed in the database. Samples available to the research and clinical communities include breast tissue, serum, urine, cells, and DNA from patients diagnosed with breast cancer, those at high risk, and unaffected individuals. Information on demographics (age, sex, race, ethnicity, family history of cancer), clinical findings (pathologic diagnosis, stage, initial therapy), and outcome (subsequent breast cancer, vital status) is also available from some institutions.

**NCI Cooperative Breast Cancer Tissue Resource.** The Cooperative Breast Cancer Tissue Resource (CBCTR), supported by the NCI, provides access to more than 8,200 cases of formalin-fixed, paraffin-embedded primary breast cancer tissues. The current specimens represent cases accessioned from 1974 through the present. Each case receives a unique identifier. Since the block is currently part of the pathology archives, a link is kept at the collecting institution. The link provides a one-way flow of information for research purposes but is not part of the research database. Associated pathology and clinical data, such as demographic data, diagnosis, extent of disease, treatment, follow-up, recurrence, survival, and vital status, are available. However, patient identification or information about other family members will not be provided. Cases representing all stages of disease from both sexes, all ages, and all races/ethnicities are available for study. Four collaborating institutions contribute tissue and data from patients treated at their hospitals: Fox Chase Cancer Center (Fox Chase Breast Cancer Tissue Registry), Philadelphia, Pennsylvania; Kaiser Foundation Research Institute, Portland, Oregon; University of Miami, Miami, Florida; and Washington University, St. Louis, Missouri. The resource was designed for large studies to validate promising diagnostic and prognostic markers for breast cancer.

**Cooperative Central Nervous System Consortium Tissue Bank.** The Central Nervous System Consortium (CNSC) is funded by the Cancer Therapy Evaluation Program and the Radiation Research Program of the Division of Cancer Treatment Diagnosis and Centers at the NCI. The CNSC conducts laboratory and clinical phase I and phase II research trials to study central nervous system (CNS) tumor biology and to discover new treatments for adult patients with malignant brain tumors. The Cooperative CNSC Tissue Bank provides the consortium with a mechanism for sharing human brain tumor specimens among investigators conducting research on the biology, clinical behavior, or therapy of CNS tumors.

**Biologic Specimen Bank for Early Lung Cancer Markers in Chinese Tin Miners.** The Biologic Specimen Bank for Early Lung Cancer Markers in Chinese Tin Miners is maintained by the Division of Cancer Prevention and Control. The specimen bank aims to collect specimens and data that can be used for validation and refinement of potential early markers of lung cancer and to establish a cohort for the study of environmental and genetic risk factors for lung cancer. Early detection and identification and alteration of etiologic factors may reduce the incidence and mortality of lung cancer. More than 7,000 miners in the Yunnan Tin Corporation (40 years of age with 10-plus years of underground and/or smelting experience) have been enrolled in an annual lung cancer screening program for the past 20 years. Since 1992, sputum samples have been collected and stored annually for future projects on early marker identification.

**NCI AIDS Malignancy Bank.** The NCI AIDS Malignancy Bank (AMB), established by the NCI in 1994, consists of five "banks" located in San Francisco, Washington, D.C., Ohio, New York, and Los Angeles. Each "bank" is actually a multi-institutional consortium. The San Francisco consortium is centered at the University of California at San Francisco, coordinated by the AIDS Immunobiology Research Laboratory at San Francisco General Hospital, and consists of investigators at the major hospitals in San Francisco, New England Deaconess Medical Center in Boston, Memorial Sloan-Kettering Hospital in New York, and the Duke University Oncology Consortium of eight hospitals in the southeastern United States. The Washington, D.C., bank is a consortium operated by the Department of Pathology at George Washington University Medical Center with participation by Children's National Medical Center, Fairfax Hospital, Howard University Hospital, University of Miami, Veterans Affairs Medical Center, and Washington Hospital Center. The Ohio State AIDS Malignancy Bank is in consortium with the University of Texas Southwestern Medical Center in Dallas, Texas. The participating institutions in New York are the State University of New York Health Science Center at Brooklyn, King's County Hospital Center, and Woodhull Medical and Mental Health Center. The University of California at Los Angeles AIDS Malignancy Bank consortium includes the University of Southern California.

The AMB is a collection of tissues and biological fluids with an associated clinical database from patients with HIV-related malignancies. Currently, the AMB contains more than 18,000 samples from 2,002 cases of HIV-related malignancies. The AMB contains formalin-fixed paraffin-embedded tissues, fresh frozen tissues, malignant cell suspensions, fine needle aspirates, and cell lines from patients with HIV-related malignancies. The bank also contains serum, plasma, urine, bone marrow, cervical and anal specimens, saliva, semen, and multisite autopsy tissues from patients with HIV-related malignancies, includ-

ing those who have participated in clinical trials. The bank has an associated database that contains prognostic, staging, outcome, and treatment data on patients from whom tissues were obtained. Follow-up clinical information will be requested every six months. The specimens and clinical data are available to qualified investigators in the United States for research studies, particularly those that translate basic research findings to clinical applications. Access to these specimens should encourage and facilitate research in HIV-related malignancies.

### **National Institute of Allergy and Infectious Disease**

The National Institute of Allergy and Infectious Disease (NIAID) provides major support for scientists conducting research on improving diagnosis, prevention, and treatment of many infectious, immunologic, and allergic diseases affecting people worldwide. NIAID is composed of four extramural divisions: the Division of AIDS; the Division of Allergy, Immunology, and Transplantation; the Division of Microbiology and Infectious Disease; and the Division of Extramural Activities. Major areas of investigation include AIDS, asthma and allergic diseases, enteric diseases, malaria and other tropical diseases, and vaccine development.

The NIH AIDS Research and Reference Reagent Program (AIDS Reagent Program), established by the NIAID in 1988, is a unique resource. The AIDS Reagent Program is an AIDS Collaborating Center of the World Health Organization. It acquires critically needed reagents for AIDS-related research and provides these reagents free of charge to qualified investigators worldwide. The program contains samples of cell lines, HIV and related viruses, opportunistic infectious agents associated with HIV infections, DNA libraries, DNA clones, antibodies, purified proteins, synthetic peptides, body fluids, and reference standards.

The AIDS Reagent Program encourages collaborative research aimed at standardizing reagents and laboratory techniques. Most of the reagents are used by and donated by scientists from the NIH, academic and nonprofit institutions, and the private sector. Any commercial use of reagents requires written permission and compensation of reagent donor(s) and notification of the AIDS Reagent Program. Currently, the program has 500 registered users of its services. During the past five years the AIDS Reagent Program has provided more than 17,000 reagents to AIDS investigators worldwide.

**DAIDS Specimen Repositories.** The Division of the Acquired Immuno-deficiency Syndrome (DAIDS) within the NIAID was established in 1986 to address the national research needs created by the HIV/AIDS epidemic. The mission of DAIDS is to increase basic knowledge of the pathogenesis, natural

history, and transmission of HIV disease and to promote progress in its detection, treatment, and prevention. DAIDS supports several multi-institutional programs in epidemiologic, therapeutic, and vaccine/prevention research. Collectively, these studies have amassed a large amount of clinical data and biological specimens. The specific fluids and tissues collected vary according to study group but include peripheral blood mononuclear cells, serum, plasma, semen, saliva, vaginal washings, urine, placenta, and autopsy samples. The clinical trial studies are described below and the longitudinal studies are described in Chapter Four.

*HIV Network for Prevention Trials.* The HIVNET efficacy trials network is a network of clinical programs established in 1994. The mission of the HIVNET network is to conduct HIV vaccine efficacy trials and prevention trials in higher-risk populations. One of the objectives of HIVNET is to determine the incidence of HIV in higher-risk populations who may serve as good study groups for future trials.

HIVNET consists of five contracts supported by DAIDS:

1. The domestic HIV/AIDS vaccine efficacy trials master contract, which evaluates the efficacy of candidate vaccines in U.S. population.
2. The international HIV/AIDS vaccine efficacy trials master contract, which supports HIV vaccine trials in international populations.
3. The statistical and data coordinating center contract, which provides statistical and data management service for both U.S. and international trials.
4. The laboratory contract for HIV/AIDS vaccine efficacy trials, which provides specialized laboratory testing.
5. The specimen repository, which collects and archives specimens from U.S. and international trials.

The HIVNET specimen repository includes serum, plasma, peripheral mononuclear cells, genital tract secretions, and saliva. HIV strains isolated from these specimens are also available. Specimens collected from individual clinical trials are routinely sent to a central laboratory for testing. The availability of specimens depends on the type requested. Peripheral mononuclear cells are potentially available for use by collaborating investigators. Fresh specimens, such as blood or mucosal specimens, are potentially available, provided that the research offers a unique or immunological/virological assessment.

*Pediatric AIDS Clinical Trials Group.* The Pediatric AIDS Clinical Trials Group (PACTG) is a multicenter national clinical trials network. It supports the development and implementation of phase I, II, and III studies designed to test and

optimize therapies to prevent and treat HIV infection in infants, children, and adolescents; conducts studies throughout the United States; and collaborates closely with the adult clinical trials groups, the FDA, pharmaceutical and biotechnology companies, and community constituencies to promote HIV/AIDS research.

Specimens collected from the PACTG trials include serum, plasma, peripheral mononuclear cells, culture supernatants, lymph node biopsies, tissues, urine, and other body fluids. Specimens are normally collected several times during a clinical trial. Specimens are usually sent to a specific laboratory for processing, testing, and storing. Stored specimens fall into one of two categories: protocol-specified batch testing and unspecified future studies. Specimens collected for protocol-specified batch testing are stored pending collection of all protocol specimens, at which time they undergo a protocol-specified test. Batch testing is more economical and feasible compared to "real-time" testing. Batch testing specimens are rarely available for other purposes. Specimens collected for unspecified future studies are additional specimens drawn and stored for future research.

*Adult AIDS Clinical Trials Group.* The Adult AIDS Clinical Trials Group (ACTG) is a consortium of 30 clinical research institutions. It conducts all phases of clinical trials designed to assess the safety and efficacy of new and improved therapies for HIV/AIDS and its associated illnesses. To date, ACTG has implemented more than 280 clinical investigations, enrolling more than 35,000 adult volunteers who are at all stages of the disease.

The goals of the ACTG are to evaluate innovative therapeutic strategies and interventions to control HIV infection; to facilitate rapid translation of basic research into clinical research and practice; and to provide a flexible resource for multidisciplinary, multicenter, clinical trials.

ACTG specimens are collected and stored several times during a clinical trial. Specimens are usually forwarded to a specific laboratory for testing. Specimens collected include serum, plasma, peripheral blood mononuclear cells, culture supernatants, lymph node biopsies, tissues, urine, and other body fluids. Specimens fall into two categories: protocol-specified batch testing and unspecified future studies, as described above for PACTG specimens.

*AIDS Vaccine Evaluation Group.* The AIDS Vaccine Evaluation Group (AVEG) evaluates candidate AIDS vaccines in phase I and II clinical trials for safety and immunogenicity. AVEG consists of six AIDS Vaccine Evaluation Units (AVEUs), a Statistical Coordinating Center, and a Central Immunology Laboratory. Specimens collected from AVEG studies include serum, plasma, peripheral mononuclear cells, genital tract secretions, saliva, and tears. Specimens are routinely sent to two laboratories for testing. The availability of specimens

depends on the type requested. Serum specimens are usually available from all volunteers and trials. Peripheral blood mononuclear cells are potentially available for use by collaborating investigators.

*Division of AIDS Treatment Research Initiative.* The Division of AIDS Treatment Research Initiative (DATRI) was established to conduct phase I and II studies for HIV and associated diseases. DATRI performs small focused studies and substudies of protocols conducted by other extramural programs. DATRI clinical specimens vary according to the study under which they were collected. Many studies intentionally set aside specimens for future investigations. Samples include serum, plasma, cells and cultured cells, and supernatant from peripheral blood mononuclear cells and plasma HIV cultures.

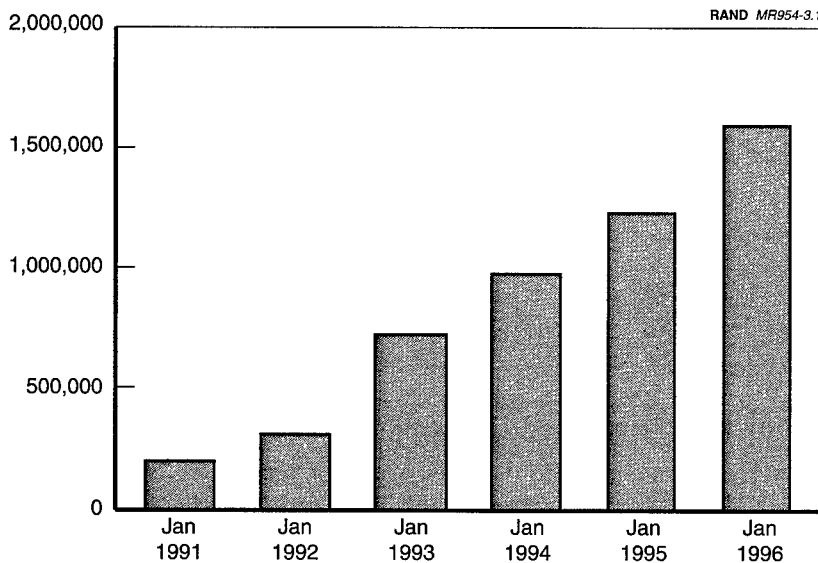
### **National Heart, Lung, and Blood Institute**

The Transfusion Medicine Branch of the National Heart, Lung, and Blood Institute (NHLBI) has a Blood Specimen Repository available for use by researchers for studies related to transfusion-transmitted diseases, other blood disorders, or diseases of the cardiovascular system. The repository is operated by McKesson BioServices Corp. in Maryland through an extramural contract with NHLBI. The repository, established in 1974, contains approximately 1.5 million well-characterized specimens of serum, plasma, and cells from NHLBI-sponsored studies. Since 1991, the Blood Specimen Repository has been storing an average of approximately 300,000 samples per year (see Figure 3.1) (National Heart, Lung, and Blood Institute, 1996). In 1995, the demand for specimens greatly increased. From 1991 to 1993, approximately 1,000 specimens per year were distributed to researchers, and in 1994 approximately 4,000 specimens were distributed, while in 1995, approximately 20,000 specimens were distributed (see Figure 3.2) (National Heart, Lung, and Blood Institute, 1996).

### **National Institute of Mental Health**

The National Institute of Mental Health was originally established in 1949, left NIH and became a separate bureau with the Public Health Service in 1967, and rejoined NIH in 1992, where it is currently located. NIMH has established four major research priorities: (1) fundamental research on brain, behavior, and genetics, (2) rapid turnover of basic discoveries into research on mental disorders, (3) research that directly impacts the "real world" settings, and (4) research on child development and childhood mental disorders.

NIMH has awarded funds to three universities, the University of Alabama at Birmingham, Harvard Medical School, and Johns Hopkins University, to estab-



SOURCE: National Heart, Lung, and Blood Institute, Blood Specimen Repository: 1996 Catalog.

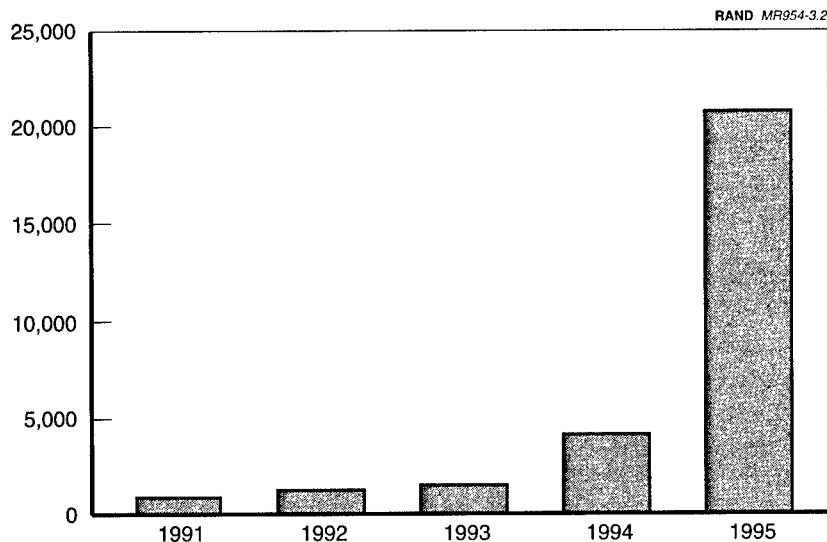
**Figure 3.1- Number of Vials Stored at the NHLBI Blood Specimen Repository**

lish a national resource to study both early and late-onset Alzheimer's disease. A collection of samples from 400 pairs of relatives, primarily sibling pairs, are available for finding susceptibility genes linked to Alzheimer's disease. This resource provides a large enough sample of families, obtained through a common protocol and diagnosed by a consensus procedure, to be useful for identifying clinical and genetic subtypes of Alzheimer's disease.

NIMH maintains a brain collection of more than 1,200 frozen or formalin-fixed brain specimens. Brain specimens are collected from cases of schizophrenia, bipolar disorder, depression, alcoholism, drug addiction, suicides, and other cases, including AIDS, Alzheimer's, and Parkinson's disease.

**National NeuroAIDS Tissue Consortium.** The National NeuroAIDS Tissue Consortium (NNTC) was established in 1998 and is jointly supported by three institutes: the National Institute on Drug Abuse (NIDA), NIMH, and the National Institute of Neurological Disorders and Stroke (NINDS). The goal of the NNTC is to provide high-quality, well-characterized tissue samples to increase research efforts on HIV infection in the human brain. Four centers currently participate in the NNTC and are described below. Tissue samples will be collected from a diverse population of HIV-infected individuals and will be





SOURCE: National Heart, Lung, and Blood Institute, Blood Specimen Repository: 1996 Catalog.

**Figure 3.2- Number of Vials Distributed from the NHLBI Blood Specimen Repository**

available for multiple studies. Detailed data at autopsy will be collected with all specimens, including drug use history, psychological evaluations, and clinical tests and treatment.

*Mount Sinai Medical Center, New York.* The Manhattan HIV Brain Bank located at the Mount Sinai Medical Center (MSSM) collects patient tissues from MSSM, Beth Israel Medical Center, and St. Luke's-Roosevelt Hospital Center in New York City. The objectives of the Manhattan HIV Brain Bank will be to identify and follow a cohort of advanced HIV patients, establish a multi-institutional clinical database, and obtain CNS, peripheral nervous system (PNS), and systemic tissues from autopsies of HIV patients; dissect, store, catalog, and distribute tissue specimens to approved investigators; and utilize pathology specimens and clinical databases in correlational studies to elucidate the pathogenesis and natural history of HIV-related neurologic diseases.

*National Neurological AIDS Bank, California.* The National Neurological AIDS Bank (NNAB) at UCLA will collect and store pre- and postmortem clinical data and neural tissues from autopsies for future distribution to investigators. The NNAB will also set up an electronic database and an Internet-based applications process so investigators may gain access to the bank's resources. There

is no cost for the use of tissue specimens for approved investigators. The bank currently has three brains/spinal cords and 25 CSF samples.

*California NeuroAIDS Tissue Network.* The objective of the California NeuroAIDS Tissue Network (CNTN) is to establish a tissue bank of CNS autopsy specimens from HIV-infected individuals who have been well-characterized neuropsychologically and neuromedically within six months of death. The CNTN represents a collaborative effort between the NIMH-funded HIV Neurobehavioral Research Center in San Diego and four California HIV network sites: University of Southern California, Cedars-Sinai/UCLA, University of California, Irvine, and the University of California, San Diego. Collectively, these sites follow more than 4,300 patients. The CNTN seeks to identify and characterize HIV-infected persons neuromedically and neurobehaviorally following a standardized protocol, to characterize neuropathologic changes associated with HIV, to establish a tissue registry, repository, and database that can support current and future studies integrating ante- and postmortem data, and to obtain control tissue specimens. By 2003, the CNTN proposes to collect 209 sets of brain and other tissues from HIV-infected individuals with detailed ante-mortem clinical data. Seventy-five control brains from immunosuppressed patients dying after transplantation or from trauma will also be collected and stored.

*Texas Repository for AIDS Neuropathogenesis Research.* The Texas Repository for AIDS Neuropathogenesis Research will be based at the University of Texas Medical Branch in Galveston. The goal of the research is to establish a Texas regional brain repository to elucidate the mechanisms underlying neuropsychological problems in AIDS patients. Frozen human brain specimens will be collected from community-based clinics in Galveston, Dallas, and Houston. Clinics in these three cities are collectively following more than 10,000 HIV-infected subjects. The brain repository will build on a prior AIDS brain repository that has almost 500 brain specimens already stored. A secure database will be established containing neuropsychiatric data, substance abuse histories, and other clinical and laboratory information.

### **National Institute on Aging**

The National Institute on Aging (NIA) supports research on the general biology of aging and age-associated diseases and disabilities. The specific areas of research on the general biology of aging include the characterization of normal aging, cell cycle regulation and programmed cell death, stress response, and DNA damage and repair. Age-associated disease and disabilities research include the study of Alzheimer's disease, cancer, cardiovascular disease and hypertension, diabetes, and osteoporosis, osteoarthritis, and frailty. The NIA

also supports the development of different intervention strategies to treat many of these age-associated diseases, such as pharmacotherapy, gene therapy, and behavioral or lifestyle changes. To provide appropriate tissue for neuropathological studies in Alzheimer's disease, the NIA maintains a Brain Bank.

As part of the NIA Research Resources Branch, the Central Laboratory Services Section (CLSS) collects, analyzes, and prepares for long-term storage blood and tissue samples. Other services provided by CLSS include phlebotomy, tissue handling and preservation, DNA extraction, cell transformations to create renewable cell lines, and inventory management of stored samples.

**Alzheimer's Disease Research Centers.** NIA funds 27 national Alzheimer's Disease Research Centers (ADRC), some of which maintain brain tissue banks described below. The ADRCs are designed to serve as shared resources to facilitate research in Alzheimer's disease. There are 14 ADRCs and 13 Alzheimer's Disease Core Centers (ADCCs). These centers provide core resources that enhance ongoing research by bringing together biomedical, behavioral, and clinical science investigators in a single center. Many of the centers provide well-characterized patients, patient and family information, and tissue and other biological samples from persons with Alzheimer's disease and from age-matched control subjects for research projects.

*Kathleen Price Bryan Brain Bank.* The Kathleen Price Bryan Brain Bank (Brain Bank), sponsored by NIA since 1985, is within the Alzheimer's Disease Research Center at Duke University. The major function of the Brain Bank is to retrieve and evaluate tissue for the presence of Alzheimer's neuropathologic changes and to select and retrieve human brain tissue, which will be used for further scientific investigations. The Brain Bank currently stores about 600 brains from Alzheimer's patients or related causes of dementia and 150 brains from patients with other neurological disorders, such as amyotrophic lateral sclerosis (ALS), Huntington's disease, and muscular dystrophy. The Brain Bank also has 150 brains donated from normal individuals. Fixed or frozen hemispheres, paraffin blocks, and histological slides are distributed for research, and clinical information is available.

*The Taub Center for Alzheimer's Disease Research Tissue Bank.* The Taub Center for Alzheimer's Disease Research Tissue Bank at Columbia-Presbyterian Medical Center is operated by the Neuropathology Core and funded by the NIA. The Tissue Bank contains flash frozen and fixed brain tissue with neurodegenerative disorders as well as normal specimens. The bank has about 300 brains stored, including those with Alzheimer's disease, Parkinson's disease, diffuse Lewy body diseases, progressive supranuclear palsy, cortico-basal ganglionic degeneration, ALS, and Creutzfeldt-Jakob disease (CJD). The bank also has peripheral blood cells and DNA stored from patients with these disorders.

*Washington University Alzheimer Disease Research Center.* The Washington University Alzheimer Disease Research Center (funded by NIA) has a tissue bank that is operated by the Neuropathology Core. The tissue bank collects, stores and distributes human brains, cerebrospinal fluid (CSF), and blood samples to investigators. CSF samples, heart blood samples, brain slices, and dissected anatomical regions are obtained from autopsies and stored at  $-80^{\circ}\text{C}$ .

*Boston University's Alzheimer's Disease Core Center.* Boston University's Alzheimer's Disease Core Center operates a Brain Tissue Resource Center that supplies tissue for ongoing research projects whose focus is on any aspect of neurodegenerative diseases, especially Alzheimer's disease. The center is supported by NIA. Flash frozen and PLP immersion-fixed tissue is available from all areas of the cerebral cortex and brainstem. Brain endothelium cell cultures created from rapid postmortem samples are also available.

*Michigan's Alzheimer's Disease Research Center Brain Bank.* The University of Michigan Alzheimer's Disease Research Center Brain Bank was established in 1989 and its goal is to further research on Alzheimer's disease and related disorders. It is supported by NIA. The Neuropathology Core is responsible for the collection of postmortem material, part of which is frozen and part of which is used for diagnosis. Currently, more than 300 brains are stored in the Brain Bank and are available to qualified investigators nationwide.

*Alzheimer's Disease Research Center at Baylor College of Medicine.* The Alzheimer's Disease Research Center (ADRC) at Baylor College of Medicine was established to conduct clinical and basic science research and to diagnose and treat patients with Alzheimer's disease and related disorders. The ADRC is funded by NIA. The goal of the ADRC is to help patients, family members, and professionals cope with Alzheimer's disease through research, patient care, and education. The ADRC's research efforts target progressive deterioration of nerve cells in Alzheimer's, exploration of the potential involvement of the immune system in Alzheimer's, and mechanisms by which the beta-amyloid protein contributes to brain cell death. The ADRC maintains a serum bank of stored blood samples donated by patients who have Alzheimer's disease as well as by spouses and normal control subjects. A Brain Donation Program for Alzheimer's Disease has also been established for the collection of brain specimens for research.

*The University of Kansas Medical Center Alzheimer's Disease Center.* The University of Kansas Medical Center Alzheimer's Disease Center (ADC) mission is to broaden research and understanding of Alzheimer's disease and other memory disorders. The main focus of the University of Kansas Medical Center's ADC is on Alzheimer's disease and Parkinson's disease, and it is supported by NIA. The ADC has four main areas of focus: a clinical program, a brain bank,

an educational program, and a research program. The clinical program has developed and maintains a large database registry of Alzheimer's disease, Parkinson's disease, and normal control subjects for research studies. The neuropathology core has established a brain bank to collect brain tissue from normal control subjects and persons with Alzheimer's and Parkinson's disease for research studies. The brain bank serves as a repository of nervous system tissue that allows for the correlation of clinical and neuropathological findings. The education program provides information about Alzheimer's and Parkinson's disease to professionals, patients, families, and the general public. A major goal of the ADC research program is the development of effective pharmacotherapy for Alzheimer's and Parkinson's disease.

*University of California, Los Angeles (UCLA), Alzheimer's Disease Center.* The UCLA Alzheimer's Disease Center (ADC) consists of five cores: administrative, clinical (including six clinical sites), imaging, pathology, and education/information transfer. The center is supported by NIA. The UCLA ADC has also established a brain bank. More than 800 patients and controls have been evaluated by the Clinical Core or are linked into the Clinical Core database, 639 structural and functional images have been obtained through the Imaging Core, and more than 100 brains have been examined in the Pathology Core.

*Rush Alzheimer's Disease Center.* The Alzheimer's Disease Center at Rush-Presbyterian–St. Luke's Medical Center focuses on four main areas of research: identifying risk factors for Alzheimer's disease, understanding the presentation and course of Alzheimer's disease, investigating underlying neurobiologic causes of Alzheimer's disease, and developing treatments for Alzheimer's disease. The Rush Center is supported by NIA. The Rush Alzheimer's Disease Center Brain Bank has two objectives: to provide neuropathological diagnosis of Alzheimer's disease by postmortem evaluation and to facilitate research of the etiology of Alzheimer's disease. More than 1,000 brain autopsies have been conducted by the brain bank since 1987. Cerebrospinal fluid samples, serum, DNA, and white blood cells are also collected by the brain bank. All tissue specimens are available to outside investigators throughout the United States.

*Indiana Alzheimer Disease Center.* The Indiana Alzheimer Disease Center (ADC) comprises six cores and is supported by NIA. The Indiana ADC has focused its studies on AD patients within the African-American community, on clinical and neuropathologic studies of familial forms of AD and other hereditary degenerative adult onset dementias, on trials for new drug therapies for AD, and on educational activities.

The Indiana ADC maintains a National Cell Repository that has collected genetic material from more than 2,200 individuals from 440 families with histories of AD. Both lymphocytes and DNA are available from most participants.

Family pedigrees are available for participating AD families. Tissues from various types of AD families are stored in the repository, including families with autopsy-confirmed cases of AD, families with multiple affected siblings, two-generation affected families, and early and late-onset AD families. Cell lines and DNA are available to approved investigators at no cost.

*Northwestern University's Alzheimer's Disease Core Center.* The goal of the Alzheimer's Disease Core Center (ADCC) at Northwestern University is to establish a clinical registry of well-characterized patients with Alzheimer's disease and other dementias and healthy elderly subjects. The center is supported by NIA. The ADCC will focus on basic mechanisms of the disease, clinical symptoms, treatments, and caregiving aspects. A brain endowment program has been established to collect normal and diseased brain tissue for research.

*University of Rochester Alzheimer's Disease Center.* The Alzheimer's Disease Center (ADC) at the University of Rochester consists of four cores: administrative, clinical (including two satellite diagnostic centers), neuropathology (brain bank), and education and information transfer. The center is supported by NIA. The ADC is designed to serve a broad range of studies, particularly in the area of clinical studies and trials of therapeutic interventions. Neuropathologic examination of brains has been expanded to distinguish Lewy bodies and plaque subtypes.

*Emory University's Alzheimer's Disease Center.* The Alzheimer's Disease Center (ADC) was established in 1991 at Emory University and is supported by NIA. The ADC consists of five cores: administrative and data management, clinical, neuropathology, molecular biology, and education and transfer. The Clinical Core examines a high proportion of African-American subjects and provides research, clinical, and educational opportunities to the African-American community. The Neuropathology Core supplies brain and other tissues from its brain bank of cases of well-characterized dementia and control cases to investigators.

*University of Washington Alzheimer's Disease Research Center.* The Alzheimer's Disease Research Center (ADRC) at the University of Washington focuses on understanding the basic mechanisms underlying the development of adult dementing disorders, specifically on susceptibility factors underlying Alzheimer's disease. The ADRC consists of five major research projects and seven supporting core units, including a cell tissue and fluid bank. The center is supported by NIA. A Clinical Registry Core has been established at a satellite site devoted to underserved populations in the region.

The ADRC Core, Cell, Tissue and Fluid Bank Cell Culture and Cytogenetics is one of the oldest repositories for familial AD pedigrees. The core maintains AD and control lymphoblastoid cell lines, fibroblasts, lymphocytes, and plasma.

Tissue specimens are available to ADRC investigators and approved investigators at the University of Washington and other institutions.

*University of California, Davis, Alzheimer's Disease Center.* The objectives of the Alzheimer's Disease Center (ADC) at the University of California, Davis, are to educate health professionals and the public about Alzheimer's disease and related dementias, to conduct research in clinical and community populations into the causes and potential treatments for dementia, and to advocate changes in health policy and practice that will enhance the recognition, treatment, and management of dementia. The center is supported by NIA. Research studies are focused on the behavioral and mental changes of dementing disorders, genetics of Alzheimer's disease, and strategies to prevent mental loss.

The Neuropathology Core at the UC Davis ADC has three major goals: to obtain brain autopsies on ADC patients and controls, to accurately diagnose brain lesions encountered at autopsy, and to preserve and distribute autopsy brain tissues to research collaborators. Brains are removed within 24 hours of death and half the brain is formalin-fixed and the other half is coronally sectioned and frozen. Twenty-five blocks of the formalin-fixed tissue are obtained for paraffin embedment from multiple neocortical, limbic, diencephalic, basal ganglia, and brainstem regions. A standard gross and microscopic neuropathology examination is performed on each new brain specimen. An inventory of all tissue specimens, the mode of processing and storage, pathological diagnosis, and autolysis interval are maintained in a neuropathology laboratory database.

*Case Western Reserve Alzheimer Center.* The Alzheimer Center at Case Western Reserve University consists of seven departments and is supported by NIA. Research projects include studies on apolipoprotein E, brain electrical studies of attention in Alzheimer's disease, clinical studies to design effective treatments for Alzheimer's disease, life history studies, changes in emotional responsivity studies, and visual spatial studies. The Neuropathology Core provides adequately preserved and well-characterized human brain tissue samples for biochemical and morphometric studies. The core has examined and stored 183 brains, 123 of which were diagnosed with pure Alzheimer's disease or in combination with other processes. The core has also examined and stored 554 brains, 397 of which with prion diseases.

### **National Institute on Deafness and Other Communication Disorders**

The National Institute on Deafness and Other Communication Disorders (NIDCD) was established in 1988, splitting off from the National Institute of Neurological and Communicative Disorders and Stroke. NIDCD conducts and supports biomedical and behavioral research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech,

and language. NIDCD also conducts and supports research and research training related to disease prevention and health promotion and addresses special biomedical and behavioral problems associated with people who have communication impairments or disorders.

NIDCD established the National Temporal Bone, Hearing and Balance Pathology Resource Registry in 1992. The registry was originally founded as the National Temporal Bone Banks Program (NTBB) in 1960 by the Deafness Research Foundation (DRF) to encourage individuals with ear disorders to donate their temporal bones at death for scientific research. The NTBB, however, became virtually inactive in the 1980s due to rising costs, dwindling funds, and a decrease of investigations in the area of temporal bone research. In 1988, a workshop cosponsored by NIDCD and DRF reaffirmed the importance of temporal bone research and NIDCD established the new registry in 1992, which would assume the responsibilities of the NTBB.

The contract of the registry was awarded to the Massachusetts Eye and Ear Infirmary and DRF. The services and functions of the registry include establishing a computerized database of human temporal bone collections, dissemination of information about the temporal bone collections, the implementation of professional educational activities in the study of human temporal bones and auditory brain stems and the development and implementation of a national acquisition network to increase the yield of human temporal bone and brain tissue from donors.

The registry's temporal bone database contains information from more than 6,300 cases (12,000 specimens) from 18 U.S. temporal bone collections. It provides basic information on the specimens and catalogues all known processed human temporal bones and related brain tissue specimens in the United States and the data associated with these specimens, such as clinical and histopathological diagnoses.

There are 26 temporal bone laboratories in the United States that possess temporal bone collections, though only 15 actively collect, process, and study temporal bone specimens. The active laboratories are listed below and their collections are described in detail in Appendix C:

Baylor College of Medicine, Houston, Texas

Bowman-Gray School of Medicine, Winston-Salem, North Carolina

Eye and Ear Institute of Pittsburgh, Pittsburgh, Pennsylvania

Goodhill Ear Center (UCLA), Los Angeles, California

Johns Hopkins University, Baltimore, Maryland



University of Michigan, Ann Arbor, Michigan

Massachusetts Eye and Ear Infirmary, Boston, Massachusetts

Mt. Sinai School of Medicine, New York, New York

New York University Medical Center, New York, New York

SUNY Health Science Center, Syracuse, New York

University of Chicago, Chicago, Illinois

The University of Iowa Hospitals and Clinics, Iowa City, Iowa

University of Minnesota, Minneapolis, Minnesota

University of Texas Southwestern Medical Center, Dallas, Texas

### **National Institute of Environmental Health Sciences**

The mission of the National Institute of Environmental Health Sciences (NIEHS) is to reduce the burden of human illness and dysfunction from environmental causes by understanding each of these elements and their interactions. NIEHS achieves its mission through multidisciplinary biomedical research programs and prevention and intervention efforts. One way NIEHS achieves its mission is by funding environmental health centers throughout the United States. The mission of these centers is multifold and includes strengthening the research focus and accomplishments of the host institution in environmental health science; supporting core facilities, which provide access to technology that enhances the research productivity of the center; and stimulating multidisciplinary research. Institutions that have NIEHS-sponsored centers include Harvard, Oregon State, Vanderbilt, University of California at Berkeley, and MIT. Several of the centers collect and store human samples for use by the center's investigators. Four NIEHS Centers that collect and store human samples for research are described below.

*Kresge Center for Environmental Health Studies.* The Kresge Center for Environmental Health Studies at Harvard University was established in 1958 to promote interactions among biological scientists, physical scientists, and engineers working on environmental problems concerning human health. Six scientific cores and four facility cores provide equipment and technicians for services for center investigators. One of the facility cores is the Human Cell Bank, Genotyping, and Tissue Culture Facility. The mission of the Human Cell Bank, Genotyping, and Tissue Culture Facility is to provide resources and services for Center investigators, including the acquisition, storage, and characterization of human cells and tissues. The primary focus of the cell bank has been on diploid fibroblasts isolated from three different populations: individuals with defined

syndromes, exhibiting an enhanced predisposition to cancer; families presenting with either multiple cancers, early onset cancers, or rarer types of cancers; and cells from individuals showing unusual clinical responses to radiation or chemotherapy. Cell lines banked in the facility include human diploid fibroblast strains, including normal cells and cells from individuals with cancer susceptibility syndromes and DNA repair defects; 16 human tumor cell lines; six engineered cell lines expressing transfected genes; strains from five hereditary retinoblastoma families; 10 colorectal cancer cell lines; six glioblastoma cell lines; and 15 head and neck cancer cell lines.

*Environmental Health Sciences Center.* The Environmental Health Sciences Center at the University of Southern California (USC) was established in 1996. The center is a consortium of almost 50 investigators from USC, UCLA, and Caltech. The center seeks to create an interdisciplinary approach to the study and advancement of research in environmental health. The center consists of an administrative core, five research cores, and four service cores. One of the four service cores is the Biological Sampling Processing Facility Core. The mission of the Biological Sampling Processing Facility Core is to provide a single center to assist researchers from about 150 clinical facilities. Services provided by the facility include development of samples handling protocols, receipt of newly collected samples, and the monitoring of the quality of incoming samples. Biological samples stored at the facility include blood, tissue, urine, other body fluids, smears, and scrapings (e.g., buccal cells). Several different research studies have contributed tissue samples to the Facility Core. The Genotyping and Risk of Asthma study has collected more than 1,000 buccal scrapings from school children from various communities. The Gene-Diet/Tobacco Interactions in Breast Cancer in Asians has collected 500 out of an anticipated 800 frozen buffy coats (white blood cells) for study of variant alleles in detoxifying enzymes. The Determinants of Childhood Susceptibility to Air Pollution study has collected 1,000 buccal smears from school children for genotype analysis.

*Center for Ecogenetics and Environmental Health.* The Center for Ecogenetics and Environmental Health at the University of Washington includes seven major research cores, six facility cores, and an administration core. The objectives of the center are to foster interdisciplinary collaborations among researchers working in the fields of toxicology, molecular biology, genetics, and environmental epidemiology and to stimulate the transition of basic mechanistic research on molecular biomarkers of disease susceptibility to studies in the human population. The Human Studies Facilities Core's objectives are to facilitate collaborations between investigators with expertise in human population-based studies and novel or complicated methodologies. The core has a  $-80^{\circ}\text{C}$  freezer and access to a fully equipped lab for preserving tissue samples. The Human Studies Resources Facility Core has worked on establishing and

promoting the use of the Registry for the Study of Genetic and Environmental Risk Factors. This registry consists of demographic data, medical history information, and DNA from blood or buccal cells. Registrants are study subjects participating in projects conducted by Center investigators.

*Institute of Toxicology and Environmental Health.* The Institute of Toxicology and Environmental Health at the University of California, Davis, is composed of five research cores and seven facility cores. The focus of the center's research is on agricultural chemicals and related xenobiotics. The Field Studies Facility Core provides services and consulting expertise related to agricultural epidemiologic investigations, field exposure assessments, and biostatistics. Human tissues and fluids are collected from the center's epidemiologic studies of subjects in agriculture. The Field Studies Service Core provides resources for the application of laboratory methods on agricultural workers and the collection of specimens for laboratory analysis. Specimens are analyzed for exposure and toxicological effects of agrochemicals. Specimens from workers include blood and urine samples.

### **National Institute of Diabetes and Digestive and Kidney Diseases**

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) split from the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases in 1988. NIDDK's Division of Intramural Research conducts studies on diabetes, inborn errors of metabolism, endocrine disorders, mineral metabolism, digestive diseases, nutrition, urology and kidney diseases, and hematology. Extramural research at NIDDK is separated into five divisions: Diabetes, Endocrinology and Metabolic Diseases; Digestive Diseases and Nutrition; Kidney, Urologic, and Hematologic Diseases; Extramural Activities; and Nutrition Research Coordination.

The Liver Tissue Procurement and Distribution System (LTPADS) is sponsored by NIDDK to provide human liver tissues from three regional centers in the United States for NIH investigators. These regional centers have active liver transplant programs to provide portions of resected pathologic liver. Frozen or fresh tissue is available for common forms of childhood and adult cirrhosis, fulminant liver failure, chronic rejection, and inborn errors of metabolism. Normal liver specimens may be requested, but the supply is much more limited and it usually takes much longer to fulfill requests.

## **NATIONAL INSTITUTE OF STANDARDS AND TECHNOLOGY AND THE U.S. ENVIRONMENTAL PROTECTION AGENCY**

Two other agencies within the federal government have tissue banks: the National Institute of Standards and Technology (NIST) and the U.S. Environmental Protection Agency (EPA). These tissue banks were established primarily to determine human exposure to pollutants and pesticides and to follow long-term trends.

### **National Biomonitoring Specimen Bank**

The National Biomonitoring Specimen Bank (NBSB) at the NIST was established in 1979 in conjunction with the EPA to determine the feasibility of long-term storage of environmental samples (Wise and Koster, 1995). In addition to the specimens contained in the human liver specimen bank supported by the EPA, the NBSB also archives specimens from three other projects supported by various government agencies, such as marine specimens and total human diet specimens. The EPA human liver specimen bank collected and archived 661 human liver specimens from 1980 through 1994 from individuals in Seattle, Baltimore, and Minneapolis. The goals of the EPA human liver project were to develop procedures for the collection, processing, and long-term storage of biologic specimens; to improve analytical methods for the determination of inorganic and organic contaminants in human tissue; to evaluate the long-term storage stability of biologic specimens; and to provide an archive of well-documented specimens of human liver for retrospective studies to determine long-term pollution trends and document the appearance of new pollutants (Wise and Koster, 1995). This archive of human liver specimens is an invaluable resource for the investigation of environmental pollution trends in human population.

### **National Human Monitoring Program**

The National Human Monitoring Program (NHMP) was established in 1967 and continued through 1993. The NHMP was designed to study changes in pesticide residues in the population of the United States. Originally part of the U.S. Public Health Service, the NHMP was transferred to the EPA in 1970. One of the primary activities of the NHMP was the National Human Adipose Tissue Survey (NHATS), a program developed to measure residues of chemicals in human adipose tissue. Through 1991, the NHATS had collected approximately 12,000 samples of adipose tissue from autopsied cadavers and surgical patients. The NHATS documented widespread exposure to pesticides in the United States and showed that reduced use of polychlorinated biphenyls (PCBs), DDT, and

dieldrin resulted in lower tissue concentrations of these compounds (Bailar, 1995).

## **RESEARCH UNIVERSITIES AND ACADEMIC MEDICAL CENTERS**

Research universities and academic medical centers maintain formal tissue banks for distribution throughout the research community as well as core facilities to support their own research. Examples of both types of tissue collections are described below.

### **AIDS Specimen Bank at the University of California at San Francisco**

The University of California at San Francisco (UCSF) AIDS Specimen Bank has been in existence since 1982 and has banked more than 76,000 samples and distributed more than 82,000 specimens to researchers worldwide. Specimens include serum, tissue, saliva, cells, and cerebrospinal fluid from HIV infected individuals. Specimen data are archived in a computerized database. The bank provides investigators with specimens for basic, epidemiological, and clinical research.

### **The Brain Bank**

The Brain Bank is one of two core facilities at the Alzheimer's Research Center (ARC) at the Medical College of Georgia. The ARC was established in 1989 with start-up funds provided by the Calloway Foundation of Georgia. The goal of the ARC is to continue to help investigators, technical scientists, and graduate trainees to better understand the causes of Alzheimer's disease and to develop new treatment strategies through research. Ongoing research at the ARC primarily involves basic science aspects of Alzheimer's disease. The Brain Bank currently stores 24 brains, mostly from Alzheimer's disease patients.

### **Brain Bank Core**

The Brain Bank Core at the Mount Sinai School of Medicine of the City University of New York will obtain, characterize, describe, dissect, preserve, and distribute brain tissues from normal controls and Alzheimer's disease subjects to different investigators involved in Alzheimer's disease research. The Brain Bank Core is supported by the NIA. The right half of the brain will be preserved in paraformaldehyde for neuropathological and neuroanatomical studies, and the left half will be dissected into coronal slabs and snap-frozen. The Brain Bank Core will serve five projects in the Department of Psychiatry: Neuropathology, Neuropsychology, Family History, Acute Phase Reactants, and Neurochemistry

projects. Tissues from the Brain Bank Core will also be available for projects funded by other grants.

### **Brain and Tissue Bank for Developmental Disorders at the University of Maryland, Baltimore, the University of Miami, and Children's Hospital of Orange County**

The Brain and Tissue Banks for Developmental Disorders at the University of Maryland, Baltimore, the University of Miami, and the Children's Hospital of Orange County, supported by the National Institute of Child Health and Human Development (NICHD), were established to advance the research of developmental and childhood disorders. The tissue banks systematically collect, store, and distribute brain and other tissues for research dedicated to improving understanding, care, and treatment of individuals with developmental disorders. The Brain and Tissue Banks store tissues, either frozen or formalin-fixed, of almost all tissue types from both normal and diseased donors. A smaller Ataxia Telangiectasia Patient Brain Tissue Bank exists as a subset of the Brain and Tissue Banks.

### **Breast Cancer Database and Biologic Resource Bank**

The University of Washington's Breast Cancer Database and Biologic Resource Bank was established to facilitate the development of a national resource of biologic materials linked to a substantial database. A comprehensive database, tumor tissue bank, and serum/lymphocyte bank was developed from breast cancer patients at the University of Washington Medical Center. Other biological specimens may be collected from these patients, such as bone marrow, skin biopsies, lymph node biopsies, metastatic tumor samples, and benign breast tissue.

### **Breast Tissue Repository**

The Breast Tissue Repository (BTR), at the Hamon Center for Therapeutic Oncology Research in the University of Texas Southwestern's Medical Center, was initiated in the early 1990s and is supported by a U.S. Army grant and funds from the Susan Komen Foundation. The goal of BTR is to create a comprehensive breast tissue/cell repository as a research source for investigators. The repository contains cell lines generated from breast tumor tissues and cryopreserved epithelial and stromal cell lines. Detailed information on the cellular, biochemical, and molecular analysis of these cell lines along with a comprehensive record of clinical and pathological data are available for the breast tumor cell lines.

### **Breast Tumor Bank**

The Breast Tumor Bank at the University of California, Los Angeles, was established for use in basic molecular, biochemical, and epidemiologic studies of human breast cancer. The tumor bank collects and archives malignant breast tissue, premalignant breast tissue, and bone marrow and peripheral blood samples from breast cancer patients. Relevant clinical, demographic, epidemiological, and pathologic data is collected along with each specimen. If sufficient tissue is available, it is processed for DNA, RNA, tissue powder, and tissue fragments (both frozen and paraffin-embedded). Tissue specimens are available for approved studies.

### **Cancer Center Tissue Core at University of California, San Francisco (UCSF)**

The UCSF Cancer Center is an interdisciplinary group that combines basic scientific study, clinical research, epidemiology/cancer control, and patient care services into one program. The Cancer Center's mission is the discovery and evolution of new ideas and information about cancer. The UCSF Cancer Center Tissue Core is a centralized facility that identifies and stores patient tissue. The goal of the Tissue Core is to provide specimens to approved investigators. The Tissue Core collects fresh, frozen, and formalin-fixed, paraffin-embedded tissue from a variety of organs, including breast, prostate, and bladder.

### **Cancer Tissue Bank**

The VA Medical Center in Minneapolis, Minnesota, maintains a bank of frozen cancer tissue and paired normal tissue sections for future research in oncogenesis and outcome studies. The tissue bank is supported by the Department of Veterans Affairs. Samples will be collected from neoplasms along with non-cancerous samples adjacent to tumors. Clinical information, such as type of treatment, exposure to cancer risk factors, and outcome data, can be obtained from the Minneapolis VA Medical Center Tumor Registry or chart review. Currently, more than 2,000 tumor samples have been collected.

### **Cell and Tissue Bank for Marker Studies of Diseases of the Bladder, Prostate, Kidney, Lung, and Breast**

The Cell and Tissue Bank for Marker Studies of Diseases of the Bladder, Prostate, Kidney, Lung, and Breast is located at the Veterans Affairs Medical Center in Oklahoma City, Oklahoma. The Cell and Tissue Bank is supported by the Department of Veterans Affairs. The bank stores blood cells and bladder

washes and tissue samples from patients with diseases, including cancer of the bladder, prostate, or kidney, and blood and tissue samples of patients with such diseases as colon and breast cancer. Patient information (e.g., outcome, demographic, medical, and lifestyle information) is collected with each sample. The Cell and Tissue Bank specimens are used in studies to characterize objective biomedical markers in cells for the purpose of improving markers for disease detection, monitoring, and risk assessment.

### **Central Prostate Cancer Serum Repository**

The NCI supports the Central Prostate Cancer Serum Repository at the VA Medical Center in Lexington, Kentucky. The objective of the repository is to establish a serum bank to collect and store serum of patients with prostate cancer entered into Southwest Oncology Group-approved studies. Serum samples will be distributed to investigators for projects on new or existing markers or other tests in a prospective or retrospective design.

### **Collection of DNA/RNA Tissue Repository for Neurodegenerative Disorders**

The Collection of DNA/RNA Tissue Repository for Neurodegenerative Disorders is located in the Department of Neurology at Baylor College of Medicine. The aims of the DNA/RNA Bank are to establish a detailed database for patients with neurodegenerative disorders and to collect blood samples for future DNA analysis. If the disease is hereditary, family members are included in the database and blood samples are collected. Subjects are asked to provide information in a questionnaire about their symptoms and family involvement. The DNA/RNA bank is for internal use only. In addition to the blood samples collected, limited brain and muscle specimens are stored at  $-80^{\circ}\text{C}$  and in liquid nitrogen, respectively. Demographic and detailed clinical data is obtained for each specimen.

### **DNA Bank to Detect Gene Polymorphisms in Heart Failure**

The Department of Veterans Affairs supports the establishment of a large bank of genomic DNA samples derived from peripheral blood lymphocytes from patients with etiologically defined heart failure and from matched population controls. The bank is located at the VA Medical Center in Little Rock, Arkansas. These samples will be frozen and stored for future studies that analyze specific genetic loci of interest. Ethnic group and family history will be collected with each sample.



### **Early Detection Research Network- Tissue Bank for Matched Tissues to Screen for Markers of Neoplastic Progression**

The VA Medical Center in Birmingham, Alabama, has collected a group of matched tissues from operations and preoperative body fluids to be stored in a tissue bank. The tissue bank is supported by the Department of Veterans Affairs. Specimens will include blood, urine, and feces from preoperative patients and remnant tissue sections from the surgical specimen. Patients with inflammatory diseases diagnosed or treated by surgery/biopsy will serve as controls. These specimens will be used in studies investigating whether chemicals present in the body, in tissues, or in fluids can be measured to predict the progression of tumors. Specimens will be analyzed for biomarkers that can be correlated with early detection, diagnosis, and prognosis of the patient's disease process.

### **Gift of Hope Brain Bank for AIDS**

The Gift of Hope Brain Bank for AIDS at the VA Medical Center in Los Angeles, California, is supported by the Department of Veterans Affairs. The brain bank recruits, collects, preserves, and banks high-quality tissue and CSF/serum specimens. All specimens are quick-frozen and available at no charge to investigators for study of AIDS dementia and other AIDS-related neurologic symptoms. Medical and neuropathological records are also available to investigators.

### **Harvard Brain Tissue Resource Center**

The Harvard Brain Tissue Resource Center (The Brain Bank), at McLean Hospital in Massachusetts, is a centralized repository for the collection and distribution of postmortem human brain specimens from both diseased and normal donors for use in research on the brain and nervous system. The Brain Bank is supported by the NIMH, the National Institutes of Neurological Disease and Stroke, the Alzheimer Disease Association of Indiana, the Hereditary Disease Foundation, the Tourette Syndrome Association, and the Wills Foundation. Research on brain tissue has contributed to the understanding of severe mental illness, the development of a genetic test for Huntington's disease, and a treatment for Parkinson's disease. The mission of the Brain Bank is to serve as a national resource for the collection and distribution of postmortem brain tissue for medical research into the causes of neurological and severe psychiatric disorders. Because the majority of research requires very small amounts of tissue, each donated brain provides a large number of samples for many researchers. Brain tissue donations are accepted by the Brain Bank from individuals or the parents, siblings, and offspring of individuals with such severe neurological dis-

orders as Huntington's, Parkinson's, and Alzheimer's diseases, with a serious psychiatric diagnosis, and various other disorders. The Brain Bank also accepts brain tissue from normal individuals with no neurological or neuropsychiatric disorders for research that needs to compare normal tissue with diseased tissue. Prospective brain tissue donors must be 18 years of age or older. Donors should discuss their wishes with their families and can register with the Brain Bank by completing the "Brain Donation Questionnaire."

Brain tissues are stored as fresh quick-frozen tissue blocks and coronal sections, passive frozen hemispheres, and formalin-fixed hemispheres. Researchers can request custom dissection of specified anatomic regions of the passive frozen or formalin-fixed hemispheres. All tissue diagnoses are confirmed by retrospective review of clinical records and a comprehensive neuropathological examination. There is no cost for distribution of brain tissues to approved researchers.

The Harvard Psychiatry Brain Collection was created as a subsidiary of the Harvard Brain Tissue Resource Center. This collection specifically attempts to collect brain tissue from families with serious mental illness. Tissues from patients with schizophrenia, manic-depression, obsessive-compulsive disorder, and first-degree relatives of individuals with these disorders are being collected for research and distributed to qualified investigators.

### **HIV-Related Malignancy Tissue/Biological Fluids Bank**

A consortium of Washington, D.C., metropolitan hospitals has established a comprehensive bank of biological fluids and tissue specimens from individuals with HIV-related malignancies. The HIV bank is supported by the Department of Veterans Affairs and is in the Department of Pathology at George Washington University. Diagnostic tissue (either fresh-frozen or formalin-fixed) and biological fluids (blood, urine, and other fluids) are collected from HIV seropositive individuals who have HIV-related malignancies. The specimens are available to researchers throughout the United States for approved requests.

### **Human Brain Bank**

The Human Brain Bank Core at the University of Pittsburgh, Department of Psychiatry was established in 1990 and is supported by the NIMH. The goal of the brain bank is to identify, recover, assess, and distribute postmortem human brain specimens from cases of schizophrenia and matched normal control and nonschizophrenic psychiatric comparison subjects. Clinical features of each specimen and its availability are stored in a database and are accessible to center investigators.

### **Human Gastrointestinal Tumor Bank**

The Human Gastrointestinal Tumor Bank was established to provide human tissue samples for the investigation of the molecular basis of carcinogenesis. The tumor bank is located at the VA Medical Center in Nashville, Tennessee, and is supported by the Department of Veterans Affairs. Tissue samples will be obtained from surgical specimens of esophageal, gastric, pancreatic, and colon carcinoma cases. Specimens are fixed or frozen. Clinical diagnoses and relevant clinical information are collected and maintained for each specimen. Current research projects utilizing these tissue samples include determination of the proliferative index by PCNA immunohistochemistry and in vitro staining and localization of the epidermal growth factor/transforming growth factor family of ligands and receptors in normal, adenomatous, and malignant tissue.

### **Human Lung Cancer Tissue Resource**

The VA Medical Center in Albuquerque, New Mexico, has established the Human Lung Cancer Tissue Resource. The tissue resource is supported by the Department of Veterans Affairs and its objective is to collect samples of lung tumors for long-term tissue banking. The tissue resource provides specimens for investigators interested in lung carcinogenesis. Data, including exposure history and employment history, are collected from each specimen. Tumor specimens as well as normal specimens are collected. Currently, the tissue resource has collected 236 tumor samples.

### **Inflammatory Bowel Disease Tissue Bank**

The Inflammatory Bowel Disease Tissue Bank at Massachusetts General Hospital, established in 1988, is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The tissue bank stores specimens from cases of Crohn's disease and ulcerative colitis, as well as colon cancer, adenocarcinoma, and diverticular disease. More than 250 cases are archived with three to five specimens from each case and data regarding final diagnosis, age, and sex of the patient are catalogued with each specimen. The specimens are available to investigators at no cost.

### **International Registry of Werner Syndrome/Cell Bank**

The University of Washington has established the International Registry of Werner Syndrome/Cell Bank supported by the NCI. Werner syndrome is a rare disorder that causes premature aging and early death. The registry has been in existence since 1990 and has collected lymphoblastoid cell lines, primary skin

fibroblasts and SV40-transformed fibroblast cultures containing a wide range of Werner syndrome mutations. A collection of sib-pairs (wild type versus heterozygotic carrier) will be available for retrospective and long-term prospective studies of the susceptibility of heterozygotes to various types of neoplasms. All specimens are available to investigators associated with the Program Project grant. In addition, cultures representative of a variety of mutations are available to the general community.

### **LSU Neuroscience Center Brain Tissue Bank**

The Neuroscience Center of Excellence at Louisiana State University maintains a Brain Tissue Bank. The Brain Tissue Bank obtains, processes, and distributes postmortem human brain tissue to investigators for neuroscience research.

### **Lung Cancer in Uranium Miners: A Tissue Resource**

The VA Medical Center in Albuquerque, New Mexico, has established a tissue bank to store samples of lung cancers and other tissues of lung cancer patients. The tissue resource is supported by the Department of Veterans Affairs. Tissue samples collected from lung cancer patients include cancer, blood, and sputum. Currently, tissue samples from 248 patients with lung cancer have been collected.

### **Massachusetts General Hospital Tumor Bank**

The Massachusetts General Hospital (MGH) Tumor Bank was established in 1996 as a joint effort by MGH Cancer Center, the Hematology/Oncology Division of the Department of Medicine, and the Department of Pathology. Its goal is to collect and distribute surgical specimens of human tumors for biomedical research. Tumor specimens are collected from surgeries conducted at MGH. Resected specimens are sent to the pathology lab for diagnosis and excess tissue is snap-frozen and stored at the Tumor Bank. Specimens are distributed to researchers for approved scientific studies.

### **Mental Health Clinical Research Center Brain Bank**

The Mental Health Clinical Research Center Brain Bank was established to provide neuroscientists with normal and abnormal brain morphology and neurochemistry in psychiatric conditions. The brain bank at the VA Medical Center in Iowa City, Iowa, is supported by the Department of Veterans Affairs. Tissues collected include brains from normal individuals and persons suffering from major mental illness. Brain specimens are sliced coronally in the fresh

state, and alternate slices are fixed or flash-frozen. Tissues are digitized to record anatomical appearances prior to storage. Tissue blocks are available to investigators for morphometric and chemical analyses.

### **Mucosal Immunology Core**

The Mucosal Immunology Core at the University of California, Los Angeles, is supported by the National Institute of Allergy and Infectious Diseases. Mucosal lymphoid tissue has been shown to be a major reservoir of replicative HIV-1. Recent studies are investigating differential rates of CD4+ T-cell depletion in lymphoid tissue versus peripheral blood. The gut-associated lymphoid tissue is the body's major lymphoid organ and is accessible by endoscopic biopsy. The Mucosal Immunology Core provides investigators with clinically well-characterized tissue specimens from gastrointestinal mucosal sites. Fresh and frozen samples will be collected from seropositive subjects and seronegative controls. Site-specific biopsies can be obtained via request for studies requiring esophageal, stomach, duodenal, ileal, colonic, and rectal tissue. Mononuclear mucosal preparations and immunoglobulin secretions from saliva or rectal mucosa may also be collected prospectively. In addition, other mucosal tissues (pharyngeal, pulmonary, vaginal, urinary system) and samples from other patient populations (women and minorities) are available.

### **Neuropathology Core**

A Neuropathology Core has been established in the Department of Microbiology at the University of Pennsylvania. The project was initiated in 1994 and is supported by the NINDS. The objectives of the core are to conduct histopathological-based studies to compare the cellular distribution of HIV and cytokines with pathological lesions and to establish a brain tissue bank. Brain tissues will be stored in various ways to optimize their use in other projects. About 10 brains will be collected each year.

### **Oral Cancer Research Center**

The Oral Cancer Research Center at the University of California, San Francisco, has established a tissue and histopathology core to provide fundamental support to research investigators. The core makes available human oral cancerous and precancerous tissues for applied research studies, develops a patient database for correlation of patient outcome with molecular tumor markers, and provides basic, technical, histologic, and immunohistologic services to center investigators. Tissue will be collected from new patients treated at UCSF clinical sites and from pathology archives of five UCSF hospitals and two large San

Francisco oral pathology biopsy services. Biopsies and surgical specimens with a diagnosis of oral epithelial dysplasia, carcinoma in situ, invasive carcinoma, and verrucal carcinoma will also be collected.

A secondary source of tissue will be five additional California oral pathology services and two west coast oral medicine clinics. More than 3,000 archived oral cancers and precancers are immediately available for study, and an estimated 125 new tumors will be accessioned annually from the San Francisco Bay area for use in prospective studies.

### **Prediagnostic Breast Cancer Serum Bank**

The Prediagnostic Breast Cancer Serum Bank was created as part of the Biological Markers Project at the NCI. Between 1977 and 1987, blood from more than 7,300 women free of breast cancer was collected. The Division of Cancer Prevention and Control maintains demographic data, and medical and reproductive histories were collected along with each blood sample. The goal of the serum bank is to provide specimens for prospective studies evaluating relations of serum concentrations of various analytes, such as hormones and antioxidant nutrients with breast cancer risk. Positive associations of bioavailable estradiol and testosterone with postmenopausal breast cancer have been found in these women.

### **Pittsburgh Cancer Institute Serum Bank and Tissue Bank**

The Pittsburgh Cancer Institute (PCI) Serum and Tissue Bank is supported by the Department of Veterans Affairs and located at the VA Medical Center in Pittsburgh, Pennsylvania. The serum bank collects specimens and freezes sera for use in current and future studies. Surgically removed tumors are banked after informed consent is obtained. These specimens and accompanying data are available to PCI investigators and collaborating physicians in the community for clinical research.

### **Program for Critical Technologies in Breast Oncology**

Yale University has established a core technical and tissue resource of human breast tissue. The goals of the tissue resource are to maximize access to human breast tissues and tumor DNA for researchers and to facilitate the application of molecular technologies in clinical breast cancer oncology. Breast tissue from patients treated at Yale New Haven Hospital and other hospitals in Connecticut is stored as fresh, fixed, or paraffin-embedded. A database has been established to support correlative multidisciplinary studies that utilize tissue samples.

Minimal fee-for-service routine molecular and histological tissue analyses of relevance to breast cancer are performed.

### **Program for Critical Technologies in Molecular Medicine**

The Program for Critical Technologies in Molecular Medicine is a shared resource of the Yale Cancer Center, within the Department of Pathology at Yale University School of Medicine. The program was established in 1992, built on the existing tissue bank in the Department of Pathology. The Tissue Procurement Module and Tissue Products Module are two components of the program. The program is supported by several sources, including the G. Harold and Leila Y. Mathers Charitable Foundation, the NCI, the U.S. Army Medical Research and Materiel Command, and the Department of Pathology.

More than 10,000 frozen tissue samples have been collected for research purposes, and more than three million archived paraffin blocks from clinical cases are available. Tissue specimens are either frozen in OCT (optimum cutting temperature) or snap-frozen. Tissue specimens may also be formalin-fixed and paraffin-embedded for research use in addition to the paraffin blocks from archived clinical cases. Approximately 25,000 cases are archived from clinical paraffin blocks each year.

Each investigator interested in obtaining tissue from the program must have a protocol for tissue use approved by the Yale Human Investigation Committee. Investigators from outside of Yale must have a Material Transfer Agreement negotiated and signed before tissue can be released. Tissue products are provided as small sections, depending on the researcher's requests, rather than as bulk tissue, as a more efficient use of a valuable resources. Patient information disclosed with each tissue specimen includes age, sex, and pathology diagnosis. However, more information can be obtained after consultation with the investigator.

### **Prostate Cancer Tumor Bank**

The Prostate Cancer Tumor Bank at the VA Medical Center in San Antonio, Texas, is funded by the Department of Veteran Affairs. The purpose of the Tumor Bank is to establish a high-quality bank of prostate tumors and an associated database of relevant clinical and follow-up data. The long-term goal for the banked tumor specimens is for use in studies for the discovery and validation of biological markers, such as oncoproteins and growth factors, which would correlate with clinical outcome and could be used as a prognostic indicator of tumor behavior.

Bank specimens are collected from excess tissue removed at biopsy or surgery. Fresh tumor specimens are snap-frozen in liquid nitrogen. In addition, archived paraffin-embedded material will be identified and assessed for potential use in immunohistochemical or molecular biological studies. The blocks are recut and reembedded if necessary and stored in the Tumor Bank under controlled conditions. Both abnormal and adjacent normal tissue is collected. More than 850 cases from paraffin-embedded archived tissues have been collected. Hematoxylin and eosin slides have been prepared, and tumor analysis has been performed and the data entered into the database. More than 180 specimens of fresh-frozen prostate tissue have been entered into the bank.

The database includes demographic, clinical, and outcome data for each specimen. Patient-specific data is obtained from existing sources, primarily hospital tumor registries, and thus, there is no direct patient contact. Access to banked material is strictly controlled, and use of specimens requires approval by the bank's executive committee.

### **Regional Tumor Bank**

A regional tumor bank has been established at the VA Medical Center in Salt Lake City, Utah, and is supported by the Department of Veterans Affairs. Fresh tumor tissue will be snap-frozen and stored, and small samples will be stored as paraffin blocks. Tumor specimens will be available for future studies for current and future hypotheses regarding tumors.

### **Resource for Tumor Tissue and Data**

The Resource for Tumor Tissue and Data at Kaplan Comprehensive Cancer Center, NYU School of Medicine, provides fresh human tissue specimens, data required for quality control as well as for correlation of research findings with clinical outcome, and identification of hospital patients with specific malignancies for administration of epidemiologic questionnaires and for recruitment for protocol studies. Services are provided free of charge. Tissue specimens can be either fixed or snap-frozen, according to the investigator's needs, and cell suspensions are also available. If no immediate need exists for tumor specimens obtained, these are stored and frozen until requested. Tissue paraffin blocks are available for immunophenotypic or immunogenotypic studies. Tumor and control blocks are provided to an investigator with a copy of the pathology report. Unused sections of the blocks must be returned on completion of the study.



## Specialized Programs of Research Excellence

The Specialized Programs of Research Excellence (SPOREs) are highly interactive, multidisciplinary programs of translational research directed at reducing the incidence, morbidity, and mortality of cancer. SPOREs are NCI-funded, NIH-Designated Clinical Research Centers at research universities and consist of cancer-specific research programs supported by core resources, including administration, tissue and serum banks, and biostatistics. SPOREs are designed to develop areas of basic science with potential impact on cancer and to move these promising areas into clinical trials. The SPOREs are also designed to communicate important findings rapidly into the research community to stimulate investigation and to bring validated translational findings into the medical community, where the research can ultimately reduce incidence and mortality of cancer. In 1993, NCI funded 22 SPOREs at a cost of almost \$20 million—nine breast cancer, two gastrointestinal (colorectal and pancreatic cancer), four lung cancer, and seven prostate cancer centers. Several SPOREs have core tissue banking facilities that support both their own research and collaboration with other SPOREs and researchers worldwide—for example, the SPORE in Prostate Cancer at the University of Michigan Comprehensive Cancer Center; SPOREs in Breast Cancer at Sloan-Kettering Institute for Cancer Research, Georgetown University Medical Center and Lombardi Cancer Center, and at Baylor College of Medicine in Houston; the SPORE in Lung Cancer at the University of Colorado Cancer Center; and SPOREs in Gastrointestinal Cancer and Prostate Cancer at Johns Hopkins.

**Gastrointestinal.** The SPORE in Gastrointestinal Cancer at Johns Hopkins is a translational research program aimed at reducing the incidence of and mortality from colorectal and pancreatic cancer. The SPORE includes four research programs involving six projects supported by four core resources. All programs in this SPORE use human specimens. The Human Tissue Resource and Logistics Core, built on an existing bank established in 1986 for the Bowel Tumor Working Group, banks a wide range of tissues from resection specimens of colorectal and pancreatic cancers. By the end of 1995, the bank contained 910 colorectal cancer resections, 169 colorectal adenoma resections, 52 colorectal polypectomy specimens, 62 hepatic resections for metastatic colorectal cancer, 201 pancreatic cancer resections, 112 xenografts of pancreatic carcinoma, 127 fecal specimens, and 2,574 blood specimens. The core also provides for the procurement of fecal and blood specimens, including peripheral blood leukocytes, plasma and serum, nasogastric and duodenal capsule fluid, and peritoneal washings. The core also maintains the Colorectal and Pancreatic Cancer Patient Registry. The registry is maintained in a database and includes family histories and food frequency questionnaires for patients evaluated for colorectal neoplasia. In addition, 2,120 families have been enrolled in the registry

based on family history, including families with hereditary colorectal cancer syndromes and familial aggregation of colorectal cancer and early onset of colorectal cancer.

The University of Nebraska Medical Center Gastrointestinal Cancer SPORE largely focuses on issues in pancreatic cancer. There are no effective clinical approaches to prevention or early detection for pancreatic cancer. Therefore, this SPORE focuses on prevention, early detection, and therapy. The Nebraska SPORE consists of three cores designed to support existing research projects and provide for future research studies: Biostatistics, Tissue Bank, and the Pancreatic Cancer Family Registry. The tissue bank and family registry provide both normal and diseased pancreatic tissues for specialized studies and serve as a clinical resource for testing strategies for prevention and early detection approaches.

A Pancreas Tumor SPORE Tissue bank has been established to provide SPORE investigators with human specimens for translational research. The tissue bank will store normal, benign (acute and/or chronic fibrosing pancreatitis), and malignant pancreatic tissues (both primary and metastatic pancreatic carcinomas), peripheral blood lymphocytes, and plasma and serum from patients with pancreatic malignancies.

**Prostate.** The Prostate SPORE at Johns Hopkins takes a multidisciplinary approach to reduce the incidence, morbidity, and mortality of prostate cancer through prevention, genetics, early detection and diagnosis, morbidity reduction, and treatment. Research in early detection and diagnosis will be correlated with cancer risk in the Baltimore Longitudinal Study of Aging, the world's largest and longest longitudinal aging study (see Chapter Five). A large core tissue bank was established to accelerate translation of human prostate research to clinical medicine. The Prostate SPORE at Johns Hopkins is an interactive clinical and basic research team dedicated to translating new discoveries into the control of prostate cancer.

The goals of the University of Michigan Comprehensive Cancer Center (UMCCC) Prostate SPORE are to reduce the morbidity and mortality of prostate cancer by supporting and establishing a translational research program directed at understanding the biology of prostate cancer as well as developing new tools for the diagnosis, prevention, and treatment of prostate cancer. The UMCCC SPORE consists of multidisciplinary projects with emphasis on molecular and clinical epidemiology and novel therapeutics. Four cores support these research projects: administration, tissue and serum bank resource, animal and cell line models, and biostatistics. The Tissue and Serum Bank provides tissue and known clinical follow-up to evaluate chromosome alterations discovered in research studies in the SPORE.

The Prostate SPORE at Baylor College of Medicine provides researchers with resources to work toward the goal of reducing the incidence, morbidity, and mortality from prostate cancer. Five translational research objectives have been designed to expand successful intervention strategies against prostate cancer. Research projects include defining new markers of progression and metastasis, identifying novel methods for low-risk definitive therapy of early stage cancer, defining chemoprevention with such biologic agents as retinoids or vitamin D analogs, and designing treatment protocols for advanced disease with biologic agents.

**Breast.** The University of North Carolina (UNC) Lineberger Comprehensive Cancer Center SPORE in Breast Cancer currently consists of seven research projects and four core resources. The goal of the UNC SPORE is to reduce breast cancer mortality and incidence in North Carolina through an interdisciplinary program of research. The UNC SPORE integrates studies in cancer prevention and control, molecular epidemiology, clinical research, and laboratory clinical research. It also targets behavioral and biologic issues relevant to the African-American population. The tissue procurement and analysis core facility will provide tissue procurement, processing, and distribution services of breast tissue to SPORE investigators. The core accesses all breast surgical procedures and obtains blood samples and fresh tissue. All collected tissues are entered into a database and may be distributed as DNA, RNA, or tissue sections to investigators.

The Carolina Breast Cancer Study, one of the seven research projects at the UNC SPORE, is a case-control study that integrates molecular biology and epidemiology in the search for causes of breast cancer. Women from eastern and central North Carolina who are diagnosed with invasive breast cancer for the first time and who are between the ages of 20 and 74 are being recruited from September 1, 1995, to March 31, 2000. Comparison subjects will be frequency-matched by age and race. It is expected that 1,600 women with invasive breast cancer and an equal number of controls will be involved in the study. Blood samples will be collected for extraction of germ line DNA from all consenting participants, and paraffin-embedded tumor specimens will be requested for all breast cancer cases. Clinical data, stage, and prognostic characteristics will be collected with each specimen. This collection of specimens and data will be the basis for studies investigating the contributions of genes and the environment to breast carcinogenesis.

The SPORE in Breast Cancer at the Sloan-Kettering Institute for Cancer Research proposes to meet the needs of the oncologic community for an integrated clinical and laboratory setting committed to reducing the incidence of and mortality from breast cancer. The SPORE consists of five main research

projects and two core resources. Research projects include studies of the erb family, BRCA-1, heregulin, and TGF-beta genes.

(Tissue banks at the Breast Cancer SPOREs at Georgetown University, Baylor College of Medicine, and Duke University are described in Table 3.1).

**Lung.** The goals of the University of Colorado Cancer Center (UCCC) Lung Cancer SPORE are to expand the understanding of the biology of lung cancer, to find new methods of diagnosis, prevention, and treatment, and to serve as a resource for the study of lung cancer. Since its inception, the UCCC SPORE has collected more than 900 sputum samples from high-risk individuals and more than 200 lung cancer specimens of all histologic types with matching pre- and postsurgical sputum samples for genetic testing of specific genes. During the next five years, the UCCC SPORE is planning to conduct eight interrelating full research projects, initiate four or five pilot projects annually, conduct more than 12 clinical trials, and support five core resources, including a premalignant and cancer bank. Specimens collected in the tissue banks will be available to scientists worldwide.

A Tissue Banks Core has been established to provide SPORE investigators well-preserved and well-characterized tumors, dysplastic lesions, benign tissues, cell lines, and cell and tissue fractions as well as associated clinical data for research projects. Tumor specimens, peripheral blood cells, urine, and sputum from patients with lung cancer or at risk for lung cancer will be collected. Tissue from invasive tumors and adjacent nonneoplastic lung tissue, pretreatment plasma, and peripheral blood cells from patients with these tumors are collected and processed from patients treated at SPORE-affiliated institutions. The Tissue Banks Core will thus serve as a national resource for uniformly typed, staged, treated, and observed tumors and preneoplastic lesions. Tissue specimens will be available to SPORE investigators and outside approved investigators.

### **Sloan-Kettering Institute**

The Memorial Sloan-Kettering Cancer Center (MSKCC) was established in 1884 and is the oldest and largest private institution dedicated to the prevention, patient care, research, and education in cancer. MSKCC is composed of two institutes, Memorial Hospital and the Sloan-Kettering Institute. The Sloan-Kettering Institute is the basic science research facility and conducts innovative programs in biology, genetics, biochemistry, structural biology, immunology, and therapeutics. The Human Tissue Procurement and Tissue Bank Facility is one of the Core Research Facilities. It serves as a collection and distribution site for human tissue specimens to be used in MSKCC research projects.

The Soft Tissue Sarcoma (STS) Project within the Sloan-Kettering Institute is one of many ongoing research projects and is supported by the NCI. The STS project seeks to implement a comprehensive and integrated multidisciplinary program focused on the biology, pathogenesis, and natural history of soft tissue sarcoma and translate the research data into improved treatment strategies. The Pathology Core provides project investigators with fresh tissue surgical specimens and pathologic and histologic characterization of all soft tissue sarcoma cases from Memorial Hospital. The core also maintains a bank of frozen sarcoma tissue and provides tissue specimens for molecular, biochemical, and genetic studies. This tissue bank is one of the largest collections of its kind in the United States.

### **St. Louis University Alzheimer's Brain Bank**

The Department of Geriatric Psychiatry at St. Louis University Health Sciences Center has established a community brain bank subsidized by the Alzheimer's Association. Almost 1,000 brains are stored at the brain bank. The brain bank specializes in degenerative brain diseases and dementias and is also involved in basic/clinical correlative research. Tissue samples are available to qualified investigators throughout the United States and abroad.

### **St. Paul-Ramsey Medical Center**

A brain bank has been established at the St. Paul-Ramsey Medical Center in Minnesota. The brain bank currently contains frozen slices of brain tissue from more than 700 people with Alzheimer's disease and other forms of dementia. Tissue samples have been sent to Alzheimer's investigators at other institutions for research into the diagnosis, treatment, and cause of Alzheimer's disease.

### **Tissue Bank for Research on HIV-Associated Malignancies**

A tissue bank for research on HIV-associated malignancies was established at the University Hospital of Downstate Medical Center in New York. The tissue bank is supported by the NCI. The goals of the tissue bank project are to maintain a central repository and database of neoplastic tissues and biological specimens of HIV-related malignancies with clinical and outcome data, to emphasize and prioritize the accrual of HIV-associated invasive and in-situ carcinoma of the uterine cervix, and to make available specimens for molecular, immunologic, genetic, and epidemiologic analysis to the scientific community. The participating institutions include the State University of New York Health Science Center at Brooklyn, King's County Hospital Center, and Woodhull Medical and Mental Health Center. Specimens may be shipped fresh to inves-

tigators, frozen as sterile, single-cell suspensions, or flash-frozen in a cryopreservative reagent. Parallel paraffin blocks to frozen specimens are also made and stored.

### **Tissue Banking for Early Detection Research Network**

The VA Medical Center in Pittsburgh, Pennsylvania, has established a tissue banking network that is supported by the Department of Veterans Affairs. Tissues from patients at risk for head, neck, and lung cancers will be obtained at surgery and stored in a tissue bank. These specimens will be used locally and distributed to requesting investigators at other institutions.

### **Tissue Core Facility at the Oral Cancer Research Center**

The Oral Cancer Research Center of the University of Texas M.D. Anderson Cancer Center maintains a tissue core facility. The tissue core facility is supported by the National Institute of Dental Research. The core will function as a central repository for patient specimens, including peripheral blood lymphocytes for different projects in the Oral Cancer Research Center. The core is responsible for the acquisition, storage, and distribution of histologically characterized samples from various lesions representing the histopathological spectrum of oral squamous neoplasia.

### **Tissue Culture Core**

The Tissue Culture Core at Weill Medical College of Cornell University serves as a common resource to provide specifically characterized cell cultures for faculty investigators. The Tissue Culture Core can provide human arterial smooth cell muscle cells, adventitial fibroblasts, umbilical vein endothelial cells, human monocyte-like cell lines, and peripheral blood monocytes. Fresh human platelets and neutrophils can be isolated per investigator request. All cell cultures are characterized immunocytochemically and tested for mycoplasma contamination.

### **Tissue/Pathology Core**

The Tissue/Pathology Core is the central facility providing tissue collection and services for investigators of the University of Michigan Specialized Center of Research (SCOR). The core processes human lung tissue from patients with interstitial lung disease and controls for protein and mRNA analysis. Human bronchioalveolar lavage fluid and cells are also collected and processed for protein and mRNA analysis.

### **Tissue Procurement and Banking Facility**

The Tissue Procurement and Banking Facility (TPBF) is an established CCSG-supported core facility at the University of Texas M.D. Anderson Cancer Center and is funded by the NCI. The TPBF provides human tumor tissues that have been removed for biopsy or therapeutic resections for ongoing research projects. The TPBF attempts to procure all pathologic tumor tissue from patient procedures for cryopreservation and characterizes tissues prior to distribution. Clinical data (epidemiology, family history, patient treatment, and patient outcome) for collected tissue specimens will be available through interactive databases.

### **Tissue Procurement Core**

The Tissue Procurement Core at the University of Michigan Comprehensive Cancer Center (UMCCC) is funded by the NIC and the University of Michigan. The Tissue Procurement Core is a service of UMCCC based in the Surgical Pathology Laboratory of the University of Michigan Hospital. The Tissue Procurement Core prospectively obtains surgically resected tissue for research and maintains a  $-80^{\circ}\text{C}$  freezer for limited storage. Tissue Procurement Core Services are available to UMCCC members only. For a nominal charge, histology services are available, including preparation of histologic sections from frozen and paraffin-embedded tissues, routine stains, and immunohistochemical stains. Acquisition of any tissue that is to be the subject of research or development requires IRB approval.

### **Tissue Procurement Core Facility**

The Tissue Procurement Core Facility at Dartmouth College is designed to serve as a central tissue acquisition and distribution facility. Tissues are obtained from the reproductive tracts of patients undergoing hysterectomy or endometrial biopsy for program project investigators. Cell suspensions and vibratome sections are made from tissues of the fallopian tube, uterus, cervix, and vagina. Pertinent patient information from chart and patient interview and clinical/pathological evaluation of tissue specimens is collected.

### **Tissue Procurement Shared Resource**

The Tissue Procurement Shared Resource (TPSR) at Ohio State University (OSU) Comprehensive Cancer Center was established as a shared service in 1975 to provide investigators with quality human tissue for research. TPSR obtains fresh tumor specimens to distribute around the world. The goals of the

center are to provide an organized structure to access human tissue; to increase availability and diversity of tissues; to provide quality specimens, pathology data, and maintain patient confidentiality; and to maintain efficient and cost-effective service. The service has handled more than 75,000 specimens, approximately 3,000 per year. TPSR currently is funded by a Cancer Center Support Grant, OSU funds, and other grants. Investigators can receive remnant surgical or autopsy tissue after filling out a TPSR application. The application must have an approved human subjects IRB evaluation. All tissues are uniquely coded, and investigators receive a pathology report specifically about the tissue. For an additional fee, TPSR will perform a histology quality-control analysis on a small sample of the investigator's specimen.

### **Tumor Bank for Solid Tumors**

The Tumor Bank for Solid Tumors at the Louisiana State University's Stanley S. Scott Cancer Center Tumor Bank, Department of Surgery, is supported by the Department of Veterans Affairs. All patients who have been previously scheduled for resection of malignancy are eligible to donate, and all tumor sites are collected. Aliquots of tumor and surrounding normal tissue are harvested. All tissue specimens are frozen, and routine pathology reports are collected with each specimen. Specimens are available for molecular analysis and correlative studies through the Stanley S. Scott Cancer Center. All tissue requests must have IRB approval and approval by the Director of the Louisiana State University Tumor Bank.

### **Western Genitourinary Tissue Bank**

The Western Genitourinary Tissue Bank is located in the Department of Pathology at the University of Pittsburgh Medical Center (UPMC). The Tissue Bank was established in the early 1990s and has successfully banked over 250 prostatectomy specimens. The bank also stores serum and lymphocyte components for each individual collected prior to the radical prostatectomy surgery.

In addition to collecting specimens in house, a collaborative effort with the Veterans Affairs Medical Center in Pittsburgh also provides tissue specimens for the bank.

### **Wisconsin's Alzheimer's Disease Brain Tissue Bank**

The Medical College of Wisconsin maintains an Alzheimer's Disease Brain Tissue Bank. More than 500 brain autopsies have been performed since its inception. Other tissue specimens and CSF samples from 267 cases are stored at  $-70^{\circ}\text{C}$ . Brain and tissue specimens are from cases of Alzheimer's, Lewy body



dementia, CJD, Huntington's, and normal controls. The brain bank no longer accepts brain tissue donations for research. All stored tissue specimens are available to investigators at the Medical College of Wisconsin and outside investigators on special request.

## COMMERCIAL ENTERPRISES

Some commercial enterprises maintain tissue banks for proprietary use, while others establish banks for storage and distribution purposes. LifeSpan BioSciences, Inc., is an example of a company that maintains a proprietary tissue bank and offers services using their tissue bank, while PathServe collects human tissues and organs to market them to the research community. Other commercial entities market products to facilitate analysis of human tissues—normal and diseased—such as Clontech. Materials with multiple tissue types, kits containing DNA/RNA samples, and even protein samples from human tissues are currently on the market. These types of products will most likely expand with the demand to find target disease genes and are useful to both academic and industry researchers.

### **LifeSpan BioSciences, Inc.**

LifeSpan BioSciences, Inc., founded in 1995, is a genomics company focused on the discovery and licensing of genes that play a role in the aging process and identifying disease-associated genes for use as therapeutic or diagnostic targets. Because highly characterized samples of normal and diseased tissues are critical in localizing disease-associated genes, LifeSpan has an on-site tissue bank. LifeSpan's Tissue and Disease Bank contains one million normal and diseased human samples. The tissue bank has more than 175 different types of tissues from virtually every organ in the body, covering all ages. The tissue bank also includes more than 1,500 different pathologic disease categories, such as autoimmune diseases, infectious diseases, degenerative diseases, cancer and benign proliferative diseases, and genetic diseases. LifeSpan BioSciences, Inc., does not sell its tissues per se but performs custom services using its tissue bank.

LifeSpan BioSciences, Inc., performs a variety of services on its proprietary tissues, including high-throughput gene expression analysis, bioinformatics, immunocytochemistry and in situ hybridization (ICC/ISH), and anatomic mapping. ICC and ISH are customarily performed using one tissue per slide and are accompanied by a pathologic report of the lesion and the result from the test.

## **PathServe**

PathServe Autopsy and Tissue Bank, established in 1990 and commercial since 1996, is a major supplier of human tissue to biotechnology and neuropathological research institutions. PathServe also serves as a main training facility of autopsy technicians for private pathologists and local hospitals. PathServe collects all types of organs and tissues, including placental and fetal specimens. Tissues are obtained through postmortem examinations, referrals from transplant banks of nontransplantable organs, and donations by next of kin. PathServe collects specimens from approximately 300 autopsies per year, and each autopsy yields approximately 100 specimens. PathServe has approximately 300 specimens stored at any one time and has distributed approximately 30,000 specimens in the last year. Consent for donation is obtained from the family. PathServe does not maintain a centralized storage facility. Instead, specimens are stored in the morgues of different hospitals.

## **Clontech**

Clontech was established in 1984 as a developer and marketer of biological products to the life sciences market worldwide. Clontech's mission is to accelerate the discovery process by providing innovative tools that enable researchers to answer complex questions more expediently. Clontech was the first to make several key technologies available to the biomedical field, including the green fluorescence protein-based reporter system, two-hybrid analysis systems for the study of protein interactions, and gene array technology for high-throughput differential expression analysis. Such recent products as RNA Master Blots and high-quality protein samples facilitate screening of normal and diseased human tissues from multiple organs. These products enable researchers to profile tissue expression patterns of known genes or expressed sequence tags (ESTs), to obtain high-throughput analysis of gene expression profiles in different tissues, and to perform rapid screenings of tissue-specific patterns of genes.

## **NONPROFIT ORGANIZATIONS (NONEDUCATIONAL)**

A variety of nonprofit institutions bank tissues for storage and distribution. Nonprofit institutions, such as the American Type Culture Collection, Coriell Institute for Medical Research, the Research Foundation for Mental Hygiene, the Rocky Mountain Multiple Sclerosis Center, the National Psoriasis Tissue Bank, the Kaiser Permanente Center for Health Research, and the Hereditary Disease Foundation, receive millions of dollars in federal funding. Descriptions of these nonprofit centers that bank tissue are detailed below.

### **American Type Culture Collection**

Since its establishment in 1925, the American Type Culture Collection (ATCC) has served as an archive of living cultures and genetic materials for researchers in the biological sciences. The mission of the ATCC is to acquire, authenticate, and maintain reference cultures, related biological materials, and associated data and to distribute these to qualified scientists in government, industry, and education. The ATCC has approximately 2,300 human cell lines. All of the human cell lines are immortalized cultures and the genetic material is mainly the products of recombinant DNA research. ATCC is creating new products to facilitate screening of multiple cell lines/tissue types. For example, the ATCC Express-Check is a kit that contains DNA from human tissue-specific cDNA libraries.

### **Biologic Specimen Bank**

The Research Institute on Addictions in New York has established a biologic specimen bank to support scientific research projects at the institute. The bank will collect and store frozen specimens of plasma, serum, cells, cell membranes, and urine from randomly selected African-American and Caucasian men and women, aged 35 to 79. Control tissue specimens will be collected from two case-control studies on myocardial infarction and lung cancer and participants in the research component project on the epidemiology of treated and untreated alcoholics. Blood samples from more than 7,500 men and women are expected to be collected and stored.

### **Biomedical Research Institute**

The Biomedical Research Institute is a nonprofit entity established in 1948 to provide research and development services. The Biomedical Research Institute specializes in tropical disease vaccines and provides biological repository services to federal agencies. The National Institute of Child Health and Human Development (NICHD) is conducting a trial of calcium supplementation in pregnancy. The Biomedical Research Institute will store, monitor, and distribute serum, plasma, and urine samples collected from this trial. More than 4,500 pregnant women are expected to enroll in this study from five clinical centers. NICHD has also contracted with the Biomedical Research Institute for banking blood specimens in a similar fashion for two other studies: Diabetes in Early Pregnancy and Successive Small-for-Gestational-Age Birth.

## **Coriell Institute for Medical Research**

The Coriell Institute for Medical Research is a basic biomedical research institution that conducts research on the causes of genetic diseases, including cancer. The Coriell Institute's three missions are research, cell banking, and public education. The largest collection of human cells for research is maintained at the Coriell Institute, and these cells are available to the general scientific community. Seminal research on the genes associated with Huntington's disease, cystic fibrosis, Alzheimer's disease, ataxia telangiectasia, and manic depression have utilized cells from the Coriell collection. In 1990, the NIMH awarded the Coriell Institute a \$5.7 million contract to establish a cell repository for the study of the genetic basis of Alzheimer's disease, manic depression and schizophrenia. New repositories have recently been established for the study of diabetes.

The Coriell Cell Repositories are supported by NIH and several foundations. More than 35,000 cell lines are currently stored, representing approximately 1,000 of the 4,000 known genetic diseases, and 60,000 cell lines have been distributed to more than 40 nations, resulting in 8,000-plus research publications. Cultures are established from both blood and skin, and the cells are stored frozen at the institute. Three-quarters of a million vials of cells are kept in 37 giant liquid nitrogen tanks. The Coriell Cell Repositories currently consist of four cell collections described below.

**Human Genetic Mutant Cell Repository.** The Human Genetic Mutant Cell Repository is sponsored by the National Institute of General Medical Sciences (NIGMS). The repository supplies scientists with materials for advancing the discovery of disease-related genes. Their resources include highly characterized, viable, contaminant-free cell cultures and high-quality DNA derived from these cultures. The repository contains both DNA and cell cultures from human and animal cell cultures, normal controls, inherited disorders and normal variants, and NIGMS extended family collections.

**NIA Aging Cell Repository.** The NIA Aging Cell Repository is a collection set up to facilitate cellular and molecular research studies on the mechanisms of aging and degenerative processes. Included in the collection are cell cultures from aging syndromes, Alzheimer's, normal fibroblasts from a lifetime study, lymphoblasts for aged sib pairs, and a variety of other cell types.

**American Diabetes Association (ADA) Cell Repository Maturity Onset Diabetes Collection.** The ADA Cell Repository Maturity Onset Diabetes Collection is derived from the ADA Genetics of non-insulin dependent diabetes mellitus/NIDDM (GENNID) Study. The purpose of the study is to establish a national database and cell repository consisting of information and genetic

material from families with well-documented NIDDM. The repository contains DNA samples and phenotypic data from subjects enrolled in Phase I ADA GENNID trials (170 pedigrees, all of which contain at least one affected sib pair, with a total of 650 affected individuals and approximately 1,200 subjects). The data set includes multiple metabolic factors, such as carbohydrate metabolism, lipid metabolism, and body size measures, as well as lifestyle variables. New additions to the collection include families and pedigrees, sib pairs, and DNA samples from Phase II of the ADA GENNID study.

**Human Biological Data Interchange Cell Repository Juvenile Diabetes Collection.** The Human Biological Data Interchange (HBDI) Cell Repository Juvenile Diabetes Collection contains quality-controlled cell lines and DNA from more than 400 families for distribution.

### **Fox Chase Network Breast Cancer Risk Registry**

The Fox Chase Network Breast Cancer Risk Registry is supported by the Department of the Army. The goal of the registry is to establish a breast cancer risk registry to serve as a resource for research activities investigating the etiology and prevention of breast cancer. Women with one or more first-degree relatives with breast cancer are identified, and information about family history, personal medical history, lifestyle and environmental factors, health practices and beliefs, and psychological status are entered into a comprehensive database. Serum and DNA from women in this high-risk registry are stored in the Fox Chase Cancer Center/Network Breast Cancer Tissue Registry. In addition, a high-risk specimen bank contains DNA, red blood cells, plasma, and breast tissue.

### **HealthPartners Human Brain Bank**

The HealthPartners Human Brain Bank in Minnesota was established by Dr. William Frey in 1977. The brain bank is supported by the Regions Hospital Foundation, pharmaceutical companies, and other private foundations and individuals. The brain bank contains frozen human brains from cases of Alzheimer's disease, multi-infarction dementia, dementia with Lewy bodies, Parkinson's disease, Pick's disease, CJD, unclassified dementias, and nondemented normal controls. More than 2,000 brain specimens have been collected. These brain specimens are available to collaborating investigators.

### **Hereditary Disease Foundation**

The Hereditary Disease Foundation of Santa Monica, California, is studying the genes involved in Huntington's disease in a Venezuelan kindred of more than

14,000 people. Through study of this kindred, the gene for Huntington's disease was localized to chromosome 4p. This kindred is a valuable resource, enabling researchers to study members who share background genes and a common environment. The Hereditary Disease Foundation is studying the unstable trinucleotide (CAG) repeat found in the Huntington's disease gene. Huntington's disease has afflicted more than 400 people and now threatens 4,697 at-risk children in this kindred. To study this protein, the Hereditary Disease Foundation is collecting tissue samples, including lymphoblast lines and sperm samples, to examine the effect of age, disease duration, birth order, and environmental factors on sperm. Brain and other postmortem tissues from genetically and clinically well-characterized members of the kindred are also being collected to understand how the Huntington protein specifically devastates striatal neurons.

### **The International Skeletal Dysplasia Registry**

The International Skeletal Dysplasia Registry at Cedars-Sinai Medical Center in California is a referral center for the diagnosis and management of skeletal dysplasias. The registry is supported by grants from NIH and the Steven Spielberg Pediatric Research Center. Materials submitted to the registry are archived and used for future research studies. Samples collected include histology blocks and slides, frozen and fixed tissue specimens, cell cultures (including fibroblasts, chondrocytes, and lymphoblastoid cells), blood (from patient and both parents), and DNA. Clinical summaries, pedigrees, photographs, and x-rays are also collected.

### **Kaiser Permanente Center for Health Research**

The Kaiser Permanente Center for Health Research (CHR) is a nonprofit health-care research institute established in 1964. More than 40 studies are under way and some involve the storage of tissue. For example, the CHR started the Benign Breast Disease Registry (BBDR), funded by the NCI. The BBDR includes data on nearly 10,000 women diagnosed between 1970 and 1994. The registry provides both benign and malignant archived tissue to researchers. In another NCI-sponsored breast cancer study, almost 16,000 breast cancer cases and associated archived tissue are available to qualified researchers for molecular studies. In the last 20 years, more than 25,000 people in the Portland-Vancouver area have voluntarily participated in the research at the CHR. Clinical trials involving archived tissue are also undertaken. For instance, the Fracture Intervention Trial is an 11-center double-blind, placebo-controlled, randomized clinical trial to determine the efficacy of alendronate in preventing frac-

tures secondary to osteoporosis. The CHR has received more than \$96 million in grants from federal and state agencies and private foundations.

### **Maryland Brain Collection**

The Maryland Brain Collection (MBC) is a collaboration between the Maryland Psychiatric Research Center and the Office of the Chief Medical Examiner of Maryland. The MBC collects material for investigators interested in studying the aspects of human postmortem brain structure and function. Specimens are collected from deceased persons with schizophrenia, suicide victims, and healthy controls. Extensive clinical information is also obtained with each specimen and is available to investigators.

### **McKesson BioServices**

McKesson BioServices, formerly Ogden BioServices Corporation, was established in 1986 to provide a cost-effective and focused process in several areas of drug development, such as regulatory affairs, formulation development, and biological specimen storage and distribution. McKesson BioServices currently stores more than 20 million biological specimens in their Biological Specimens Repository. Some of the nationally known collections of biological specimens stored by McKesson BioServices are briefly described in Table 3.2.

### **National Disease Research Interchange**

The National Disease Research Interchange (NDRI) is a nonprofit organization that arranges for the procurement and distribution of human tissues and organs for biomedical researchers. NDRI has been operating for 17 years and has provided more than 125,000 tissue specimens of more than 100 types of tissues to scientists nationwide. NDRI is composed of three programs with different objectives to facilitate the use of human tissues and organs for researchers:

- **Human Tissues and Organs for Research (HTOR):** This unit focuses on retrieval and distribution of tissues and organs from autopsy and surgical procedures, as well as specimens obtained from eye and tissue banks. Examples include whole or partial organs, such as heart, lung, kidney, brain, liver, eyes, and bones and joints.
- **Human Biological Data Interchange (HBDI):** This unit stores genetically valuable family collections for use in the advancement and study of the genetic basis for disease. The HBDI repository currently holds biomaterials from more than 500 families and also contains family and medical history data on more than 6,500 families with diabetes.

- **Odyssey One:** This unit was established to respond to new and emerging needs of biomedical researchers in innovative areas related to the use of human materials in research. The unique and hard-to-get tissues that they have provided include pancreatic islet cells, malignant tumors and normal adjacent tissue, and bone marrow stem cells.

**Table 3.2**  
**McKesson BioServices- Biological Specimen Repository**

Collection	Description
Army-Navy Serum Repository (ANSR)	The ANSR contains more than 18 million sera specimens collected from active-duty and reserve personnel. This repository is the largest collection of normal human sera from all race and ethnic groups and all geographic areas in the United States. This repository provides the Army with a seroepidemiology resource to assess exposure to infectious and toxic agents during deployment, to estimate immunity prevalence for a variety of diseases, and to determine the causes of, risk factors for, and determinants of acute and chronic diseases associated with military operations.
NHLBI-sponsored studies	The National Heart, Lung, and Blood Institute (NHLBI) contracts with McKesson BioServices to maintain a repository of blood specimens from NHLBI-sponsored studies. These specimens will be made available to investigators for research projects related to transfusion-transmitted diseases and a variety of other disorders of blood or the cardiovascular system. A serum, plasma, and cell repository is maintained and serologic and virologic assays are performed.
Collaborative Perinatal Project (CPP) Serum Repository	The CPP was a prospective cohort study of pregnancy and child development administered by the National Institute of Neurological and Communicative Disorders (NINCD). The purpose of the project was to enroll pregnant women between 1959 and 1966 and conduct follow-up neurological, psychological, pediatric, and speech-hearing studies on the children to determine factors responsible for the development of neurological disorders of childhood. The CPP collected serum from the women during pregnancy, delivery, and postpartum, and umbilical cord serum from the newborns, and serum from the infant at 4 months of age. More than 833,000 vials of serum were collected.
Diet Intervention Study in Children (DISC) Study Effort	The objectives of the DISC project are to determine whether a fat-modified diet during childhood and adolescence will lower LDL-cholesterol and to assess the feasibility and safety of this diet. The DISC project is being conducted at 6 clinical centers and a coordinating center. More than 600 children, between the ages of 8 and 10 who had LDL-cholesterol levels between the 80th and 98th percentiles and other criteria were randomized into the intervention or control group. Serum samples were collected at baseline and 12, 36, 37, 60, and 84 months and at 18 years of age after follow-up.



Table 3.2- continued

Collection	Description
National Health and Nutrition Examination Survey (NHANES) Serum Bank	The CDC NHANES project is a national probability sample survey program serving as a source of data obtained by standardized health examinations. Serum has been drawn from over 30,000 participants and stored at $-80^{\circ}\text{C}$ for future studies. These samples are available to government agencies and for other approved sociodemographic studies.
Polyp Prevention Trial (PPT)	The PPT is a multicentered randomized clinical study to determine if a low-fat, high-fiber, vegetable-, and fruit-enriched diet would decrease the rate of recurrence of large bowel adenomatous polyps. Under subcontract with Westat, Inc., McKesson BioServices provides biological repository services involving blood and tissue/biopsy specimen receipt, cataloging, storage, and inventory control.
Vaccine Evaluations	The NICHD conducts the Group B Streptococcus Study. McKesson BioServices is subcontracted by Westat, Inc., to provide biological repository services. An estimated 65,000 vials of serum and isolates will be collected and stored by McKesson BioServices sent by participating clinical centers. A computerized inventory system will be established for tracking and retrieval of all specimens.

### National Neurological Research Specimen Bank

The National Neurological Research Specimen Bank (NNRSB) was established in 1961 to provide a vital resource to neuroscientists. The NNRSB is supported by NINDS/NIMH, the Department of Veterans Affairs, and private organizations, such as the National Multiple Sclerosis Society. The NNRSB at the VA Medical Center in Los Angeles, California, collects, cryogenically stores, and distributes donated tissue to research scientists around the world. The specimen bank stores pre- and postmortem tissues and cerebrospinal fluid/blood and other neurological specimens from patients with multiple sclerosis, Huntington's disease, Parkinson's disease, Alzheimer's disease, and HIV/AIDS.

### National Psoriasis Tissue Bank

The National Psoriasis Tissue Bank (NPTB) is the only international public source of genetic material for psoriasis research. The bank is dedicated to finding the genetic causes of psoriasis and psoriatic arthritis. The stored tissue is available for use by international experts. The NPTB is supported by private donations through the National Psoriasis Foundation (NPF), a voluntary non-profit national health agency. The NPTB consists of nearly 300 Epstein-Barr virus (EBV)-transformed cell lines, isolated DNA, fibroblasts from families with psoriasis and psoriatic arthritis, and blood samples from sibling pairs providing an additional 1,000 DNA samples. Researchers can obtain the cell line, DNA,

family history, and medical history of any individual in the bank; however, names and locations of contributors remain anonymous. There is a small fee for the service. Blood and skin samples are obtained by a medical team at the Baylor Psoriasis Center, a regional referral Center at Baylor University Medical Center in Dallas, Texas.

### **New York State Multiple Sclerosis Consortium**

The New York State Multiple Sclerosis Consortium brings together research and clinical expertise of 15 major medical centers in New York in an effort to further define the multiple sclerosis (MS) population in terms of demographic, clinical, functional, quality-of-life, and treatment parameters. The Department of Neurology at Buffalo General Hospital is the coordinating center for the New York State MS Consortium. Current research efforts involve the development of an MS patient registry and centralized database of MS patient information and the collection of specimens, including blood, tissue, and cerebrospinal fluid, for member centers. Tissue specimens are stored at the Baird Multiple Sclerosis and Neuroimmunology Tissue Repository, which was established in 1991 and is funded by a grant from the Baird Foundation to the Millard Fillmore Health, Education, and Research Foundation. The repository has collected more than 1,000 tissues and fluids from MS patients, along with detailed demographic and neurologic data.

### **Rocky Mountain Multiple Sclerosis Center Tissue Bank**

The Rocky Mountain Multiple Sclerosis Center (RMMSC) Tissue Bank, one of the largest MS tissue banks in the world, was established in 1976 to procure, process, preserve, and distribute MS brain tissue to research laboratories from all over the world involved in finding the cause of and cure for MS. More than 170 CNS samples have been banked at RMMSC, representing material from a well-defined patient population. The stored tissue has led to several key discoveries in the pathogenesis of MS. The bank is funded by the National Multiple Sclerosis Society.

### **St. Luke's- Roosevelt Institute for Health Sciences**

The Neuropathology Core at St. Luke's-Roosevelt Institute for Health Sciences has established a bank of CNS tissues from children who died with HIV-1 infection. The tissue bank is supported by the NINDS. Snap-frozen tissue blocks have been collected from 25 cases, and formalin-fixed, paraffin-embedded tissue blocks have been stored from these cases and from an additional 50 cases. Tissues will also be collected from HIV-1 negative control cases and HIV-1-

infected and negative adults. Tissue specimens are available to core investigators from the Neuropathology Division of Columbia-Presbyterian Medical Center. The core provides neuropathology support and tissue immunocytochemistry services.

### **The Stanley Brain Collection and Neuropathology Consortium**

The Stanley Brain Collection and Neuropathology Consortium was set up in 1994 and is privately funded by the Theodore and Vada Stanley Foundation. Its mission is to make postmortem brain tissue from individuals with schizophrenia, bipolar disorder, major depression, and normal controls available for scientific investigations. The Stanley Foundation supports approximately half of all research in the United States directly related to bipolar disorder. The Stanley Foundation Brain Collection obtains brains through designated medical examiners in several cities. The brains are then forwarded to the NIMH Neuroscience Center at St. Elizabeth's Hospital in Washington, D.C. More than 200 brains have been collected so far and hospital and outpatient records are obtained with each brain to establish a firm diagnosis. All brains are fixed in a uniform manner: Half of the brain is frozen, and the other half is formalin-fixed. Selected areas of the brain thought to be involved in severe psychiatric disorders (e.g., hippocampus, basal ganglia, and prefrontal cortex) are dissected out and then sectioned into thin slices that are fixed to a glass slide.

The Stanley Foundation Neuropathology Consortium is a collection of 60 brains. The collection consists of four sets of 15 brains each from persons with schizophrenia, bipolar disorder, depression, and normal controls. The four sets are matched for age (mean age is 40), sex, race, side of brain, postmortem interval, and quality of brain DNA.

There are four main goals of the Stanley Foundation Neuropathology Consortium. The first is to make brain tissue from individuals with severe psychiatric disorders available to researchers. Secondly, different laboratories can measure the same thing in this uniform brain collection and be able to compare results. Thirdly, the consortium attempts to provide a composite picture of what is wrong in the brains of these individuals and how each differs from normal controls. Lastly, the consortium will be able to compare results on the brains of individuals with schizophrenia, bipolar disorder, severe depression, and normal controls to determine differences and similarities.

The 60 consortium brains are available at no charge to researchers worldwide. The brain specimens are distributed coded so that the research is conducted as a blind study. When the research is completed, the results are sent to Washington, and the codes are then sent to the investigators.

### **State of Florida Brain Bank**

A brain bank was established by the State of Florida in 1985 and is supported by state funds. The bank was established as part of the state's Alzheimer's Disease Initiative (ADI), which supports research, service, and training in Alzheimer's disease and related memory disorders. The objectives of the ADI Brain Bank are to provide tissue for Alzheimer's disease research, to establish a diagnosis for use in clinical and pathological studies, and to provide families with a confirmed diagnosis. The bank is at the Mount Sinai Medical Center in Miami, Florida, and thirteen institutes in the state serve as sources of brains.

Brain tissue specimens are stored either frozen or fixed and more than 1,000 brains have been autopsied and stored. Tissue specimens are available to approved investigators at no cost.

### **Tissue Accrual and In Situ Imaging Core**

The Wistar Institute maintains a tissue accrual and in situ imaging core to collect tissue specimens from melanomas, nevi, and blood samples. The core is supported by the NCI. The core has one of the largest collections of primary melanocytic cell cultures and freshly isolated DNA collections from these tissues. The core also has access to human tissue biopsies, including thousands of pigmented lesions from affiliated laboratories, such as Surgical Pathology (20,000 accessions per year).

### **Tumor Bank Facility at the Herbert Irving Comprehensive Cancer Center**

The Tumor Bank Facility at Columbia-Presbyterian Medical Center's Herbert Irving Comprehensive Cancer Center in New York was established in 1972 to maximize investigational use of human tissues removed at surgery or autopsy. The core facility provides a mechanism for optimal collection, examination, and distribution of all human tissues for investigative purposes. The Tumor Bank contains both "targeted" and "nontargeted" specimens. The nontargeted specimens are tumors and tumor/normal tissue pairs collected and cryopreserved in substantial numbers. Most tissue specimens are snap-frozen to facilitate subsequent preparation of frozen sections for histology, immunohistochemistry, and other types of analyses and to preserve tissue for DNA/RNA isolation. Columbia-Presbyterian Cancer Center members may request specific tissues types. Users of the Tumor Bank Facility must be members of the Herbert Irving Comprehensive Cancer Center, and there is no charge for the specimens.



A tumor registry is a cancer data system that provides continued follow-up care on all cancer patients in a given location, hospital, or state. A tumor registry documents and stores all significant elements of a patient's history and treatment. Many registry databases include information concerning demographics, medical history, diagnostic findings, primary site, histological type of cancer, stage of disease, treatment(s), recurrence, subsequent treatment, and end results. A variety of studies and reports can be generated from the information contained in tumor registries.

Several registries also collect patient specimens, such as blood samples or slides of resected tumors. These specimens may be used for educational purposes as case studies or for research purposes. Several tumor registries that collect tissue specimens are described below as well as some of the larger tumor registries. For a more complete listing of tumor registries, see Appendix F.

#### **THE NATIONAL FAMILIAL PANCREAS TUMOR REGISTRY**

The National Familial Pancreas Tumor Registry was established in 1994 at Johns Hopkins Hospital in Maryland. The goals of the registry include documenting whether or not neoplasms of the pancreas occur in families, evaluating selected families to gain a better understanding of the genetic basis for development of carcinoma of the pancreas, and serving as a resource to other investigators interested in pancreatic cancer. Currently, 131 families have been entered into the registry. Families referred to the registry will be asked to fill out a questionnaire, and medical records and pathology slides of each affected family member are reviewed to confirm all cases. Blood samples are drawn from selected cases for genetic analysis. The registry is currently supported by private donors.

### **CALIFORNIA TUMOR TISSUE REGISTRY**

The California Tumor Tissue Registry is a nonprofit organization committed to the enhancement of patient care. It was established in 1947 and was first funded by the California Medical Association. The registry is at the Loma Linda University School of Medicine in California. The goals of the registry are to educate and improve patient care, to provide high-quality consultation, and to serve as a resource for rare tumors. Through its education program, the registry provides subscribers with slides of rare and unusual tumors. A repository is maintained by the registry with more than 30,000 accessions and 30,000 consultations. Although the registry's influence is predominantly in California, it has provided materials to several other states, countries, and pathology teaching programs.

### **NCI COOPERATIVE FAMILY REGISTRY FOR BREAST CANCER STUDIES AND NCI COOPERATIVE FAMILY REGISTRY FOR COLORECTAL CANCER STUDIES**

The Cooperative Family Registry for Breast Cancer Studies (CFRBCS), initiated by the NCI in 1995, contains biological specimens from patients with a family history of breast cancer, breast/ovarian cancer, or Li-Fraumeni syndrome and from their relatives. Six CFRBCS sites collaborate to ascertain families at high and intermediate risk for breast cancer.<sup>1</sup> Specimens are in the form of tissue sections from paraffin-embedded breast and ovarian cancers, peripheral blood lymphocytes, serum, fresh-frozen tissue, and other biological fluids. The CFRBCS provides related family history (pedigrees), clinical, demographic, and epidemiologic data on risk factors exposures but will not provide patient identification. In addition, the CFRBCS provides follow-up epidemiologic data as well as data on recurrence, new morbidity, and mortality from participating families. The CFRBCS repository and related databases are available to researchers to provide a resource for interdisciplinary and translational breast cancer research.

The Cooperative Family Registry for Colorectal Cancer Studies, a similar resource for colorectal cancer, was established in 1998. NCI supports six registries throughout the world including four in the United States: the University of Washington in Seattle, the University of Hawaii, the Mayo Clinic in Min-

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<sup>1</sup>The six CFRBCS collaborating sites are the Australian Breast Cancer Family Registry, the Metropolitan New York Registry of Breast Cancer Families, the Northern California Cooperative Family Registry, the Ontario Registry for Studies of Familial Breast Cancer, the Philadelphia Familial Breast Cancer Registry, and the Utah Cooperative Breast Cancer Registry.

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nesota, and the University of Southern California. These registries perform several tasks, including assembling and maintaining comprehensive lists of families with histories of colon cancer, collecting detailed information about possible factors involved in the cancer process, and serving as a storehouse of blood samples and tumor biopsies from family members for research purposes. The data and samples collected at any of these registries are available to investigators worldwide.

### **FAMILIAL BRAIN TUMOR REGISTRY**

The mission of the Familial Brain Tumor Registry is to identify families who are at high risk for brain tumors and multiple cancer. The Familial Brain Tumor Registry is located at the University of Texas M.D. Anderson Cancer Center. The registry serves as a resource of families at high risk of cancer and allows for the study of genetic factors associated with the disease. Enrollment of families requires the occurrence of a brain tumor and another cancer in the immediate family. A short interview is conducted with the family to obtain a detailed family history of cancer. Blood samples or buccal smears are collected from family members.

### **SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS PROGRAM**

The Surveillance, Epidemiology, and End Results (SEER) Program was established in 1971 and is supported by NCI. The goals of the SEER Program include assembling and reporting estimates of cancer incidence and mortality in the United States; monitoring annual cancer incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups; providing continuing information on changes over time in disease, trends in therapy, and patient survival rates; and promoting studies designed to identify factors amenable to cancer-control interventions, such as dietary or environmental exposures, screening practices, and treatment practices.

The SEER Program collects cancer data on a routine basis from designated population-based cancer registries in nine areas of the United States. The geographic areas represent an estimated 14 percent of the U.S. population. Trends in cancer incidence, mortality, and patient survival as well as many other studies are derived from the SEER database. The database contains information on approximately 2.3 million in situ and invasive cancers diagnosed between 1973 and 1996, with approximately 125,000 new cases accessioned each year.



## **NEW YORK STATE CANCER REGISTRY**

The New York State Cancer Registry in Albany, New York, is administered by the New York State Department of Health with supporting funds from the Centers for Disease Control and Prevention. The registry collects, processes, and reports information about every New Yorker diagnosed with cancer. The New York State Cancer Registry is one of the oldest cancer registries in the country and has been collecting information on patients with cancer for more than 50 years.

The Cancer Registry includes reports of all malignant cancers, except selected skin cancers. The Cancer Registry receives more than 135,000 case reports each year, representing more than 83,000 new tumors. It collects data on the anatomic site of the tumor, the stage of diagnosis, morphology, and treatment information. It also collects specific sociodemographic information on each individual. In total, more than 100 different pieces of information on each person are collected.

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## **TISSUE COLLECTIONS CREATED FROM LONGITUDINAL AND INDIVIDUAL RESEARCH STUDIES**

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Research on human disease or human physiology has long required the examination of human tissue from multiple research subjects. Tissues from both affected patients and normal controls are necessary for comparison studies to ascertain the etiology and pathology of a particular disease. By studying diseased tissue, researchers can delineate the normal pathway and understand the mechanisms underlying growth, development, and function. Thus, an advantage exists in obtaining tissue from affected persons for scientific study.

In a world where time and money are scarce, it is extremely costly for researchers who require tissue samples from a select group to wait for these persons to enter their hospitals or clinics. Often, different research projects may require the same set of tissue samples. This chapter briefly describes several research studies that have already collected or are continuing to collect human tissue samples. Depending on how these tissues were obtained, they may be available for other research studies.

### **LONGITUDINAL STUDIES**

Longitudinal studies, in which the same group of individuals is studied at intervals over a prolonged period, often collect large numbers of specimens that can be used for both retrospective and prospective research. Several well-known longitudinal studies have been conducted over the years, including the Physicians' Health Study, the Nurses' Health Study, and the Framingham Heart Study. Other large longitudinal studies include the Women's Health Initiative, the Health Professionals Follow-Up Study, the MRFIT study, and the National Health and Nutrition Examination Surveys. Several longitudinal studies are described below.

### **The National Institutes of Health Women's Health Initiative**

The NIH Women's Health Initiative (WHI), established in 1991, is the largest preventive study of women's health in the United States. The WHI is a 15-year research program, concluding in 2005, that focuses on the major causes of death, disability, and impaired quality of life in postmenopausal women. The overall goal of WHI is to reduce coronary heart disease, breast and colorectal cancer, and osteoporosis in postmenopausal women through prevention, intervention, and risk factor identification.

The WHI will involve more than 168,000 women of all races and socioeconomic backgrounds aged 50–79. Recruitment began in September 1993 and concluded in January 1998. The WHI conducts three studies: a randomized clinical trial, an observation study, and a community prevention study. Almost 70,000 women are enrolled in the randomized clinical trial that consists of three study groups: hormone replacement therapy, dietary modification, and calcium and vitamin D supplementation. Eligible women could choose to be in one, two, or all three of the study groups. The observational study will track the medical history and health habits of approximately 100,000 women to examine the relationship between lifestyle, health and risk factors, and disease. The clinical trial and observational study are conducted at 40 clinical centers nationwide. The Fred Hutchinson Cancer Research Center in Seattle, Washington, is the WHI Clinical Coordinating Center for data collection, management, and analysis.

The 168,000 women enrolled in both the clinical trial and the observational study will be followed for eight to 12 years and will provide multiple blood samples throughout the course of the study. Participants sign a consent form that states that the collection of blood samples is for use in future research, which may include genetic research, and participants will not be informed of any test results. Participants may opt out of having their samples used for genetic research if they so desire. The clinical trial participants provide a blood sample at their initial visit and at their one-year visit, and a subset of participants have samples drawn at three, six, and nine years. Blood samples are also collected from participants in the observational trial at their initial visit, and then again at their three-year visit. Blood samples are divided into serum, plasma, and buffy coat and are stored at a central facility in Rockville, Maryland. Participants' charts contain identifying information, including name, Social Security number, and address and telephone number, which are bar-coded. Blood samples are labeled with matching bar codes to link them to the charts. Approximately 27,000 women will be enrolled in the hormone replacement therapy trial, some of whom will also undergo an endometrial biopsy to

rule out endometrial hyperplasia or cancer.<sup>1</sup> These biopsies are stored at the individual clinical centers within the pathology departments and are labeled with a pathology accession number. In cases where abnormalities are detected, slides of the biopsy are bar-coded and sent to a central laboratory at NIH. Participants and their physicians are informed of any abnormalities found in the endometrial biopsy. All study records will be kept indefinitely for analysis and follow-up.

The third component of the WHI, the community prevention study, is a five-year collaborative effort with the Centers for Disease Control and Prevention (CDC) to study community approaches to developing healthy behaviors. This study will include women of all races and socioeconomic backgrounds, aged 40 and over. Eight university-based prevention centers will conduct and evaluate health programs that encourage women to adopt improved diet, nutritional supplementation, smoking cessation, exercise, and early detection of treatable health problems, among other healthy behaviors.

### **Baltimore Longitudinal Study of Aging**

The Longitudinal Studies Branch of the NIA is responsible for the operation and management of the Baltimore Longitudinal Study of Aging. The Baltimore Longitudinal Study was initiated in 1958, enrolling only men until 1978, when women were included. The Longitudinal Studies Branch has a research program based primarily on the Baltimore Longitudinal Study because it offers a unique opportunity to study a number of aging-related diseases and disabilities, including frailty, Alzheimer's disease, cardiovascular disease, cancer, osteoporosis, and menopause.

Storage of blood samples and blood fractions began in 1963 and has been systematically continued since. Serum, plasma, lyophilized erythrocytes and whole-blood plasma (including leukocytes), and aliquots of 24-hour urine collections have all been stored. Over the years, samples have been used for various approved protocols. For example, a longitudinal study of prostate-specific antigen (PSA) was retrospectively performed and demonstrated that continued monitoring of PSA levels could detect prostatic cancer many years earlier than usual clinical measures could.

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<sup>1</sup>It is estimated that approximately one-third of the women enrolled in the hormone replacement therapy trial will have had a hysterectomy and therefore will not undergo the endometrial biopsy.

### **The Nun Study**

The Nun Study is a longitudinal study of aging and Alzheimer's disease funded by the NIA. The Nun Study is based at the University of Kentucky, Sanders-Brown Center on Aging. A total of 678 women between the ages of 75 and 103 were drawn from the School Sisters of Notre Dame religious congregation. Each participant is annually assessed on her cognitive and physical function, and a brief medical exam is performed and a blood sample taken. Investigators have full access to each participant's archival and medical records. Each study participant has also agreed to donate her brain at death for further scientific study.

### **Bogalusa Heart Study**

The Bogalusa Heart Study, ongoing since 1972, is the longest and most detailed study of children in the world. The Bogalusa Heart Study is an NIH-sponsored Specialized Center of Research (SCOR) at Louisiana State University Medical Center, run by a multidisciplinary team of anthropologists, biochemists, cardiologists, epidemiologists, geneticists, nurses, nutritionists, psychologists, sociologists, and statisticians. The study seeks to understand the environmental and hereditary aspects of early coronary artery disease, essential hypertension and cardiovascular risk factors in African-American and Caucasian children in the semirural community of Bogalusa, Louisiana. In addition, 160 substudies have been conducted, including special studies on socioeconomic evaluations, blood pressure, lipid levels, genetics, exercise, heart murmurs, and pathology. Knowledge gained in the Bogalusa Heart Study has been applied to develop, test, and evaluate methods for cardiovascular risk intervention.

The Bogalusa Heart Study has conducted cross-sectional and longitudinal observations on more than 14,000 children and young adults. For example, a post-high school study currently follows subjects until 38 years of age. Blood samples have been sent to Boston, Baltimore, Sweden, and Finland for special analysis. More than 632 publications, three textbooks, and numerous monographs have been produced using samples and data from the Bogalusa Heart Study.

### **National Health and Nutrition Examination Survey**

Since 1960, the National Center for Health Statistics (NCHS) of the CDC has conducted seven health examination surveys of the population of the United States: the National Health Examination Surveys (NHES) Cycles 1, 2 and 3, the National Health and Nutrition Examination Surveys (NHANES) I, II and III, and the Hispanic Health and Nutrition Examination Survey (HHANES). The surveys

are designed to assess the health and nutritional status of children and adults in the United States periodically through interviews and direct physical examinations. The surveys employ interviews to answer questions about demographics, socioeconomic status, dietary habits, health-related issues, and physical and dental examinations, which include physiologic assessments and laboratory tests. Blood samples are collected as part of the physiologic assessments and placed in storage banks after laboratory tests are completed.

Cumulatively, the health examination surveys have analyzed and banked samples from more than 85,000 participants. The most recent survey, NHANES III, conducted between 1988 and 1994, performed laboratory tests on approximately 30,000 people of all races aged 2 months and older from 81 counties in 26 states. Some of the 30 topics investigated in the NHANES III included high blood pressure, high cholesterol, obesity, secondhand smoking, lung disease, osteoporosis, HIV/AIDS, hepatitis, helicobacter pylori, immunization status, diabetes, allergies, growth and development, anemia, dietary intake (including fats), antioxidants, and nutritional blood measures. The NHANES I analyzed blood and urine samples from 23,808 study participants, and NHANES II analyzed 20,322 samples. The HHANES was a one-time survey conducted from 1982 to 1984 that provided data on 11,653 people of Hispanic origin.

### **National Institute of Allergy and Infectious Disease- Division of AIDS**

The Division of the Acquired Immunodeficiency Syndrome (DAIDS) was formed in 1986 to address the national needs of the cause and spread of HIV/AIDS. The mission of DAIDS is to increase basic knowledge of the pathogenesis, natural history, and transmission of HIV disease and to promote research in the detection, treatment, and prevention of the disease. DAIDS supports a number of longitudinal as well as clinical trials programs in the epidemiologic, therapeutic, and vaccine/prevention research as described below and in Chapter Two.

Individually and collectively, these studies have amassed a wealth of data that provides detailed information on the natural history and clinical and laboratory course of HIV disease in various populations. Specific fluids and tissues collected from the various studies include peripheral blood, mononuclear cells, serum, plasma, semen, saliva, vaginal washings, urine, placenta, and autopsy samples. These samples together with the huge database to which they are linked provide a rich resource for multidisciplinary investigations to scientists.

**The Multicenter AIDS Cohort Study and the San Francisco Men's Health Study.** The Multicenter AIDS Cohort Study (MACS) and the San Francisco Men's Health Study, awarded in 1983 by DAIDS, is a longitudinal study of HIV infection in approximately 5,000 homosexual and bisexual men. The goals of

the study are to provide an appropriate epidemiological basis for laboratory-based studies of HIV pathogenesis; to study the changing natural history of HIV infection; to define subgroups of HIV-infected individuals with unique HIV-related outcomes; and to identify individuals who remain HIV seronegative despite ongoing or prior high-risk sexual activity. Clinical specimens are collected on a regular basis (every six months) and include cells, serum, plasma, and tissue (including lymph node tissue and tissue collected at autopsy).

**The Women and Infants Transmission Study.** The Women and Infants Transmission Study (WITS) is a collaborative, multisite, longitudinal study of U.S. women with HIV infection and their offspring. As of September 1995, more than 1,200 women and almost 1,000 infants have been enrolled in the study. The goals of the study are to determine maternal cofactors related to maternal-infant HIV transmissions; to ascertain the timing of perinatal transmission and the risk factors for ante- versus intrapartum transmission; to evaluate HIV disease progression among both pregnant and nonpregnant HIV-positive women; to assess the natural history of infants born to HIV-positive women and determine factors affecting disease progression; and to establish effective means for early diagnosis of HIV infection in infants. Adult specimens collected during the study include blood, urine, and genital samples. Pediatric specimens include blood and urine.

**The Women's Interagency HIV Study.** The Women's Interagency HIV Study (WIHS), awarded in 1993, is a collaborative, multisite, longitudinal study established to investigate the impact of HIV infection on U.S. women. As of September 1995, more than 2,300 women were enrolled. The goals of the study are to describe the spectrum and course of clinical manifestations of HIV infection in women; to describe the pattern of immune markers in HIV-infected women; to investigate factors that may delay or accelerate HIV-induced immune dysfunction and specific HIV-related conditions; and to study the length of survival and quality of life of women living with HIV infection. Specimens routinely collected from study participants include blood, oral/pharyngeal swabs, urine, vaginal and cervical swabs, and cervicovaginal lavage fluids.

### **Framingham Heart Study**

Since 1948, the federal government has followed a representative sample of 5,209 adults in Framingham, Massachusetts. These people have been tracked using standardized biennial cardiovascular examinations, daily surveillance of hospital admissions, death information, and information from physicians and other sources outside the clinic. The goal has been to study the epidemiology of cardiovascular diseases and to learn the circumstances under which they arise, evolve, and terminate fatally in the general population. The study is also

designed to differentiate those who develop cardiovascular diseases from those who remain disease-free over a longer period of time.

### **Physicians' Health Study**

The Physicians' Health Study, conducted at Brigham and Women's Hospital in Massachusetts since 1982, is a randomized, double-blind, placebo-controlled trial studying the role of aspirin and beta-carotene in decreasing risks of cardiovascular disease and cancer. The study has been conducted entirely by mail among 22,701 U.S. male physicians between the ages of 40 and 84 years of age. In addition, blood specimens have been collected from each participant.

The Physicians' Health Study II will evaluate the effects of beta-carotene, vitamin E, vitamin C, and multivitamin supplements on the prevention of cancer, especially prostate cancer in a randomized, double-blind, placebo-controlled trial. Fifteen thousand U.S. male physicians will be enrolled in this study.

### **Nurses' Health Study**

The Nurses' Health Study began in 1976 at the Harvard School of Public Health. Since then, 117,000 nurses have entered the study. The study was designed to serve as a prospective follow-up study to examine a possible relationship between oral contraceptive use and breast cancer. Follow-up questionnaires have been mailed to participants every two years, and blood specimens were collected at the time of enrollment. Extensive details of lifestyle practices have been collected for each participant. The Nurses' Health Study has been a part of many studies investigating the relation between use of hormones, diet, exercise, and other lifestyle practices as related to the development of various illnesses, including diabetes, breast cancer, and colon cancer.

### **Health Professionals Follow-Up Study**

The Health Professionals Follow-Up Study was initiated in 1986 at Harvard University. More than 51,000 male health professionals aged 40 to 75 years were followed, and blood specimens were obtained from each of the participants. This study has been the basis for several prospective studies investigating factors that are potentially important in the development of prostate cancer, colon cancer, colorectal adenoma, cardiovascular disease, chronic dental disease, kidney disease, multiple sclerosis, and Parkinson's disease.



### **MRFIT Study**

The Multiple Risk Factor Intervention Trial (MRFIT) was a cardiovascular disease intervention trial. MRFIT began by screening 361,662 males between the ages of 35 and 57 from 1973 to 1975. More than 12,000 men were then enrolled in the intervention trial. Lifestyle data were collected from each participant as well as blood serum samples. Data have been used in studies measuring the relationship between such factors as serum cholesterol, smoking, hypertension, and stress with the development of cardiovascular disease.

### **Women's Health Study**

The Women's Health Study, conducted at Brigham and Women's Hospital, will evaluate the balance of benefits and risks of low-dose aspirin and vitamin E in reducing the risks for cardiovascular disease and cancer in women. The study population will consist of 40,000 U.S. female health professionals age 45 and older.

### **RESEARCH THAT SIMULTANEOUSLY CREATES TISSUE COLLECTIONS OR CONTRIBUTES TO A TISSUE BANK**

Most research projects that use human tissue obtain specimens from pathology laboratories or existing tissue banks. However, some research studies require unique samples and must collect specialized tissue. Therefore, some research will create tissue collections and may end up contributing these samples to an established tissue bank for storage. Several examples of research that simultaneously creates tissue collections or contributes to a tissue bank are described below.

### **National Institute of Child Health and Human Development**

NICHD performs and supports several research projects in pregnancy, delivery, and child development-related issues that involve collection and storage of tissue samples. To fulfill its needs for storage, monitoring and distribution of existing and yet-to-be-collected specimens, the NICHD contracts with commercial enterprises. For example, the Maternal Fetal Network Project, conducted by the Pregnancy and Perinatology Branch of NICHD, has contracted with Biotech Research Laboratory to establish a repository that will contain frozen plasma and sera samples from patients studied in several clinical protocols. This repository is a valuable source of biological markers for the study of preterm births and preeclampsia. In addition, two NICHD-funded research studies, the Diabetes in Early Pregnancy Study (DIEP) and a Longitudinal Study

of Fetal Growth and Perinatal Outcome, have contracted with Biomedical Research, Inc., to provide storage, monitoring, and distribution of serum samples. Both studies involved collecting multiple blood samples throughout the course of the study. Biomedical Research, Inc., also provided storage, monitoring, and distribution of serum, plasma, and urine from a double-blind, randomized, clinical trial of supplemental calcium for the prevention of preeclampsia during pregnancy. Five clinical centers, enrolling 4,500 women over a two-year period, contributed samples from study participants at baseline, early and late in the third trimester of pregnancy, and at the time of diagnosis of preeclampsia.

### **Prostate Cancer Intervention Versus Observation Trial**

The primary objective of the Prostate Cancer Intervention Versus Observation Trial is to determine which of these two strategies is superior for the management of clinically localized prostate cancer: radical prostatectomy with early intervention or expectant management with reservation of therapy for palliative treatment. The VA Medical Center in Minneapolis, Minnesota, is the central location of the study, and the project is supported by the Department of Veterans Affairs. One thousand patients from 80 medical centers with clinically localized prostate cancer who are under 75 years of age and potential candidates for radical prostatectomy will be included in the study. A central laboratory will examine tissue specimen samples for confirmation of histopathologic diagnosis of prostate cancer. Also, a centralized serum bank will be established for PSA assays and future studies.

### **Smoking Cessation Program for Patients Enrolled in SPORE Projects**

The VA Medical Center in Denver, Colorado, is conducting a study to understand the epidemiologic finding that former smokers remain at elevated risk for many years after cessation of smoking. The study is supported by the Department of Veterans Affairs. The aims of the study include assessing the degree and time course of reversion of preneoplastic markers to normal after smoking cessation in smokers who are at high risk for lung cancer and to characterize individuals who do not show reversion of these markers to normal after smoking cessation. A bank of sputum cytology samples will concurrently be established for a cohort of high-risk subjects. Samples from high-risk subjects before and after smoking cessation will be used for rapid pilot testing of new lung cancer markers.

### **Genetics of Familial Polycystic Ovary Syndrome**

Researchers at the Milton S. Hershey Medical Center in Pennsylvania are studying polycystic ovary syndrome (PCOS) to find a genetic marker that would be useful in identifying women at risk for developing PCOS prior to the onset of complications. The study will include a few large, three-generation kindreds of PCOS to reduce genetic heterogeneity. A DNA bank of complete PCOS pedigrees is being assembled for genetic studies. A normative database will be established for age, weight, and ethnicity matched controls. Previously identified kindreds of familial PCOS will be phenotyped for clinical, biometric, and biochemical abnormalities. All available pedigree members—male and female—will be phenotyped. By identifying women at risk for PCOS, medical resources could be focused on preventing complications.

### **Molecular Basis of Split Hand/Split Foot Malformation**

The University of North Carolina at Chapel Hill is characterizing the molecular defect responsible for split hand/split foot (SHSF) malformation, a human developmental disorder that results in abnormal hands and feet. A repository of cell lines from individuals with SHSF and related malformations is being established. This resource will facilitate cloning of the SHSF gene as well as future investigations of genotype-phenotype relationships in SHSF. SHSF pedigrees will also be analyzed. Isolation of the SHSF gene will provide an opportunity to investigate the molecular basis of pattern formation in the human limb.

### **Molecular Epidemiology of Breast Cancer**

Case Western Reserve University in Cleveland, Ohio, is pursuing a study to understand the molecular epidemiology of breast cancer entitled "Establishment of an at-risk cohort and methods to improve the collection and use of risk." The study is funded by the Department of the Army and will specifically investigate molecular markers and their interaction with other epidemiologic risk factors toward identification of relative risk factors for breast cancer development in Caucasian and African-American women with benign breast disease. More than 5,000 women are expected to be followed to yield an estimated 250 breast cancer cases. Benign breast disease and cancerous tissue samples will be archived in a specimen bank. A questionnaire will be developed to identify risk factors and will be used to construct an exposure index for lifetime exposure to sex hormones.

### **Human Conceptual Tissue: Characterization for Transplantation**

The Puget Sound Blood Center of Seattle, Washington, is committed to determining the availability and suitability of embryonic tissue for transplantation research and therapy. In this project, investigators will focus on development and assessment of protocols for the collection, processing, and cryopreservation of embryonic tissue and will also characterize hematopoietic stem cells derived from embryonic fetal liver. This project is supported by the National Institute of Child Health and Human Development. Three institutions participate in this project (the Central Laboratory for Human Embryology, the Northwest Tissue Center, and the Fred Hutchinson Cancer Research Center), and together they have formed the Northwest Fetal Tissue Program. For more than 30 years, the Central Laboratory for Human Embryology has collected and processed more than 15,000 embryos and fetuses. The other groups have expertise in storage and cryopreservation of tissue and stem cell replacement therapy research.

### **Epidemiology of EBV-Defined Hodgkin's Disease**

The Northern California Cancer Center is conducting a study to explore the epidemiology of subtypes of Hodgkin's disease defined by Epstein-Barr virus. The study will collect specimens archived between 1990 and 1995 from Hodgkin's disease cases reported to the California Cancer Registry; apply standard techniques to classify each case as Epstein-Barr virus-positive or -negative; calculate risks of Epstein-Barr virus-positive and -negative Hodgkin's disease for multiple variables; calculate incidence rates of Epstein-Barr virus-positive and -negative Hodgkin's disease; and bank tumor specimens for future testing. It is expected that tumor specimens will be requested for more than 2,500 subjects.

### **Therapy and Biological Correlations of Soft Tissue Sarcoma**

Fifty percent of patients who undergo surgery in conjunction with radiotherapy do not have successful survival rates, usually due to pulmonary metastases. These metastases can only be marginally controlled by toxic chemotherapy agents if they are not resectable. Other problems surrounding the understanding and successful treatment of soft tissue sarcomas include different and non-interconvertible staging systems, a lack of information about molecular determinants of sarcoma proliferation and metastasis, and long-term clinical trials due to the rarity of the disease resulting in slow drug production. This project at the University of Texas M.D. Anderson Cancer Center, supported by the NCI, will focus on these obstacles in the area of soft tissue sarcomas. A bioresource facility has been established that contains a tissue bank, short-term culture explants and cell lines, and paraffin-embedded tissue blocks.

### **Lifetime Alcohol Exposure and Breast Cancer Risk**

The Department of the Army funds a population-based, case-control study to investigate the relationship between alcohol exposure and the risk of breast cancer at the State University of New York at Buffalo. African-American and Caucasian women, aged 35 to 79, both pre- and postmenopausal will be selected. Matched controls will be randomly selected. A specimen bank will be created to store biological samples for future studies.

### **Prospective Randomized Study of Adjuvant Chemotherapy Versus Vinorelbine and Cisplatin in Completely Resected NSCLC with Companion Tumor Marker Evaluation**

This phase III study will be conducted at the VA Medical Center in East Orange, New Jersey, and is supported by the Department of Veterans Affairs. The study compares the overall survival between completely resected patients with T2NO, T1-2NI non-small cell lung cancer (NSCLC) who have received either adjuvant chemotherapy with vinorelbine and cisplatin or observation alone. A comprehensive tumor bank will be established and linked to a clinical database. These tissue specimens will be used for further study of molecular markers in resected NSCLC.

### **Case-Control Study of Hodgkin's Disease in Children**

This is an ongoing study at the University of Pittsburgh supported by the NCI to investigate the epidemiologic, virologic, and genetic components of the rare cases of Hodgkin's disease in children. Previously, epidemiologic data had been gathered from 300 cases and 484 controls by telephone interviews. The project will be expanded to 415 cases and 675 controls. Tissue specimens will be collected from all 415 cases for virologic assays and to create a biologic specimen bank for future studies.

### **Markers for Differential Diagnosis and Virulence of Prostate Cancer**

A project on molecular markers for differential diagnosis and virulence of prostate cancer is being conducted at the VA Medical Center in Seattle, Washington, and supported by the Department of Veterans Affairs. This study will focus on the development of reagents and immunoassays for various serum forms of PSA, to determine whether CD44 and specific isoforms enable prostatic cells to metastasize to specific sites and to construct cDNA libraries from a prostate cancer xenograft model. A human tumor/sera bank will also be established for multiple other projects.

### **The Role of IL-1 Cytokines in Colorectal Cancer**

The VA Medical Center in Pittsburgh, Pennsylvania, is conducting a project to delineate gene products that are inappropriately expressed in colorectal tumors that may affect clinical outcome. A second goal of the project is to identify gene products essential to tumor cell proliferation and may serve as therapeutic targets. A tumor bank has been established of frozen tumors and polyps from more than 200 cases. A database contains clinical and pathological findings for each stored specimen.

### **Markers for Malignant Progression in Prostate Cancer**

A study investigating molecular prognostic markers to assist in clinical management and classification of patients into clinical trials is being conducted at Georgetown University. The goal of the study is to identify molecular markers and activated oncogenes that indicate poor prognosis in prostate cancer. The study will actively accrue freshly frozen surgical material to a prostate tissue bank. The tumor bank will maintain demographic information and pathology records and blocks.

### **Pulmonary Hypertension- Mechanisms and Family Registry**

This project will be conducted at Vanderbilt University Hospital in Nashville, Tennessee, and is supported by NHLBI. The goals of the project will be to investigate the basic mechanisms of primary pulmonary hypertension and to establish a registry and database of familial primary pulmonary hypertension pedigrees to determine the mode of inheritance. A tissue bank will be set up for DNA samples and transformed lymphocytes from families and patients with primary pulmonary hypertension. These samples will be made available to investigators both locally and nationwide.

### **Blood Test to Predict Prognosis in Patients with Gynecologic Cancer: Plasma Assay of GLB and GLB:TIMP-1 Complexes**

The Department of Veterans Affairs supports this study at the VA Medical Center in Northport, New York. It is believed that the production and activation of enzymes known as gelatinases (GLA and GLB) are essential components for tumor metastasis. An ELISA test has been developed to measure the concentrations of GLB and its complexes in plasma from patients with cancer. It has been demonstrated that these enzymes are increased in plasma from patients with gynecologic and colorectal cancer. The goals of this study are to establish a plasma bank from patients with gynecologic cancers (ovarian, cervical, uter-

ine, vaginal), to measure the plasma concentration of GLB and its complexes and to determine whether the plasma concentrations of GLB and its complexes can be used as a prognostic and response factor to different treatment regimens.

### **AIDS-Malignancy Clinical Trials Consortium**

The University of Southern California AIDS-Malignancy Clinical Trials Consortium (AM-CTC) helps design, develop, and conduct collaborative, innovative phase I and II clinical trials, employing novel agents and approaches in patients with various AIDS-related malignancies. In addition, the AM-CTC provides tumor tissue and other relevant biologic materials, derived from patients accrued into clinical trials, to the NCI-funded Tissue and Biological Fluids Bank of HIV Associated Malignancies. Since 1987, the AIDS Clinical Trials Group (ACTG) has accrued more than 470 patients onto various AIDS-malignancy protocols. The University of Southern California AIDS Malignancy Program has been actively engaged in phase I and II trials related to HIV-related cancers, with participation in 45 such studies, resulting in 17 publications, and 30 published abstracts.

### **Pancreatic Cancer Case-Control Study in San Francisco**

This population-based, case-control study in men and women will examine the hypotheses linking adenocarcinoma of the exocrine pancreas and detailed occupational history and chemical exposures. This study is supported by the NCI. One thousand cases and 1,150 controls will be interviewed during a 3.5-year period. The study is based at the University of California, San Francisco, and will include participants from six San Francisco Bay area counties. Blood samples for genetic investigations will be drawn, and cells samples will be frozen in the Irwin Memorial Blood Bank. Whole-blood specimens will also be stored for future genetic and biomarker studies.

### **Exogenous Toxicants and Genetic Susceptibility in Amyotrophic Lateral Sclerosis**

Stanford University is investigating the role of environmental toxicants and genetic susceptibility factors in the etiology of Amyotrophic Lateral Sclerosis (ALS) by conducting a case-control study of 175 incident ALS and 550 age- and gender-comparable control subjects. All 175 ALS cases and a subset of 350 control subjects will undergo measurement of bone lead stores using x-ray fluorescence and will have a venous blood sample drawn for copper-zinc superoxide dismutase (SOD1) enzyme genotyping and DNA banking. The collection

of detailed information regarding the duration and timing of environmental exposures will enable the evaluation of dose response trends and estimation of latent periods between putative exposure and the development of ALS. It is hoped that the proposed study will advance knowledge of neurotoxic and endogenous susceptibility factors important in the etiology of ALS.

### **National Institute of Allergy and Infectious Disease- Division of AIDS**

DAIDS was created in 1986 to address the national research needs created by the cause and spread of HIV/AIDS. Several clinical research trials groups are sponsored by DAIDS and have collectively amassed a large number of specimens that are available for research.

**The HIV Network for Prevention Trials.** The HIV Network for Prevention Trials (HIVNET), established in 1994, is a network of clinical sites to conduct HIV vaccine efficacy trials and prevention trials in higher-risk populations. HIVNET consists of five contracts supported by DAIDS: the domestic HIV/AIDS vaccine efficacy trials, the international HIV/AIDS vaccine efficacy trials, a statistical and data coordinating center, a specialized laboratory testing center, and a specimen repository. As of September 1995, more than 3,600 volunteers had participated in HIVNET. Specimens collected from HIVNET trials are routinely sent to a central laboratory for testing. HIVNET specimens include serum, plasma, peripheral mononuclear cells, genital tract specimens, and saliva. The availability of specimens depends on the type of specimen requested.

**The Pediatric AIDS Clinical Trials Group.** The Pediatric AIDS Clinical Trials Group (PACTG), awarded in 1987, is a multicenter clinical trials network. The goals of this study group are to support the development and implementation of phase I, II, and III studies designed to test and optimize therapies to prevent and treat HIV infection and its sequelae in infants, children, and adolescents; to conduct studies throughout the United States at more than 50 pediatric AIDS Clinical Trials Units; and to collaborate closely with the adult ACTG studies. Specimens collected from PACTG trials included serum, plasma, peripheral mononuclear cells, culture supernatants, lymph node biopsies, tissues, urine, and other body fluids.

**The Adult AIDS Clinical Trials Group.** The Adult AIDS Clinical Trials Group (Adult ACTG), established in 1987, is a consortium of 30 clinical trial research groups. The goals of the adult ACTG are to evaluate innovative therapeutic strategies and interventions to control HIV infection and complications in adults; to facilitate rapid translation of basic research into clinical research and practice; and to provide a flexible resource for state-of-the-art, multi-disciplinary clinical trials. To date, more than 35,000 adult volunteers at all stages of the disease have enrolled. Specimens collected during the clinical



trials include serum, plasma, peripheral mononuclear cells, culture supernatants, lymph node biopsies, tissues, urine, and other bodily fluids.

**The AIDS Vaccine Evaluation Group.** The AIDS Vaccine Evaluation Group (AVEG), consists of six AIDS Vaccine Evaluation Units that evaluate candidate AIDS vaccines in phase I and II clinical trials for safety and immunogenicity. As of October 1995, more than 1,800 volunteers had enrolled in AVEG trials. Specimens collected during clinical trials include serum, plasma, peripheral mononuclear cells, genital tract secretions, saliva, and tears. The availability of specimens depends of the type of specimen requested.

**The Division of AIDS Treatment Research Initiative.** The Division of AIDS Treatment Research Initiative (DATRI), established in 1991, conducts phase I and II studies of therapies for HIV and associated diseases. The DATRI Network performs small, focused studies and substudies of protocols conducted by other extramural programs. Clinical specimens will vary according to protocol and include serum, plasma, cells and cultured cells, and supernatant from PBMC and plasma HIV cultures.

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**PATHOLOGY SPECIMENS**

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A large number of tissues are collected for diagnostic or therapeutic reasons. These tissues are usually sent to a clinical, diagnostic or pathology laboratory for examination. These laboratories may be located at GME teaching institutions, physicians' offices, community hospitals, or independent laboratories. These tissues may sometimes be used for research, educational, and quality-control purposes, though the vast majority are not. Most patients sign a general consent stating that after completion of any diagnostic tests, some of the sample can be saved/used for research purposes.

To be accredited, laboratories must keep pathological specimens for a minimum amount of time. The Clinical Laboratory Improvement Amendments of 1988 (CLIA) set forth the conditions that laboratories must meet to be certified to perform testing on human specimens. CLIA stipulates that laboratories must retain cytology slides for a minimum of five years, histopathology slides for a minimum of 10 years, and paraffin blocks for a minimum of two years (CLIA, 1996). In addition, some states have regulations that require retention of pathology specimens for longer than the time specified in the CLIA regulations. For example, New York, which has some of the most stringent regulations, requires that laboratories retain abnormal cytology slides for 10 years, cytology slides with no abnormalities for five years, and histopathology slides and paraffin blocks for 20 years. Once the regulated length of time for storage is met, institutions may continue to store pathology specimens based on the room they have for storage, the philosophy of the institution, and several other variables.

**PATHOLOGY DEPARTMENTS AT GRADUATE MEDICAL EDUCATION  
TEACHING INSTITUTIONS**

Medical education in the United States can be divided into three major phases. The first phase, medical school, provides instruction in the sciences that underlie medical practice and in the application of those sciences to health care. In 1997, there were 125 medical schools in the United States (including three in

Puerto Rico) (American Medical Association, 1997). The second phase, graduate medical education (GME), prepares physicians for independent practice in a medical specialty. GME programs, usually called residency programs, are based in hospitals or other health-care institutions, some of which have and some of which lack formal relationships with medical schools. GME teaching institutions include medical schools, U.S. armed forces hospitals, VA medical centers, the Public Health Service, state, county, and city hospitals, nonprofit institutions, and health maintenance organizations. In 1997, 1,687 accredited GME teaching institutions operated in the United States (including 22 programs in Puerto Rico) (American Medical Association, 1997). Continuing medical education (CME), the third phase of medical education, updates medical professionals' education throughout their careers.

Collectively, pathology departments at GME teaching institutions constitute the largest and oldest stores of tissue samples in the United States. Two techniques were used to estimate the total number of cases accessioned per year at all GME institutions and the number of tissues stored at each institution. The first estimate used information found in the American Medical Association's Graduate Medical Education Directory 1997-1998 about residency programs in pathology at GME institutions (American Medical Association, 1997). However, information was not available about all pathology specialties. Therefore, a second estimate was made from information obtained from several chairs of pathology departments attending a meeting of the Universities Associated for Research and Education in Pathology (UAREP), hosted by the Federation of American Societies for Experimental Biology (FASEB).<sup>1</sup>

The number of pathology residency positions at a GME teaching institution is determined by the caseload of the pathology department. The Graduate Medical Education Directory stipulates that programs should have a sufficient number of cases to ensure that residents have a broad exposure to both common and unusual conditions and that the number of resident positions requested by an institution not exceed the educational resources available in a program (American Medical Association, 1997). The actual number of GME programs and residency positions in 1995-1996, and the number of programs and proposed residency positions for 1997-1998 are shown in Table 6.1. Table 6.2 shows the recommended number and types of cases/specimens residents should examine during their training in anatomic and clinical pathology, dermatopathology, forensic pathology, neuropathology, or pediatric pathology.

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<sup>1</sup>Medical schools represented at the UAREP meeting included those at the University of Pittsburgh, Johns Hopkins University, University of Minnesota, Robert Wood Johnson Medical School, University of Kansas, Case Western Reserve University, University of Pennsylvania, University of Iowa, Northwestern University, Thomas Jefferson University, and Memorial Sloan-Kettering.

This information was not available for the specialties of cytopathology, chemical pathology, hematology, immunopathology, or microbiology.

An analysis was performed to estimate the total number of cases accessioned per year at all GME teaching institutions in the pathology specialties of anatomic and clinical pathology, dermatopathology, forensic pathology, neuropathology, and pediatric pathology. This calculation was based on several criteria: the number of GME pathology programs in each specialty; the number of resident positions open in these programs for the academic year; the recommended number of cases per program to meet the training requirements of the residents; and the duration of the program in years. Table 6.3 contains data for the academic year 1995–1996, and Table 6.4 contains data for 1997–1998. Information on the recommended number of cases per resident was not available for all pathology specialties. However, an effort was made to obtain information on the average number of cases/specimens accessioned per institution each year for cytopathology and hematopathology, the two other pathology specialties in Table 6.1 with large numbers of residency positions.

Of the pathologic specialties, anatomic and clinical pathology, cytopathology and hematopathology specimens probably account for the largest collection of tissues. For the academic year 1996–1997, there were 180 anatomic and clinical pathology programs with 2,675 residents (see Table 6.1). To have enough cases to fulfill the educational needs of their residents, institutions would have had to

**Table 6.1**  
**GME Pathology Programs and Residency Positions**

Pathology Specialty	1996–1997 <sup>a</sup>		1997–1998 <sup>b</sup>	
	Number of Programs	Number of Residents	Number of Programs	Number of Residents
Anatomic and Clinical	180	2,675	180	2,656
Cytopathology	68	74	68	101
Chemical Pathology	7	4	7	6
Dermatopathology	41	54	41	72
Forensic Pathology	39	47	39	73
Hematopathology	54	51	54	119
Immunopathology	9	6	9	12
Microbiology	9	5	9	9
Neuropathology	47	37	47	66
Pediatric Pathology	20	12	20	28
Total	474	2,965	474	3,142

<sup>a</sup>Graduate Medical Education, 1997.

<sup>b</sup>American Medical Association, 1997.

accession more than five million total cases/specimens, an average of 28,050 cases/specimens per program (Table 6.3). Similarly, in 1997–1998, the 180 anatomic and clinical pathology programs with 2,656 residency positions would have to accession more than five million total cases/specimens, an average of 27,851 cases/specimens per program (Table 6.4). Some of the specimens collected by anatomic and clinical pathology may be referred to in another specialty, such as dermatopathology, neuropathology, or immunopathology, and given a separate accession number within that specialty. Therefore, some specimens listed in Tables 6.3 and 6.4, especially for dermatopathology and neuropathology, may also have been accounted for as anatomic and clinical pathology cases. Forensic pathology cases are accessioned separately from the other specialties. It is recommended that forensic pathology programs conduct approximately 500 medicolegal autopsies per year and approximately 300 additional autopsies for each additional residency position. Therefore, forensic pathology programs would have had to conduct 21,900 autopsies<sup>2</sup> in 1996–1997, and 29,700 in 1997–1998 to provide enough cases for resident training.

**Table 6.2**  
**Recommended Specimens for Pathology**  
**Residency Programs**

Pathology Specialty	Recommended Cases/Specimens per Resident
Anatomic and Clinical	≥75 autopsies ≥2,000 surgical pathology specimens ≥1,500 cytologic specimens ≥200 intraoperative consultations (frozen sections)
Dermatopathology	≥5,000 new accessions
Forensic Pathology <sup>a</sup>	250–350 autopsies
Neuropathology <sup>b</sup>	≥50 neuromuscular biopsy specimens
Pediatric Pathology	≥40 pediatric autopsies ≥2,000 pediatric surgical pathology specimens ≥50 intraoperative consultations (frozen sections/smears)

SOURCE: American Medical Association, 1997.

<sup>a</sup>In addition to the 250–350 autopsies recommended for residents in Forensic Pathology, it is recommended that forensic pathology programs conduct approximately 500 medicolegal autopsies per year and approximately 300 additional autopsies for each additional residency position requested.

<sup>b</sup>In addition to the minimum of 50 neuromuscular biopsy specimens recommended for residents in neuropathology, it is recommended that neuropathology programs conduct at least 200 necropsies and examine at least 100 neurosurgical specimens per year.

<sup>2</sup>A single autopsy case may generate several slides and paraffin blocks.

**Table 6.3**  
**Specimens and Autopsy Cases Accessioned in 1996- 1997**

Pathology Specialty	Number of Specimens <sup>a</sup> per Year	Number of Programs	Number of Specimens <sup>a</sup> per Program per Year
Anatomic and Clinical <sup>b</sup>	5,049,063	180	28,050
Dermatopathology	270,000	41	6,585
Forensic Pathology	21,900	39	562
Neuropathology	14,100	47	300
Pediatric Pathology	25,080	20	1,254

<sup>a</sup>Includes autopsy cases.

<sup>b</sup>Anatomic and Clinical Pathology programs range in length from 18–24 months. Therefore, the number of specimens per year represents the number of programs multiplied by the number of residents (Table 6.2) divided by two years (24 months) as a minimum estimate.

**Table 6.4**  
**Specimens and Autopsy Cases Accessioned in 1997- 1998**

Pathology Specialty	Number of Specimens <sup>a</sup> per Year	Number of Programs	Number of Specimens <sup>a</sup> per Program per Year
Anatomic and Clinical <sup>b</sup>	5,013,200	180	27,851
Dermatopathology	360,000	41	8,780
Forensic Pathology	29,700	39	762
Neuropathology	14,100	47	300
Pediatric Pathology	58,520	20	2,926

<sup>a</sup>Includes autopsy cases.

<sup>b</sup>Anatomic and Clinical Pathology programs range in length from 18–24 months. Therefore, the number of specimens per year represents the number of programs multiplied by the number of residents (Table 6.2) divided by two years (24 months) as a minimum estimate.

In some institutions, pediatric pathology cases may go directly to the pediatric pathology department. However, in some institutions, they may first be accessioned in anatomic and clinical pathology. The 12 residents in pediatric pathology programs in 1996–1997 would have conducted 480 pediatric autopsies and examined 24,000 pediatric surgical pathology specimens and 600 intraoperative consultations (frozen sections, smears). To support 28 pediatric pathology resident positions in 1997–1998, a total of 58,520 specimens and autopsy cases would have to be accessioned. A conservative estimate is that an average of approximately 30,000 anatomic and clinical, forensic, and pediatric pathology and autopsy cases are seen per GME teaching institution each year.

An estimate of the number of cases/specimens accessioned in cytopathology and hematopathology programs was obtained by averaging the number of

cases/specimens reported on various GME teaching institutions' Web sites. Table 6.5 shows information obtained for cytopathology, and Table 6.6 shows information about hematopathology. Cytopathology programs accession an average of approximately 50,000 cytology specimens per year (range of 14,000 to 100,000 cases/specimens). Hematopathology programs accession an average of 750 bone marrow aspirations and biopsies and resections of lymph nodes and related tissue.

As an independent method to estimate the average number of pathology cases accessioned per institution each year, chairs of pathology departments attending the UAREP meeting were asked several questions about the pathology

**Table 6.5**  
**Cytopathology Programs**

Program	Specimens per Year
University of North Carolina	>24,000
Emory University	65,500
University of Wisconsin	100,000
University of Michigan	47,500
Georgetown University	14,000
Total	251,000
Average	50,200

**Table 6.6**  
**Hematopathology Programs**

Program	Specimens per Year <sup>a</sup>
NYU Medical Center	750
Emory University	1,000
University of Michigan	500
Total	2,250
Average	750

<sup>a</sup>The College of American Pathologists Minimum Guidelines for the Retention of Laboratory Records and Materials recommends a retention time of 10 years for bone marrow specimens but only 24 hours for serum, cerebral spinal fluid, and other body fluids and seven days for peripheral blood and body fluid smears (<http://www.cap.org>). Therefore, specimens recorded here represent the number of bone marrow aspirations and biopsies and resections of lymph nodes and related tissue accessioned at each institution listed.

departments at their institutions. Information was obtained about the size of their institution, the number of cases accessioned per year, the age of the oldest tissues archived, how long the tissue samples are stored, what identifying information is kept with the tissues, and who has access to the samples. The medical schools represented had facilities that ranged from 250 beds to approximately 2,000 beds and accessioned from approximately 10,000 to approximately 60,000 cases per year. The medical schools accessioned an average of 40 cases per bed with a range of 20–60 cases per bed. Most of the pathology departments stored tissue samples indefinitely, with the oldest tissues archived anywhere from 20 years old to more than 100 years old. Stored specimens are either labeled with a pathology accession number linked to the patient's medical record or labeled directly with the patient's name and medical record number. People who have access to the specimens include the pathologists, researchers, other physicians, and anyone with a court order. Each institution accessions an average of approximately 30,000 cases per year, with approximately 3.8 million total cases accessioned per year at all 125 medical schools in the United States.

## **DNA DIAGNOSTIC LABORATORIES**

### **GeneTests**

GeneTests is an online national directory of DNA diagnostic laboratories. GeneTests seeks to promote the appropriate use of genetic counseling and testing in patient care. GeneTests maintains a comprehensive list of clinical service and research laboratories performing inherited disease-specific clinical molecular genetic testing for single-gene and contiguous-gene disorders. GeneTests is funded by the National Library of Medicine and the Maternal and Child Health Bureau and administered through the Children's Hospital Regional Center in Seattle, Washington. In January 1994, 148 laboratories were listed in GeneTests—131 in the United States, 16 in Canada, and one in Mexico (McEwen and Reilly, 1995). One hundred and thirty-seven of the labs were academically based or within government agencies, and 11 were commercial laboratories (McEwen and Reilly, 1995).

In a 1994 survey of GeneTests (formerly known as HELIX) DNA diagnostic laboratories, 90 percent of the respondents (93 of 148 (63 percent) laboratories surveyed responded) stated that they banked DNA (McEwen and Reilly, 1995). DNA banks ranged in size from fewer than 100 to more than 1,000 samples in storage (McEwen and Reilly, 1995). Most laboratories banked DNA as a service to referring physicians or for individuals and families at risk for a particular genetic disorder, for such research purposes as gene mapping, and as a service to clinical, forensic, or research laboratories (McEwen and Reilly, 1995). More



than half of the respondents stated that their laboratories had released samples to researchers after stripping the samples of identifiers (McEwen and Reilly, 1995).

## **CLINICAL SERVICE AND DIAGNOSTIC LABORATORIES**

The majority of clinical service and diagnostic laboratories are not associated with GME teaching institutions. These include laboratories within physicians' offices or community hospitals and independent laboratories. In 1991, approximately 640,000 clinical laboratories and other facilities performed laboratory tests on human specimens (Department of Health and Human Services, 1991). The number of tissues stored at these laboratories varies greatly, but the minimum storage time is determined by CLIA and state regulations and College of American Pathologists guidelines.

## **CENTERS FOR DISEASE CONTROL AND PREVENTION INSTITUTES**

The Centers for Disease Control and Prevention (CDC), in Atlanta, Georgia, is an agency of the Department of Health and Human Services. The CDC's mission is to promote health and quality of life by preventing and controlling disease, injury, and disability. The CDC is made up of six centers, one institute, and four offices.<sup>3</sup> Several centers have stored tissue samples, including the National Center for Environmental Health and the National Center for Infectious Disease.

### **National Center for Environmental Health**

The National Center for Environmental Health (NCEH) is involved in several areas of research, including biomonitoring, breast cancer-related projects, and genetic research. The NCEH has also prepared DNA specimens from approximately 8,000 NHANES (describe in Chapter Five) participants to be used by researchers around the country. In 1996, eight breast cancer-related projects collected more than 3,500 serum samples for analysis in such studies as "Breast Cancer Among Women Exposed to Polybrominated Biphenyl" and "Breast Cancer Among Native Alaskan Women Exposed to Organochlorines."

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<sup>3</sup>The institute, offices, and centers within the CDC are the National Center for Chronic Disease Prevention and Health Promotion, the National Center for Environmental Health, the National Center for Health Statistics, the National Center for HIV, STD, and TB Prevention, the National Center for Infectious Diseases, the National Center for Injury Prevention and Control, the National Institute for Occupational Safety and Health, the Epidemiology Program Office, the Office of Global Health, the Public Health Practice Program Office, and the office of Genetics and Disease Prevention.

### **National Center for Infectious Diseases**

The National Center for Infectious Diseases (NCID) plans, directs, and coordinates a national program to improve the identification, investigation, diagnosis, prevention, and control of infectious diseases. The NCID also maintains several tissue banks. The NCID's Scientific Resources Program maintains a bank of serum specimens of epidemiological and special significance to CDC's research and diagnostic activities. The NCID is also responsible for the integrity, security, and maintenance of a computer inventoried serum bank consisting of 250,000 aliquots of serum from 100,000 Alaskan Natives.

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**STATE SCREENING LABORATORIES  
AND FORENSIC DNA BANKS**

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The collection of blood specimens for disease testing, paternity testing, or forensic testing has grown enormously in the last quarter of the twentieth century. As biomedical technology advances, more and more testing will be performed on smaller and smaller sample sizes. Although tissue samples may be collected for a specific purpose, it is not unlikely for them to be used for other reasons. These large collections of human tissue samples have been a matter of concern for privacy advocates.

**NEWBORN SCREENING LABORATORIES**

Archives of newborn screening cards for inborn errors of metabolism (Guthrie cards) represent an enormous source of banked DNA. Guthrie cards are used to screen newborns for several diseases, including congenital hypothyroidism, phenylketonuria, galactosemia, hemoglobinopathies (e.g., sickle-cell anemia), biotinidase deficiency, homocystinuria, Maple Syrup Urine disease, and cystic fibrosis. These newborn screening tests utilize bacterial inhibition assays and automated enzymatic methods. However, as new genetic screening tests are developed, and the Human Genome Project discovers new disease-related genes, it is likely that newborn screening tests may become DNA-based. In addition, scientific interest in using Guthrie cards for populationwide genetic epidemiological studies has grown, given the stability of DNA in dried blood and the ability to analyze the DNA in these samples (McEwen and Reilly, 1994).

A 1994 survey of all newborn-screening programs in all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands revealed that the majority of laboratories have accumulated less than 500,000 Guthrie cards over the years, seven have amassed more than 500,000, four reported collections of between one million and five million cards, and one reported a collection of six million (McEwen and Reilly, 1994). The number of cards collected over a one-year period ranged from <10,000 in four labs to >500,000 in two especially populous

states (McEwen and Reilly, 1994). For example, better than 99 percent of the 550,000 children born each year in California are tested for three genetic conditions (Reilly, 1992).

The trend in most states is to save Guthrie cards for longer and longer periods of time. Eleven laboratories indicated that their state departments of public health have issued written regulations on the retention of Guthrie cards, while 29 stated that their laboratories have internal written policies on this matter (McEwen and Reilly, 1994). Forty of the state newborn screening laboratories retain all the Guthrie cards they receive through their newborn-screening programs, including those cards that test negative, at least for a short period of time (McEwen and Reilly, 1994). Twenty-three laboratories indicated that they keep their cards for a year or less, 10 plan to keep their cards for one to five years, 13 will keep them for longer than five years, three save all their cards for 20–25 years, and four plan to keep their cards indefinitely (McEwen and Reilly, 1994). Thirteen other respondents discard their cards within several weeks or months (McEwen and Reilly, 1994).

Guthrie cards contain identifying information, such as the mother's name and address, hospital of birth, baby's medical records number, and the name and address of the baby's doctor. The conditions under which Guthrie cards are stored vary from state to state. Some store the cards in boxes at room temperature, some keep them in boxes or folders in a freezer, refrigerator, or climate-controlled room, some keep them in boxes or folders in a basement or warehouse, and some keep them in a cabinet either in folders or biohazard bags (McEwen and Reilly, 1994). Fourteen state laboratories periodically check the condition of their stored cards (McEwen and Reilly, 1994).

All states participate in some form of newborn screening, but few have issued regulations that explicitly define the scope of permissible use of Guthrie card samples (Andrews, 1995). Seven state departments of public health have issued written regulations on third-party access to Guthrie cards, and 10 of the laboratories have internal written policies on this matter (McEwen and Reilly, 1994). Over a five-year period, 28 laboratories estimated that they had received either no requests or fewer than six third-party requests, seven received six to 20 requests, two received 21–100 requests, and one, from a very large state, received more than 100 requests (McEwen and Reilly, 1994).

## **FORENSIC DNA BANKS**

In 1989, the Virginia Division of Forensic Science was the first state laboratory to offer DNA analyses to law enforcement agencies and the first to create a DNA databank of previously convicted sex offenders. By November 1997, 48 states had established forensic DNA data banks of convicted criminals, especially vio-

lent sex offenders and other violent felons (Finn, 1997). The two states without forensic DNA banks, Vermont and Rhode Island, are planning legislation to create them (Finn, 1997). In addition, the Federal Bureau of Investigation (FBI) is exploring ways to create a forensic DNA bank for the District of Columbia (Finn, 1997).

The DNA Identification Act of 1994 (Pub. L. No. 103-322, 1994 HR 3355, 108 Stat. 1796, §210304), a federal law enacted in fall 1994 as part of the Omnibus Crime Control Law, created a national oversight committee to develop guidelines for DNA forensics and established a five-year, \$40 million grant program to assist state and local crime laboratories in developing or improving forensic DNA testing capabilities. The DNA Identification Act also formally authorized the FBI to establish Combined DNA Index System (CODIS) for law enforcement identification purposes (TWGDAM, 1989). CODIS is a national computer network containing DNA profiles of convicted offenders, unknown suspects, and population samples (used for statistical purposes only). Using CODIS, federal, state, and local law enforcement agencies can compare DNA profiles from crime scenes to DNA profiles of felons in the CODIS database.

CODIS provides a framework for storing, maintaining, tracking, and searching DNA specimen information. Currently, CODIS has been implemented in 45 states, encompassing greater than 90 percent of the U.S. population. Each CODIS database consists of three distinct indexes—casework, convicted offender, and population. The casework and convicted felon indexes are used to search for matching DNA profiles of specimens from crime scenes.

In addition to collecting specimens from sex offenders and violent felons, a number of states require samples from juvenile offenders, nonviolent felons, such as drug or white collar offenders, and those convicted of misdemeanors (McEwen, 1997). South Dakota requires samples from people merely arrested (not convicted) of a sex offense (Finn, 1997), with several other states considering similar bills (McEwen, 1997). There is also a proposal to establish a federal DNA databank that would include profiles from people convicted in federal or military courts of offenses similar to those covered by most state laws (McEwen, 1997).

Convicted offenders are required to provide blood, or in some cases saliva, either at sentencing or before release from prison (McEwen, 1997). Some states also require samples from people already incarcerated before laws' effective dates (McEwen, 1997). The DNA from these samples is analyzed for its unique identification characteristics. Nationwide, samples from about 380,000 offenders have been collected, mostly in Virginia and California, and about 116,000 samples (30 percent) have been analyzed (McEwen, 1997). These DNA identification profiles are stored, along with the samples themselves, to help identify

suspects by matching biological evidence found at crime scenes to state DNA databases.

DNA profiles prepared from these samples have already proven valuable for tracing biological material found at crime scenes to felons with prior convictions. By February 1997, forensic DNA databanks had achieved more than 200 cold hits linking serial rape cases or identifying suspects by matching DNA extracted from biological evidence found at a crime scene to that of a known offender whose DNA profile was in the databank. For example, Minnesota's DNA data bank was used to tie the same individual to 18 separate assaults (McEwen, 1997).

DNA testing has the power to not only implicate an individual in a crime, but also to exonerate an apparently innocent individual. Recently, a Texas man who had served 12 years in prison for rape was pardoned after he was cleared of the crime by DNA tests (Holmes, 1997). Semen samples kept from 1985 were tested and failed to match his DNA. Several private laboratories have been established in the last 20 years that offer DNA testing services, such as paternity testing, parentage testing, forensic DNA analysis, and expert witness services.

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**CRYOPRESERVATION FACILITIES/STORAGE BANKS**

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The concept of storing human tissue for future use by either the donor or an anonymous person is a concept that arose during the last half of the twentieth century. Organ transplants were the first surgical procedure to be performed that involved the placement of a person's organs into the body of another to replace a diseased organ. Organs, though, cannot be stored for long periods and thus must be transplanted within hours of removal from the donor (as described in Chapter Nine). Today, sperm and embryos can be frozen and thawed and still be viable for artificial insemination procedures or implantation. The newest type of human tissue storage for future use is the storage of umbilical cord blood.

**SPERM, OVUM, AND EMBRYO BANKS**

Artificial insemination or donor insemination (DI) is a procedure to achieve conception when natural methods have failed. Sperm may be donated by a woman's husband or by another donor. The first successful artificial insemination was performed in 1790, and donor insemination was first successfully performed in 1884. Both procedures used fresh semen samples. The concept of storing human sperm for long-term use was not realized until the 1970s when the first commercial sperm banks opened, although the first successful donor insemination using frozen sperm occurred in 1953. It was not until 1985 that frozen sperm became the standard for donor insemination. The public recognition of the dangers of AIDS posed a new threat to the use of fresh semen samples, and several organizations began to discourage the use of fresh semen and recommended that only frozen sperm that had been quarantined for a minimum of six months be used for DI. In 1995, there were more than 280 fertility clinics in the United States and 57,000 assisted reproductive technology (ART) cycles were performed. Most of these cycles used the couple's own egg and sperm to produce embryos.

A few of the major cryobanks and fertility clinics that store human embryos, sperm, and/or oocytes are described below. A more comprehensive list of cryopreservation facilities and fertility clinics with storage services can be found in Appendix I.

### **California Cryobank, Inc.**

California Cryobank, Inc., founded in 1977, is one of the largest full-service sperm banks. The California Cryobank provides physicians and their patients a comprehensive resource for semen cryopreservation and specialized reproductive services. It is accredited by the American Association of Tissue Banks, and licensed by the state departments of health in California, Maryland, Massachusetts, and New York. The California Cryobank offers the following services: the freezing and storing of anonymous human sperm for use in artificial insemination; long-term semen storage for men facing the possibility of sterilization, reduction in fertility potential, or genetic damage due to vasectomy, chemotherapy, radiation therapy, and high-risk occupational exposures; long-term storage of preimplantation embryos; and andrology laboratory services, such as semen analysis, fertility testing, sperm washing, and sex selection. California Cryobank's staff includes physician medical directors, genetic counselors, donor matching counselors, and technical staff.

The California Cryobank's donor catalog currently contains more than 200 donors, who agree to leave semen donations at least once per week for nine to 12 months. Donors must complete a donor profile that contains a detailed, three-generation medical and genetic history that includes information about the donor's parents, siblings, grandparents, aunts, and uncles. This donor profile is provided to the patient. Donor profiles also include personal information, such as the donor's religion, physical characteristics, favorite sports, favorite pets, SAT scores, educational background, and work experience. All donors undergo genetic testing for sickle-cell anemia, Tay-Sachs disease, and cystic fibrosis carrier status. Donors are also tested for infectious diseases, including hepatitis B and C, CMV, sexually transmitted diseases, and HIV/AIDS. All semen specimens are quarantined for at least six months, during which donors are retested every three months for these infectious diseases. Both donor and patient records are kept indefinitely.

California Cryobank has written standard operating procedures pertaining to the storage and maintenance of reproductive tissue. These procedures require a designated secure area for storage tanks that is locked at all times and has limited access, extensive external and internal security systems, personnel to monitor the liquid nitrogen level of each storage tank daily, and complete records of all tissues stored and all activities pertaining to the stored tissues.



Quality-control measures include racially color-coded donor specimens and an electronic identification system to identify donors prior to each deposit.

### **Cryobanks International, Inc.**

Cryobanks International, Inc. (CI), is a "Cryocenter" that unites parallel technologies of freezing autologous blood, semen, and umbilical cord blood within one facility. One of the services of CI is to provide anonymous donor semen to couples and individuals.

### **Genetics & IVF Institute**

The Genetics & IVF Institute (GIVF), founded in 1984, is one of the largest, fully integrated providers of infertility treatment and genetics services. The GIVF has a main facility in Fairfax, Virginia, and a second facility in Gaithersburg, Maryland. In the Fairfax facility, the GIVF provides medical diagnosis and treatment; genetic and reproductive laboratory testing, including paternity testing; and cryobank services.

The GIVF's Cryopreservation Division, established in 1986, produced the first frozen human embryo twins in the United States. The cryobank services include embryo cryopreservation and storage, sperm banking, and human ovarian tissue cryopreservation. The institute's embryo cryopreservation program currently freezes 2,300 embryos annually and has produced more than 250 pregnancies.

### **Fairfax Cryobank**

The Fairfax Cryobank, a sperm bank, was established in 1986 to provide patients at GIVF with anonymous frozen donor semen. Fairfax Cryobank was the first sperm bank in the United States to test for genetic carriers of BRCA1, Gaucher's disease and Canavan's disease in Jewish donors and cystic fibrosis, alpha-1 antitrypsin, and HIV by polymerase chain reaction (PCR) in all donors. Fairfax Cryobank also tests for Tay-Sachs in Jewish donors, thalassemia in Asian, Middle Eastern, and Mediterranean donors, and sickle-cell anemia and other hemoglobinopathies in African-American donors. Fairfax Cryobank is one of the largest human sperm banks in the country and has provided donor specimens throughout the United States and abroad.

## UMBILICAL CORD BLOOD BANKS

Stem cells—progenitor cells, which produce all other blood cells—are used to treat patients with blood diseases, patients with certain genetic disorders, and patients receiving chemotherapy and/or radiation treatment for cancer. Until scientists discovered that umbilical cord blood contained hematopoietic stem cells, the only known source of stem cells was bone marrow. The retrieval of bone marrow, though, is invasive, may be painful, requires general anesthesia, and is expensive. In contrast, retrieval of umbilical cord blood is noninvasive, painless, and generally takes only a few minutes to complete. After a baby is delivered and the umbilical cord is cut, blood is withdrawn from the umbilical cord and placenta with a syringe and then cryogenically stored. In addition, bone marrow is difficult to match between donor and recipient, while cord blood is compatible with more people. Cord blood transplants also have a lower incidence of graft versus host disease (GVHD) and are less likely to transmit infectious diseases.

In 1988, the first successful human cord blood transplant was performed in a child with Fanconi's anemia using cord blood from a sibling (Gluckman et al., 1989). Since then, over 500 autologous and allogeneic umbilical cord blood transplants have been performed worldwide, with the majority done in the past two to three years (Perdahl-Wallace, 1997). Approximately two-thirds of the cord blood transplants have been performed for malignant conditions, including acute lymphocytic leukemia, acute myelocytic leukemia, chronic myelogenous leukemia, and neuroblastoma (Wagner et al., 1995). The other one-third have been for a variety of genetic disorders, including Hurler's syndrome and Hunter's syndrome, adrenoleukodystrophy, osteopetrosis, severe aplastic anemia, severe combined immunodeficiency, and hemoglobinopathies, such as beta thalassemia and sickle-cell anemia (Wagner et al., 1995; Wagner et al., 1996). The majority of transplants have been in children, although a few adults have been transplanted as well.

Under an NIH-sponsored program, cord blood is now being collected and stored at several large banks around the United States, including the New York Blood Center, Duke University, Indiana University, and the University of Minnesota. The International Cord Blood Registry, maintained by the University of Minnesota, matches requests for allogeneic transplants with cord blood banks. In addition, the NHLBI is sponsoring a five-year, \$30 million study to show whether cord blood transplantation is a safe and effective alternative to bone marrow transplantation. The collection and storage centers for this study are at Children's Hospital of Orange County, Duke University, and the University of California at Los Angeles.

In the last few years, privately owned companies have also begun offering umbilical cord blood banking services to individuals and families. When dealing with private storage companies, users pay a one-time fee for the collection, testing, and freezing of the blood. An annual fee is charged for storing the blood in liquid nitrogen. The stored cord blood may be withdrawn if illness occurs later. In contrast, when parents donate their baby's cord blood to a public bank, they generally pay no fees, but they give up all rights to the sample to help build the public supply of cord blood for use in transplantation and research. Even though umbilical cord blood banking has become popular, the Working Group on Ethical Issues in Umbilical Cord Blood recently concluded that "until additional data are obtained regarding safety and efficacy, umbilical cord blood banking and use ought to be considered an investigational technology rather than a proven treatment" (Sugarman et al., 1997).

### **Public Donor Umbilical Cord Blood Banks**

**American Cord Blood Program.** The American Cord Blood Program, located at the University of Massachusetts Medical Center, is the first nonprofit umbilical cord blood bank in New England. The American Cord Blood Program, partially funded through a grant from the National Children's Cancer Society, is only the eighth public donor cord blood bank in the world. To date, the American Cord Blood Program is the only academic health center in the country with a comprehensive program of cord blood collection, banking, transplantation, and research.

The first donation of cord blood was made on January 2, 1997. Since then, the American Cord Blood Program has collected more than 1,000 cord bloods and hopes to get 10,000 cord blood donations by 2007. Expectant mothers are asked to contact the program between 28 and 30 weeks of pregnancy to become donors. The mother is given a kit to bring to the hospital on the day of delivery. However, hospitals keep spare kits on hand. Blood collected from the umbilical cord vein is sent to the University of Massachusetts to be typed, frozen, and stored at the American Cord Blood Bank until a match is found.

The research component of this program is conducted at the University of Massachusetts. Research continues in several areas, including investigating the ways cord blood cells divide, studying engraftment of transplanted cord blood cells in mice, and developing other applications of cord blood transplantation, such as for gene therapy.

**Chicago Community Cord Blood Bank.** The goal of the Chicago Community Cord Blood Bank (CCCBB) is to collect units of cord blood, test them for infectious diseases, identify the protein markers (HLA molecules) required for matching the cord blood to patients, and store them for future transplantation

into patients with cancer or other life-threatening diseases. The CCCBB, at University of Chicago Children's Hospital, is a community resource dedicated to providing units of cord blood for stem cell transplantation and medical research. The CCCBB is currently supported by grants and private donations, which cover the cost of collection, testing, and storage (approximately \$1,000 per cord blood unit).

The CCCBB has been in operation for about two years and has collected approximately 300 cord blood units. The majority of cord blood is donated for use in unrelated allogeneic transplants. However, less than 10 percent of cord bloods stored at CCCBB are family donations for use in related transplants for family members at risk or in need of stem cell transplants. There is no charge to donors for the processing and storage of cord blood units.

Expectant mothers who donate their baby's cord blood are asked to consent to providing medical, ethnic, and related information, donating the cord blood to the cord blood bank for transplantation and/or research, allowing blood to be drawn from the mother for tests, including HIV testing, and granting permission to track the newborn's medical history for up to one year. No blood is drawn from the baby for the cord blood bank. A minimum of 50 cc of cord blood is necessary for use in transplantation. However, approximately 10 percent of cord blood collections yield less than 50 cc and are used for research or quality-control purposes.

**International Cord Blood Foundation.** The International Cord Blood Foundation, established in 1995, is a nonprofit, public bank that stores umbilical cord blood for use in unrelated, anonymous transplants. The foundation holds the policy that before prospective donors decide to donate, they must be fully educated about the importance of cord blood, its potential uses, and the options available (family banking versus donation to a public bank versus disposal). Donors are required to supply a variety of personal information to ensure the safety of the donated cord blood. The foundation keeps all information confidential and does not provide it in a form allowing personal identification unless compelled to by legal order or other lawful authority.

The International Cord Blood Foundation does supply cord blood for research purposes to universities and other institutions. Cord blood is normally used for research when it is not suitable for transplantation, such as when not enough blood is collected from the placenta or not enough nucleated cells are in the specimen. The possibility that the donated cord blood may be used for research is mentioned in the informed consent that donors sign.

**New York Blood Center.** The New York Blood Center's (NYBC) placental blood program, established in 1993, was the nation's first program for storing umbilical cord blood for allogeneic transplantation. The NYBC placental blood pro-

gram currently has an inventory of approximately 7,000 units of frozen umbilical cord blood (Torloni, 1997). The NYBC placental blood program is a nonprofit storage program funded by the NHLBI.

**St. Louis Cord Blood Bank.** The St. Louis Cord Blood Bank at Cardinal Glennon Children's Hospital/St. Louis University is a public donor bank, not a private storage bank. In cooperation with other cord blood banks, the St. Louis Cord Blood Bank serves as a worldwide resource for children in need of stem cell transplants. The banking program includes community and donor education, cord blood collection, processing in the cord blood laboratory, release of the cord blood product, and evaluation of transplant outcomes. As of April 1997, more than 1,800 banked and fully characterized cord blood units were available at the St. Louis Cord Blood Bank.

**Puget Sound Blood Center Cord Blood Bank.** The Puget Sound Blood Center has recently established the Cord Blood Bank program. It is the only cord blood bank in the state of Washington and will be used by patients around the world. The Cord Blood Bank will seek 400 donations this year from donor mothers who deliver at Swedish Medical Center in Seattle and Kapiolani Medical Center for Women and Children in Honolulu.

**Related Umbilical Cord Blood Bank for Hemoglobinopathy Patients.** The Related Umbilical Cord Blood Bank for Hemoglobinopathy Patients at Children's Hospital Oakland in California is supported by the NHLBI. Umbilical cord blood has been recognized as a source of hematopoietic stem cells and has been used in transplants in patients with hemoglobinopathies. The purpose of this project is to store umbilical cord blood for genetically related patients with hemoglobinopathies for transplants. The bank will serve as a resource to hemoglobinopathy centers. The bank will also serve as a research resource for evaluation of the role of umbilical cord blood transplantation in patients with hemoglobinopathies.

### **Private Umbilical Cord Blood Banks**

**Cord Blood Registry.** Cord Blood Registry, in partnership with the University of Arizona School of Medicine, provides state-of-the-art facilities for the collection, processing, and long-term cryogenic storage of umbilical cord blood for parents who wish to store their newborns' cord blood. Cord Blood Registry also established the Designated Transplant Program to allow qualified families in imminent need of stem cell transplants to store their newborns' cord blood free of charge. Umbilical cord blood stem cells banked at the Cord Blood Registry have been used for both related and unrelated transplants.

Families not in imminent need of stem cell transplants store umbilical cord blood with Cord Blood Registry on the remote chances that the child it came from or another family member may need a stem cell transplant in the future. Cord Blood Registry requires mothers to sign an informed consent at least 30 days prior to collection of the cord blood. Each client who privately stores cord blood receives a certificate of legal ownership for their deposit. When samples are not suitable for transplantation due to small sample size or shortage of nucleated cells in the sample, the family is given a refund and recontacted as to the disposition of the sample. Families are given the choice to donate the cord blood for use in research or to request that the sample be disposed of.

Cord Blood Registry also has programs in education and research. In 1996, more than a million pieces of educational material were distributed to the public and medical communities through Cord Blood Registry's national network of Medical Education Specialists and Cord Blood Educators outreach programs. Cord Blood Registry also sponsors continuing medical education programs led by cord blood experts in major institutions across the country. As a founding member of the International Cord Blood Foundation (see "Public Donor Umbilical Cord Blood Banks"), Cord Blood Registry provides substantial support to help fund the foundation's educational and public health initiatives and assists with the National Marrow Donor Program to educate the transplant and research communities. In addition, Cord Blood Registry makes a \$200 donation from each privately banked cord blood to the foundation to help in the collection and processing of cord blood. Combined, the Cord Blood Registry and the International Cord Blood Foundation have collected more than 8,000 umbilical cord blood units.

**New England Cord Blood Bank.** The New England Cord Blood Bank, Inc., is part of the New England Cryogenic Center, Inc., a private cryogenic laboratory. Since its establishment in June 1997, New England Cord Blood Bank has stored more than 200 units of umbilical cord blood for use in autologous transplants or for related transplants in family members. New England Cord Blood Bank does not store cord blood for unrelated allogeneic transplants. If a family decides to terminate their storage agreement at New England Cord Blood Bank, the sample can be donated to a public bank to help others in need of stem cell transplants.

**Cryobanks International, Inc.** Cryobanks International, Inc. (CI), also cryogenically stores human umbilical cord blood in its multiservice complex. The purpose of CI's bank is to develop a registry of donated umbilical cord blood for transplantation, to provide affordable personal umbilical cord blood storage, to provide storage for vital blood tissues, and to provide anonymous donor semen to couples and individuals.

**Reproductive Genetics Institute.** For almost a decade, the Reproductive Genetics Institute (RGI) has provided state-of-the-art genetics services, including genetic counseling, prenatal diagnosis, DNA diagnosis, forensic identification, paternity testing, IVF, and preimplantation genetic diagnosis. Established in 1990, RGI is a private enterprise and was one of the first to provide chorionic villus sampling in the United States. Scientists at RGI are involved in basic research in human genomics, experimental embryology, and cell genetics. The Cell and Tissue Bank, including an umbilical Cord Blood Bank, contains living biological samples available for research and practical application. Types of the cells/tissues available include 107 diploid cell strains from embryos of different gestational ages, chromosomally abnormal cell strains obtained from spontaneously aborted embryos and abnormal embryos, cell strains from skin fibroblasts of patients with single gene disorders, more than 100 human umbilical cord blood samples, hundreds of sperm samples, and dozens of donor oocytes.

**Viacord.** Viacord, Inc., is a medical service company that provides private family cord blood banking. Physicians refer expectant families to Viacord to have their newborn's cord blood processed and banked for another immediate family member in need or at risk of needing a stem cell transplant arising from a known malignancy, genetic blood disorder, or other relevant disease. In addition, families with no apparent need or risk also bank cord blood at Viacord, although the chances of needing it within the family are relatively small.

Viacord's comprehensive cord blood banking services include everything from training of the obstetrician and labor and delivery staff on proper collection procedures to testing and typing, cryopreservation, and storage of umbilical cord blood. Expectant mothers and their physicians complete an extensive health questionnaire and appropriate informed consents. The expectant mother is tested for infectious diseases once during the third trimester and again at delivery. The cord blood is tested for the number of stem cells (CD34-positive cells) and bacterial and fungal contamination and typed for blood type (ABO and Rh) and histocompatibility (HLA-A and HLA-B). The testing and typing results are provided to the referring physician.

A number of insurance companies have begun to pay for Viacord's services when the newborn's sibling or parent is in need of or has significant risk of needing a stem cell transplant. Blue Cross Blue Shield, Aetna Health Plan, Prucare, and even some state Medicaid providers have paid in full for collection, processing and storage of cord blood for these families.

## **ORGAN BANKS**

Organ and tissue banks recover, process, store, and distribute human organs, bone, and tissue for transplantation. Donations are made from people who agree to donate upon their death. A single organ and tissue donor can save or improve the lives of 40–50 people: by donating up to seven vital organs, two eyes for corneal transplants, and bone and soft tissue to benefit 30–40 others. Some organ and tissue banks may also have tissue available for educational and research purposes. However, the demand for organs, bone, and tissue usually exceeds the supply. Therefore, only organs and tissues not suitable for transplantation are available for research. A few organ and tissue banks are described below, and Appendix H contains a partial list of organ and tissue banks in the United States.

Eye banks have been one of the fastest growing types of tissue banks in the latter half of this century. The first eye bank opened in 1946 in New York City and was operated by Dr. R. Townly Paton, who is known as the father of modern eye banking. Currently, almost 100 banks operate in the United States. The advancing technologies in corneal transplant have stimulated the growth of eye banks, and, as with other organs, the demand for transplant tissue is greater than the supply. In 1997, more than 85,000 eye donations (corneas or whole globes) were reported from U.S. Eye Banks (Eye Bank Association, 1998). In 1997, more than 43,000 eye donations were used for corneal transplants and more than 21,000 were used in research (Eye Bank Association, 1998). More than 550,000 cornea transplants have been performed since 1961 with a 90 percent success rate in restoring sight (Eye Bank Association, 1998).

Many of the nonprofit eye banks are funded by local Lions Clubs. Several eye banks are briefly described below that donate tissue for research purposes as well as transplantation procedures. For a more complete list, refer to Appendix H for a state-by-state listing of organ banks.



### **Northwest Tissue Center**

A division of the Puget Sound Blood Center, the Northwest Tissue Center provides musculoskeletal and cardiovascular tissue for transplantation in Washington, Alaska, Montana, and Idaho. Established in 1988, the center is the region's only full-service, nonprofit tissue bank. Each year tissue is provided for more than 4,000 allografts. The donor's medical history and circumstances surrounding the donor's death are gathered from the health-care provider. The donors are screened for infectious, neurological, and autoimmune diseases as well as cancer and drug abuse. Additional information is provided by family members. Laboratory testing for HIV, HTLV-I and-II, hepatitis B and C, and syphilis ensures the safety of the donated tissue. The process is confidential, and the recipients do not know from whom the tissue was received.

### **New England Organ Bank**

The New England Organ Bank (NEOB), a collaborative enterprise of six Boston hospitals started in 1968, is the oldest independent organ bank in the United States. Currently it is a federally designated organ procurement organization for all parts of the six New England states, including thirteen transplant centers with the capability to perform all types of organ and tissue transplantation. Through the United Network for Organ Sharing (UNOS), the NEOB provides organs for transplant outside of New England when a compatible recipient cannot be found in New England. NEOB Tissue Services began recovering bone and other musculoskeletal tissues for orthopedic surgeons in 1988. All tissues procured are collected, processed, tested for infectious diseases, stored, and distributed according to the Standards for Tissue Banking of the American Association of Tissue Banks.

### **Rochester Eye and Human Parts Bank, Inc.**

The Rochester Eye and Human Parts Bank, Inc., was originally founded as the Rochester Eye Bank and Research Society in 1952 by the Downtown Lions Club. In 1968, the eye bank expanded to include the collection of all organs and tissues and adopted its current name. The bank currently procures, processes, preserves, and distributes eyes, skin, and cardiovascular and musculoskeletal tissues for transplant, research, and medical education.

### **Old Dominion Eye Bank**

The first eye bank in Virginia was established in 1956 through the Medical College of Virginia. In 1962, the eye bank was reorganized and came under the

direction of the Old Dominion Eye Foundation, Inc., a nonprofit organization, and the Old Dominion Eye Bank (ODEB). ODEB is supported by multiple Lions Clubs. ODEB serves as a receiving, processing, research, and distribution center for donated eye tissue. ODEB coordinates events from the time of the donor's death to the transplantation of the eye tissue. ODEB provides human eye tissue for corneal transplants, ophthalmic research, and educational training.

### **Utah Lions Eye Bank**

The mission of the Utah Lions Eye Bank is to procure, test, evaluate, and distribute quality eye tissue for transplantation and research. The eye bank accepts donor tissue from donors of any race, religion, or age. Tissue specimens are supplied to researchers investigating macular degeneration and retinal cell transplantation at the John A. Moran Eye Center. Tissue may also be requested by physicians and other professionals for teaching, research, and development of new surgical techniques at the University School of Medicine.

### **Iowa Lions Eye Bank**

The Iowa Lions Eye Bank in the Department of Ophthalmology and visual science at the University of Iowa was established in 1955. The eye bank is a nonprofit service committed to the restoration and preservation of sight through the collection, processing, and distribution of human ocular tissue for transplantation and research. Research areas include eye pathology, ocular melanoma, macular degeneration, and molecular ophthalmology. Tissue is first made available to Iowa surgeons for transplant. If it cannot be used in Iowa, it is then offered to other states and abroad. If the tissue is unsuitable for transplant, it is distributed to various research programs in the Department of Ophthalmology at the University of Iowa and to surgeons throughout the state. In 1995, the eye bank received 30 percent more eye donations than the previous year, 15 percent more in 1996, and 7 percent more in 1997. In 1995, the number of eyes distributed for transplant almost equaled the number distributed for research and training. In 1997, though, the number of donated eyes used for research was almost double the number used for transplants.

### **Kentucky Lions Eye Bank**

The Kentucky Lions Eye Bank was founded in 1954. Its objective is to procure and distribute human donor eye tissue for transplant and ophthalmic research. In 1996, the eye bank had 204 eye donations. Tissue from eye donors aged 5-75 is suitable for transplantation if no problems are detected during the physical

assessment or medical chart review of the donor. Tissue specimens that are distributed for research include whole eye, conjunctiva, lens iris/ciliary bodies, posterior poles (whole eye with the cornea removed), and cornea retina.

### **Central Florida Lions Eye and Tissue Bank, Inc.**

The Central Florida Lions Eye and Tissue Bank, Inc. (CFLETB), was founded by a group of Tampa Lions in 1973. The eye and tissue bank is committed to the recovery, evaluation, and distribution of eye tissue for transplantation, research, and education. CFLETB has donated eye tissue to more than 20,000 individuals worldwide.

### **Mid-America Transplant Services**

The Mid-America Transplant Services (MTS) is a fully accredited private, not-for-profit corporation designated by Medicare to coordinate the procurement of vital organs, eyes, bone, and soft tissue in hospitals throughout Missouri, southern Illinois, and northeastern Arkansas. Vital organs donated include heart, kidney, lung, liver, intestine, and pancreas. Tissues donated include eyes, long bones from the legs, heart valves, and tendons.

In 1995, MTS procured 318 vital organs from 97 local donors and imported another 147 vital organs. MTS also had 234 bone/soft tissue donors and 1,215 eye donors. All potential organ and tissue donors are carefully tested for cancer, infectious diseases, and AIDS before donation can proceed. Organ and tissue donation can proceed only after death has been declared and the next of kin has given consent. There is absolutely no cost to the donor family for organ or tissue donation.

The MTS Eye Banking Services recovers human eye tissue from recently deceased donors and then processes and preserves the tissue for distribution to ophthalmologists for corneal transplantation surgery. Donor eyes not suitable for transplantation may be given to researchers studying the causes and possible cures of blindness and to ophthalmology residency programs for education purposes, and for practicing ophthalmic surgery procedures. MTS also acts as a coordinating center for sharing of tissue among eye banks through its Tissue Sharing Services.

The eye tissue that MTS provides for research purposes includes whole eyes, posterior poles, lens, conjunctiva, retina, and choroid. Tissues can be preserved to meet the needs of individual researchers. Eyes from individuals with known eye diseases are especially valuable for study. In addition, MTS is involved in research to explore the possibility of retinal cell transplantation as a therapy for

such diseases as retinitis pigmentosa and age-related macular degeneration. Donor tissue used for research on eye disease is extremely valuable to medical progress in treating blindness.

### **American Red Cross Tissue Services**

The American Red Cross Tissue Services, established in 1984, collects, processes, and distributes human allograft tissue for use in transplantation. The Red Cross is one of the largest tissue collection-and-distribution organizations in the United States, supplying approximately one-quarter of the nation's tissues for transplantation. There are 17 tissue centers throughout the country and a national office in Washington, D.C. The American Red Cross Tissue Services distributes more than 70,000 units of tissue procured from more than 2,000 donors per year. For example, the Greater Northeast Area Tissue Services, the smallest of six Red Cross Tissue Centers, stores thousands of bone, skin, connective tissue, and heart valve samples from cadavers for transplantation, some research, and some education.

Tissue is obtained from deceased or surgical donors. Donors range in age from newborn to over 80. Tissue donors can sign a donor card but must make their wishes known to their families because the family's consent is required before tissues can be donated after death. All tissues are tested for diseases, such as AIDS, hepatitis, and syphilis.

The Red Cross distributes heart valves, skin, ligaments, tendons, bone, major blood vessels, and fascia, which covers muscles. These tissues are used in orthopedic, neurologic, ophthalmologic, plastic, cardiovascular, and oral reconstructive surgery for a wide range of medical procedures, such as salvaging limbs after tumor surgery, reconstructing hip and knee joints, replacing corneas, and correcting curvature of the spine. Tissue transplantation does not require the donor and the recipient to have the same blood type.

The Tissue Services Research program was established to provide research and development support to optimize human bone processing methods and to ensure the safety of American Red Cross allograft bone. It is a multidisciplinary effort with several departments, including Biochemistry, Coagulation Proteins, Experimental Pathology, Immunology, Molecular Biology, Plasma Derivatives, Platelet Biology, Product Development, Transmissible Diseases, and Virology. The Tissue Services Research program conducts *in vivo* and *in vitro* studies with human demineralized bone matrix to determine the bioactivity of various lots of bone. They are also developing a new bone delivery system for handling demineralized bone matrix during patient surgery. The Tissue Services Research program is also studying growth factors and viral inactivation.

### **Missouri Lions Eye Research Foundation**

The Eye Research Foundation is located in Columbia, Missouri, and operates several different programs, including Eye Research, Operation of the Missouri Lions Eye Tissue Banks in three Missouri cities, Glaucoma Screening, Eyeglass Recycling, Amblyopia Screening, Indigent Patient Care, and Public Education. The foundation conducts research into eye diseases and disorders and ways to provide tissue of a higher quality for transplant purposes. In response to specific requests, the Foundation provides eye tissue for three corneal projects (University of Missouri, Kansas State University, and NIH), two glaucoma projects (St. Louis University, University of Nebraska), and two retinal cell transplant projects (Washington University, NIH).

### **BLOOD BANKS**

During World War I, it was demonstrated that blood could be safely stored. Prior to World War I, a physician would screen a patient's friends and relatives until the proper type was found and then would bleed the donor and immediately transfuse the patient. Several discoveries in the early twentieth century, however, allowed for creation of blood banks today. In 1914, Luis Agote demonstrated that small, nontoxic quantities of sodium citrate could prevent coagulation of the blood, which led to the development of blood storage. In 1943, John Freeman Loutit and Patrick Loudon Mollison acidified the citrate and added dextrose, which allowed for the storage of red cells at 4°C for a period of 21 days. Further addition of adenine increased the storage time of blood in the liquid form. The first blood bank in the United States opened in 1937.

Whole blood can only be stored for a limited time, but various components of blood (red blood cells, platelets, albumin, and plasma fractions) can be frozen and stored for a year or longer. The cryoprotective agent glycerol protects red blood cells from destruction in freezing temperatures. Most blood donations, therefore, are separated and stored as components by blood banks. A single unit of blood can potentially serve the varying needs of five or more patients.

Blood banks exist in every state in the United States. As is common with organ banks, there are often shortages of specific types of blood, and blood drives are held to maintain existing stocks of all blood types. The American Association of Blood Banks (AABB) is an international organization of blood banks, transfusion and transplantation services, and those working in these groups—more than 2,200 institutions (community and hospital blood banks, hospital transfusion services, and laboratories) and 8,500 individuals are AABB members. The AABB also has an accreditation program that strives to improve the quality and

safety of collecting, processing, testing, distributing, and administering blood and blood products.

America's Blood Centers (ABC), founded in 1962, is a national network of non-profit community blood centers. ABC members collect almost half (47 percent) of the U.S. blood supply at 450 donation sites in 46 states. ABC members are licensed and regulated by the U.S. Food and Drug Administration. Some of the nation's blood centers are briefly described below. For a more complete listing of U.S. blood centers, see Appendix H.

### **American Red Cross**

The American Red Cross collected approximately 5.8 million blood donations in 1996. However, the Red Cross represents about half of all U.S. blood donations, so annually, about 12 million units of blood are donated in the United States. The American Red Cross usually maintains about a three-day supply of fresh blood as well as approximately 20,000 units of frozen blood at any one time. The American Red Cross also maintains the world's largest registry of frozen rare blood. Approximately 1,000 units of rare blood a year are supplied to recipients around the globe.

The Food and Drug Administration (FDA) requires the tracking of blood from "arm to arm," however this information is confidential and coded. Donors who test positive for HIV are notified and counseled. The consent form signed by donors asks if excess or expired blood may be used for research.

Fresh red blood cells have a shelf life of 21–42 days depending on the preservative used, and platelets have a shelf life of five days. Plasma can be stored frozen for one to five years, and frozen whole blood can be stored for at least 10 years. Platelets and red cells that expire are sold for research purposes. Researchers are informed that the samples have been found negative for all FDA required tests and only by special request may researchers be provided with the donor's age and gender. Plasma that cannot be transfused is used for making blood derivatives, such as Factor VIII for hemophiliacs, or for making diagnostic reagents. Nothing goes to waste.

### **Navy Blood Program**

The Navy Blood Programs collects almost 150,000 units of blood per year. These units are stored for 35 days (like all blood). Also, 17,000 frozen units are kept on hand at all times. There is only a 6 percent expiration rate. A small amount of the blood that has passed the expiration date for transfusion may be used for research, but no specific program exists for supplying blood for

research purposes. Any blood that tests positive for a disease is destroyed and not used for research purposes.

### **Community Blood Bank**

The Community Blood Bank of Erie County, Pennsylvania, was founded in 1966 and was initially established as a donor recruitment agency. In 1985, the Community Blood Bank took on the responsibility of collection, processing, testing and distribution of blood and blood products. The Community Blood Bank exists as a nonprofit organization with the mission of providing a safe and adequate supply of voluntarily donated blood for patients in Erie County. The Community Blood Bank is the sole supplier of blood and blood products to Erie's six hospitals and to blood centers across the United States in need of emergency blood and blood products. The Community Blood Bank is an accredited AABB member.

### **Thomas Jefferson University Hospital Blood Bank**

The Thomas Jefferson University Hospital Blood Bank is the oldest blood bank in the Philadelphia area. About 25 percent of all blood and blood components transfused at Jefferson are collected through the donor center (volunteer, autologous, and directed donors), and the remainder is obtained from the American Red Cross. The blood bank consists of four divisions: the Donor Center, Transfusion Unit, Pheresis Center, and Tissue Typing Laboratory. The blood bank is an accredited AABB member.

### **Blood Bank of Alaska, Inc.**

The Blood Bank of Alaska, Inc., is a nonprofit organization established more than 25 years ago that serves 30 regional medical centers and hospitals. The blood bank offers services, including autologous donations, directed donations, platelet apheresis, allogeneic donations, and therapeutic phlebotomy. The Blood Bank of Alaska, Inc., is an AABB member.

### **New York Blood Center**

The New York Blood Center (NYBC) has been in operation for more than 30 years. The NYBC is the nation's largest independent blood distribution and services organization, providing blood and blood products for more than one million transfusions annually, about 10 percent of the nation's blood supply. The NYBC serves more than 200 hospitals in New York, New Jersey, and Connecticut. The Lindsley F. Kimball Research Institute is housed in the NYBC and

is a leading center for basic and applied research in hematology and transfusion medicine. The institute consists of 18 research laboratories committed to the study of blood and the prevention, treatment, and cure of bloodborne and blood-related diseases. NYBC also operates a Placental Cord Blood Program, and, since 1993, more than 500 transplants have been performed using cord blood provided by NYBC's Cord Blood Program. NYBC is a not-for-profit corporation and is an AABB member.

### **Puget Sound Blood Center**

The Puget Sound Blood Center and Program was founded in 1944 and is the major resource for blood, tissue, and specialized services in the western Washington area. The Blood Center serves patients in more than 70 hospitals and clinics with blood services and provides tissue and transplantation support through the Northwest Tissue Center to 185 hospitals across the northwest United States. In 1997–1998, there were more than 170,000 volunteer blood donors. The Blood Program also maintains a research facility recognized internationally for advancements in transfusion and transplantation medicine.



Tissue collections vary considerably, ranging from formal repositories to the informal storage of blood or tissue specimens in a researcher's freezer. Appendix A reviews the sources of stored tissue samples described in this report. Archives of human tissue range in size from less than 200 to more than 92 million specimens. Appendix B provides estimates for the number of cases and specimens of stored tissue for each category of tissue collection and an estimate of the overall number of stored tissue samples in the United States. Conservatively, more than 307 million specimens from more than 178 million cases of stored tissue exist in the United States, accumulating at a rate of over 20 million per year.

The two largest tissue repositories in the world, the National Pathology Repository and the DNA Specimen Repository for Remains Identification, are housed in a single institution, the AFIP. These two repositories alone store more than 94 million specimens (Appendix A). The tissue repositories supported by NIH may not be as large as those at AFIP, but NIH is probably the largest funder of extramural tissue repositories, supplying more than \$53 million in FY 1996. Finally, the pathology departments at GME teaching institutions collectively constitute the largest and oldest stores of tissue samples in the United States, with some specimens more than 100 years old. The tissue bank with the oldest samples in the world is the Egyptian Mummy Tissue Bank in Manchester, England, which contains mummy tissue dating back to 2686 B.C.

The vast majority of tissues were originally collected for diagnostic or therapeutic reasons. Three sources—the AFIP National Pathology Repository, GME teaching institution pathology departments, and Newborn Screening Laboratories—represent more than 265.5 million diagnostic and therapeutic specimens from more than 176 million cases. At the AFIP National Pathology Repository alone, more than 92 million pathologic specimens from more than 2.5 million cases are stored (Appendix A). Of the 1,687 GME Teaching Institutions with residency programs in cytopathology (68 institutions), hematology (54 institutions), and clinical and anatomic pathology (180 institutions), well

over eight million cases are accessioned cumulatively per year. Pathology departments at GME teaching institutions without pathology residency programs also accession pathology specimens but most likely not at the same rate as institutions with pathology residency programs. Most GME teaching institutions retain pathology specimens indefinitely, with the oldest tissues anywhere from 20 years old to more than 100 years old. Therefore, at a rate of eight million cases a year for 20 years, conservatively more than 160 million cases are stored at GME teaching institutions with pathology residency programs with several million more stored at those without pathology residency programs. By 1994, the majority of Newborn Screening Laboratories had accumulated less than 500,000 Guthrie cards over the years, seven have amassed more than 500,000 (greater than 3.5 million), four reported collections of between one million and five million cards (greater than four million), and one reported a collection of six million for a conservative estimate of more than 13.5 million Guthrie cards stored in the United States, Puerto Rico, and the Virgin Islands. Tissues collected for diagnostic or therapeutic reasons may sometimes be used for research, educational, and quality-control purposes. However, the vast majority are not.

Several repositories have been established specifically for use in research (see "Large Banks, Repositories, and Core Facilities" in Appendixes A and C). In addition, several very large longitudinal studies collect and bank samples from their study participants. Likewise, a fair amount of research simultaneously creates tissue collections or contributes to tissue banks. Collectively, these contain more than 2.3 million specimens. Because these tissues are collected specifically for research purposes, it is not surprising that the use of these tissues has resulted in numerous research publications: more than 8,000 publications have resulted from the use of cells from the Coriell Institute; 2,000 publications have resulted from studies using tissues from the Cooperative Human Tissue Network (CHTN); and more than 632 publications, three textbooks, and numerous monographs have been produced using samples and data from the Bogalusa Heart Study.

Other than for diagnostic purposes or for use in research, tissues are also collected and stored for a variety of reasons. Blood banks collect approximately 12 million units of blood a year, but only about 20,000 to 40,000 units are stored at any one time. Also, most of the blood collected is used for transfusions. Very little is used for research and quality control. Organ banks do not collect the same volume of tissue that blood banks do but are very similar in the respect that most of the organs and tissues collected are used for transplants and very little is available for research. Forensic DNA banks collect and store tissues for use in criminal investigations. The DoD DNA Specimen Repository and some commercial DNA banks store DNA samples for remains identification. Sperm,

ovum, and embryo banks store specimens for anonymous donation or for later use by the individual storing the material. Umbilical cord blood banks also store blood for anonymous donation and later use by families banking their newborns' cord blood.

Many valuable specimens and data resources exist from a variety of sources, but no centralized database allows researchers to obtain access to and information about them. The NCI is developing a national information database of breast cancer resources to centralize information on biological specimens available to the research and clinical community, promoting access to the specimens, and facilitating collaboration among basic, clinical, and epidemiologic researchers. This database will fulfill one of the priorities of the National Action Plan on Breast Cancer (NAPBC). However, this database is not an exhaustive national listing of all facilities holding breast cancer tissue but is limited to resources that have a breast tissue bank and have the capability and desire to provide tissues or to participate in collaborations.

This RAND national resource brings together information about several sources of stored tissue samples in the United States. It represents the first time that this information has been assembled in a single document and the first time the magnitude of the archives of stored tissues has been assessed. This document may serve as a reference for researchers to identify potential tissue resources. It may also serve as a basis for developing a national database.

**QUANTITY OF STORED TISSUE SAMPLES  
IN THE UNITED STATES**

Type of Repository/Institution	Number of Cases	Number of Specimens	Cases/Year
<b>Large Tissue Banks, Repositories, and Core Facilities</b>			
AFIP DNA Specimen Repository		>2.8 million	10,000
AFIP National Pathology Repository	>2.5 million	>92 million	50,000
Brain and Tissue Banks for Developmental Disorders	2,507	34,943	
Cancer Tissue Bank—VAMC Minneapolis		>2,000	
Case Western Reserve Alzheimer's Center		554	
Coriell Institute for Medical Research		>35,000	
Eastern Cooperative Oncology Group (ECOG)		18,000	3,000
Environmental Health Sciences Center	2,500	2,500	
Gastrointestinal SPORE—JHU		4,207	
Gynecologic Oncology Group Tissue Bank (GOG)	3,176	3,176	
Harvard Brain Tissue Resource Center/Harvard Psychiatry Brain Collection		>5,000	~350
HealthPartners Human Brain Bank	2,150	2,150	
Hereditary Disease Foundation	14,000	14,000	
Human Lung Cancer Tissue Resource		236	
Indiana Alzheimer Disease Center National Cell Repository	2,200	2,200	
Inflammatory Bowel Disease Tissue Bank	>250	>750	
Intergroup Rhabdomyosarcoma Study	>2,400	>2,400	
Kaiser Permanente Center for Health Research		>26,000	
Kathleen Price Bryan Brain Bank	900	900	
Kresge Center for Environmental Health Studies		53	
LifeSpan BioSciences, Inc.		1 million	
Lung Cancer in Uranium Miners: A Tissue Resource		248	
Lung Cancer SPORE—University of Colorado Cancer Center		>1,100	
McKesson BioServices		18.5 million	
Medical College of Georgia Human Brain Bank	24	912	5
Michigan's ADRC Brain Bank		300	50
National Human Monitoring Program	12,000	12,000	
National Neurological Research Specimen Bank	>11,000	>11,000	
National Psoriasis Tissue Bank		1,300	

Type of Repository/Institution	Number of Cases	Number of Specimens	Cases/Year
National Temporal Bone, Hearing, and Balance Pathology Resource Registry	>6,300	12,000	
National Wilms Tumor Study Group	440	440	
NCI AIDS Malignancy Bank	2,002	>18,000	
NCI Breast Cancer Specimen System	>130,000	>240,000	>460
NCI Cooperative Breast Cancer Tissue Resource	8,200	8,200	
NCI Cooperative Human Tissue Network (CHTN)		>100,000	
New York State Multiple Sclerosis Consortium		>1,000	
NHLBI Blood Specimen Repository		1.5 million	300,000
NIH AIDS Research and Reference Reagent Repository		17,000	
NIMH Brain Bank		1,200	
NIST Human Monitoring Program	12,000	12,000	
NIST National Biomonitoring Specimen Bank	661	661	
Oral Cancer Research Center—UCSF	>3,000	>3,000	125
PathServe Human Tissue Bank	300	30,000	300
Pediatric Oncology Group	>50,000	>50,000	
Prediagnostic Breast Cancer Serum Bank	>7,300	>7,300	
Program for Critical Technologies in Molecular Medicine		3 million	25,000
Prostate Cancer Tumor Bank		>1,030	
Radiation Therapy Oncology Group (RTOG)	(fixed) 4,400 (frozen) 70	4,700 290	1,500
Rocky Mountain Multiple Sclerosis Center Tissue Bank		170	
Rush Alzheimer's Disease Center		>1,000	
Southwest Oncology Group—Intergroup Breast Tissue Bank		>4,000	
St. Louis University Alzheimer's Brain Bank	1,000	1,000	
St. Luke's—Roosevelt Institute for Health Sciences	75	>75	
St. Paul—Ramsey Medical Center Brain Bank	>700	>700	
Stanley Foundation Brain Collection		>200	
Stanley Foundation Neuropathology Consortium		60	
State of Florida Brain Bank		>1,000	
Taub Center For Alzheimer's Disease Research Tissue Bank		300	
Texas Repository for AIDS Neuropathogenesis Research		450	
UCLA Alzheimer's Disease Center		>100	
UCSF AIDS Specimen Bank		76,000	
Western Genitourinary Tissue Bank		>250	
Wisconsin's Alzheimer's Disease Brain Tissue Bank		267	
<b>Longitudinal Studies</b>			
Bogalusa Heart Study	14,000	14,000	
Framingham Heart Study	5,209	5,209	
National Health and Nutrition Examination Surveys	85,000	85,000	
NIH Women's Health Initiative	168,000	>336,000	
The Nun Study	678	>678	
Physicians' Health Study	22,701	22,701	

Quantity of Stored Tissue Samples 139

Type of Repository/Institution	Number of Cases	Number of Specimens	Cases/Year
Women and Infants Transmission Study	2,200	>2,200	
Women's Health Study	40,000	40,000	
Women's Interagency HIV Study	2,300	>2,300	
<b>Pathology Specimens</b>			
Graduate Medical Education Teaching Institutions	>160 million	>160 million	>8 million
<b>Newborn Screening Laboratories</b>			
50 states, District of Columbia, Puerto Rico, and Virgin Islands	>13.5 million	>13.5 million	<10,000 to >500,000
<b>Forensic DNA Banks</b>			
48 states with Forensic DNA Banks	1.4 million	1.4 million	
<b>Sperm, Ovum, and Embryo Banks</b>			
California Cryobank	>200	>7,600	
Genetics and IVF Institute		2,300	2,300 embryos
<b>Umbilical Cord Blood Banks</b>			
American Cord Blood Program	>1,000	>1,000	
Chicago Community Cord Blood Bank	>300	>300	
Cord Blood Registry (CBR) & International Cord Blood Foundation (ICBF)	>8,000	>8,000	
New England Cord Blood Bank, Inc.	>200	>200	
New York Blood Center Placental Blood Program	7,000	7,000	
St. Louis Cord Blood Bank	>1,800	>1,800	
<b>Organ Banks</b>			
American Red Cross Tissue Services		>70,000	>70,000
Mid-America Transplant Services		>1,500	>1,500
Northwest Tissue Center		4,000	4,000
<b>Blood Banks</b>			
American Red Cross		~5.8 million	~5.8 million
Navy Blood Program		140,000	140,000
All Other Blood Banks		~6 million	~6 million

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**OVERALL SUMMARY OF STORED TISSUE SAMPLES  
IN THE UNITED STATES**

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Type of Repository	Number of Cases	Number of Specimens	Cases/Year
Large Tissue Banks, Repositories, and Core Facilities	>2.8 million	>119.6 million	390,790
Longitudinal Studies	>340,088	>508,088	
Pathology Specimens	>160 million	>160 million	>8 million
Newborn Screening Laboratories	>13.5 million	>13.5 million	<10,000 to >50,000
Forensic DNA Banks	1.4 million	1.4 million	
Sperm, Ovum, and Embryo Banks	>>200	>9,900	>2,300
Umbilical Cord Blood Banks	>18,300	>18,300	
Organ Banks		>75,500	>75,500
Blood Banks		~12 million	~12 million
Grand Total	>178.0 million	>307.1 million	>20.5 million

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Appendix C

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**SUMMARY OF TISSUE BANKS/REPOSITORIES  
BY TISSUE TYPE**

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**Table C.1**  
**Summary of Tissue Banks/Repositories by Tissue Type**

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
<b>Adipose</b>	National Human Adipose Tissue Survey	12,000 samples of adipose tissue from autopsied cadavers and surgical patients	
<b>Brain</b>	Stanley Foundation Brain Collection	>200 brains from individuals with schizophrenia, bipolar disorders, severe depression, and normal controls Brains are half frozen, half formalin-fixed	
Stanley Foundation Neuro-pathology Consortium	60 brains: 15 each from individuals with schizophrenia, bipolar disorder, severe depression, and normal controls	Brains are distributed coded; on disclosure of results to consortium, codes will be supplied to researchers	None specified
Harvard Brain Tissue Resource Center/Harvard Psychiatry Brain Collection—McLean Hospital	>5,000 brains from individuals mostly with Alzheimer's, Huntington's, or Parkinson's diseases Specimens are fresh quick-frozen tissue blocks and coronal sections, passive frozen hemispheres, or formalin-fixed hemispheres (researchers can request custom dissection of specified anatomic regions of passive frozen or formalin-fixed hemispheres)	Age, gender, cause of death, postmortem time, and a neuropathology report (clinical records are available for approved investigators to read for themselves if they wish to visit the brain bank facility)	None specified

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Alzheimer's Disease Research Center at Duke University— Kathleen Price Bryan Brain Bank	>600 brains from Alzheimer's patients or related causes of dementia >150 brains from patients with other neuro- logical disorders (ALS, Huntington's, muscu- lar dystrophy) 150 normal brains Fixed/frozen hemispheres, paraffin blocks, histological slides	Limited clinical information Demographic information	No distribution to third parties No cost except shipping fees
Taub Center for Alzheimer's Disease Research Tissue Bank	300 flash-frozen and fixed brain tissue specimens from patients with neuro- degenerative disorders and normals Also store peripheral blood cells and DNA from patients with these disorders		
Boston University Alzheimer's Disease Center—Tissue Resource Center	Normal, demented, and diagnosed Alzheimer tissue samples available from frontal lobe, temporal lobe, parietal lobe, occipital lobe, motor lobe, somato-sensory lobe, visual lobe, olfactory cortex, insular cortex, spinal cord, cerebellum, putamen, prefrontal cortex, cau- date, amygdala, hippocampus, and thalamus Specimens are flash-frozen or plp immersion fixed Brain endothelial cell cultures from rapid postmortem samples available	Extensive neurological data Demographic data	Specimens are for research purposes only; no portion of tissues may be given to third parties Any publication resulting from or related to use of tissues must acknowledge BU-ADC

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Brain Bank—Medical College of Georgia	24 brains: 20 are Alzheimer's brains and the others are Parkinson's, other Lewy body disorders, and normals 1 hemisphere is sectioned and frozen, the other hemisphere has 18+ regions sampled with duplicative blocks fixed either in 10% NBF or 70% ETOH; some are paraffin-embedded Blood and DNA specimens from 138 individuals (48 Alzheimer's; 50 neurologic controls; the rest from different neurological disorders)	Some demographic data Clinical data on recently acquired cases	Does not provide tissues for commercial uses Shipping costs must be paid
HealthPartners Human Brain Bank	>2,000 frozen brain specimens from cases of Alzheimer's, Parkinson's, multi-infarction dementia, dementia with Lewy bodies, Pick's disease, unclassified dementia 150 normal controls	Sex, age, neuropathological diagnosis, and clinical diagnosis	No distribution to third parties or use in creating cell lines or commercial uses outside of center's research aims Collaboration usually required Other confidentiality restrictions and assurances that funds flow back into the research from any commercial collaborators Depends on circumstances—may be no cost to individuals, but pharmaceutical companies are required to pay collection, storage, and shipping costs
State of Florida Brain Bank	>1,000 brain specimens Fixed or frozen	Clinical data, age, sex, and race	Acknowledgment of tissue source Shipping costs must be paid
NIMH Brain Bank	450 specimens, mostly frozen; some are formalin-fixed, some are half frozen/half fixed	Demographic and clinical data	Protocol required; no commercial uses

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Southern Illinois University School of Medicine's Center for Alzheimer's Disease Brain Bank	More than 400 brains, fixed and frozen (avg. 20 brains collected per year)	Age, sex, clinical diagnosis	Collaboration required
Michigan Alzheimer's Disease Research Center Brain Bank	>300 frozen brains	Clinical and basic demo- graphic data	Brain specimens are only available to qualified investigators
<b>Blood</b>			
POG—Acute Lymphoblastic Leukemia Cell Bank	Thousands of frozen cell suspensions from leukemia patients (avg. 500–600 cases per year)	Only information requested for project type will be disclosed if approved	Cells may only be used for proposed research project; no subsequent redistribution to other investigators or use for other projects allowed without obtaining permission Collaboration required Cost depends on what is requested
NHLBI Blood Specimen Repository	1.5 million well-characterized specimens of serum, plasma, and cells from NHLBI- sponsored studies	Basic study information	Can only use samples for specified research protocols; may not dis- tribute samples to any other persons Investigator pays shipping costs Tissue source must be acknowledged
DoD DNA Specimen Repos- itory for Remains Identif- ication	2 million DNA specimens (2 bloodstain cards and 1 buccal swab for each individual)		

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
<b>Breast</b>			
NCI Cooperative Family Registry for Breast Cancer Studies (CFRBCS centers: Australian Breast Cancer Family Registry; New York Registry of Breast Cancer Families; Northern California Cooperative Family Registry; Ontario Registry for Studies of Familial Breast Cancer; Philadelphia Breast Cancer Registry; Utah Cooperative Breast Cancer Registry)	Paraffin-embedded breast and ovarian cancers, peripheral blood lymphocytes, serum, frozen tissue, and other biological fluids More than 5,600 families have been ascertained 2,458 affected specimens and 1,840 unaffected specimens available	Related family history (pedigrees) Clinical, demographic, and epidemiological data	CFRBCS repository and related databases are available for interdisciplinary and translational breast cancer research; material can only be used for approved protocol CFRBCS must be referenced in manuscript title Fees for processing, extracting, and shipping of specimens must be paid
NCI Cooperative Breast Cancer Tissue Resource (CBCTR) participating centers: Fox Chase Center, Philadelphia, Pennsylvania; Kaiser Research Foundation Institute, Portland, Oregon; University of Miami; Washington University, St. Louis, Missouri)	>8,200 cases of formalin-fixed, paraffin-embedded primary breast cancer tissues Cases represent all stages of disease from both sexes, all ages, and all races/ethnicities	Associated pathology and clinical data Demographic data Outcome/follow-up data	Specimens may be used for research purposes only; tissues and their products cannot be sold for commercial purposes nor distributed to third parties for purposes of sale Collaborations may be established between researchers and resource investigators to provide necessary additional services \$10/case plus a \$2 to \$10/slide charge plus shipping and handling fees

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Breast Tissue Repository	21 breast tumor cell lines (18 derived from primary breast tissues; 3 from cultured metastatic breast tissues); 13 of the 21 tumor cell lines are paired cell lines with corresponding blood lymphocyte lines 25 primary cultures of normal epithelial and/or stromal mammary cells (5 correspond to tumor-derived cell lines)	Clinical and pathological features of breast tumors used for initiation of cell lines Extensive cellular, molecular, and genetic abnormalities data available Some pedigrees available	Tumor cell lines and lymphoblastoid cell lines available from ATCC; see ATCC limitations Costs are variable, see ATCC catalog
National Surgical Adjuvant Breast and Bowel Project (NSABP) Tissue Bank	Paraffin-embedded tumor specimens available from 25 NSABP trials; 40,479 cases enrolled; 18,529 with blocks or unstained slides; 36,242 with stained slides; and 17,240 with both	Complete clinical follow-up information as well as demographic information	Investigators with novel projects that conform to the research goals of NSABP may apply for tissue; priority given to NSABP membership institutions that regularly submit tissue blocks; tissue will not be distributed to commercial laboratories
<b>Gastrointestinal</b>			
Gastrointestinal Cancer at SPORE Johns Hopkins University	Banks wide range of tissue from resection specimens of colorectal and pancreatic cancer >716 colorectal cancer resections >142 colorectal adenoma resections >398 colorectal polypectomy specimens >47 hepatic resections for metastatic cancer >80 pancreatic cancer resections >107 fecal specimens >1,338 blood specimens	Family histories Food frequency data from questionnaire	

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Inflammatory Bowel Disease Tissue Bank	>775 specimens from about 225 cases 150 cases are inflammatory bowel disease (Crohn's disease and ulcerative colitis); remainder are colon cancer, adeno- carcinoma, and diverticular disease	Final diagnosis Gross description of specimen Age and sex of patient	
<b>Genital</b> Gynecologic Tissue Group Tissue Bank	Benign, malignant, and normal ovarian and cervical tissue and serum from >3,176 patients Snap-frozen, formalin-fixed, OCT embedded primary tumors, touch imprint slides	Clinical Age, race Institutional pathology/ operative reports	
<b>Hepatic</b> NIST-EPA Human Liver Specimen Bank	661 normal liver specimens flash frozen	Demographic data Cause of death Histology report	Acknowledgment of tissue bank required Cost to be ascertained per proposal request
Liver Tissue Procurement and Distribution System	>1,500 frozen specimens from more than 60 types of diseased and normal livers	Demographic data Clinical data Family history (investigators should state areas of interest)	Samples are for NIH investigators only \$110 per sample with each additional sample costing \$15
<b>Inclusive</b> MGH Tumor Bank	>7,500 specimens have been collected and catalogued Normal and tumor specimens are snap-frozen	Verified pathologic diagnosis Some clinical information	\$20/specimen

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
National Pathology Repository	50 million microscopic slides; 30 million paraffin tissue blocks; 12 million preserved wet tissue specimens Specimens represent the entire spectrum of human disease		Requests for loan of material or provision of data for research purposes require submission and approval of research protocol; request from individuals and organizations other than the original contributor must be accompanied by a properly executed authorization signed by the patient or designated representative
Yale Program for Critical Technologies in Molecular Medicine	More than 10,000 frozen tissue samples; more than 3 million archived paraffin blocks from clinical cases	Age, Sex, pathology diagnosis	Approved protocol by the Yale Human Investigation Committee; Material Transfer Agreement from non-Yale investigators; fee-for-service costs
NCI Cooperative Human Tissue Network (CHTN)	From 1987-1996, supplied >100,000 specimens to ~600 investigators Provides biomedical researchers access to fresh surgical or biopsy specimens of normal, benign, precancerous, and cancerous tissues; only rare specimens are stored to anticipated future requests	Minimal demographic information Histology/pathology reports	Tissues provided by the CHTN are only for research purposes and cannot be sold or used for commercial purposes
Radiation Therapy Oncology Group	Collects 3-5 frozen tissue fragments per case from Phase III protocols of cervical, lung, head and neck, esophageal, and anal cancers; >290 specimens from ~70 cases (two-thirds of specimens from cervical cancer) Beginning in 1995, RTOG archived paraffin blocks and tissues from all RTOG Phase III trials; tissue from ~4,400 cases have been collected and stored	No clinical information released that might allow for patient identification or linkage to treatment or demographics	Frozen tissue for use in correlative and translational research; paraffin blocks and tissues for population-based studies



Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
<p>NCI AIDS Malignancy Bank (research centers: Ohio State University, University of California—San Francis- co, George Washington University, State University of New York, University of California—Los Angeles)</p>	<p>&gt; 18,000 samples from &gt;2,000 cases of HIV malignancy-related diseases Formalin-fixed paraffin-embedded tissues, fresh-frozen tissues, malignant cell suspen- sions, fine needle aspirate, cell lines Tissues include serum, plasma, urine, bone marrow, cervical and anal specimens, saliva, semen, and multisite autopsy tissues</p>	<p>Clinical data</p>	<p>Specimens may be used for research purposes only; specimens and their products shall not be sold or used for commercial purposes, nor be dis- tributed to third parties for purposes of sale or producing for sale Shipping cost of specimens must be paid</p>
<p>Tumor Bank Facility at the Herbert Irving Comprehen- sive Cancer Center</p>	<p>Tumors and tumor/normal pairs Members can request specific types of tissue for their research protocols Tissues are snap frozen</p>		<p>Users must be Herbert Irving Compre- hensive Cancer Center members</p>
<p>Brain and Tissue Bank for Developmental Disorders</p>		<p>Clinical data Demographic data</p>	<p>Tissue specimens may only be used for the specified study; research beyond that described in original request may only be carried out pursuant to another agreement signed by both parties; investigator shall not dis- tribute tissue to third parties Acknowledgment of Brain and Tissue Bank for Developmental Disorders required Investigator will provide Director with written summary every 6 months on receipt of tissue Shipping and handling costs plus \$50/ per tissue processing fees must be paid</p>

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
<i>University of Maryland, Baltimore</i>	12,000 brain sections; 53 body fluids; 1,500 cardiovascular tissue; 1,300 endocrine tissue; 6,000 gastrointestinal tissue; 700 genital tissue; 1,600 hematopoietic tissue; 1,000 integumentary tissue; 1,800 musculoskeletal tissue; 2,000 respiratory tissue; 1,900 spinal cord tissue; 1,600 urinary tissue; 800 other types of tissue	Tissue samples are frozen or fixed	
<i>University of Miami</i>	All tissue types from 854 cases of 142 disease types and normals Myoblast, fibroblast and/or lymphoblast cell cultures exist from some cases		
<i>Children's Hospital of Orange County</i>	Currently have tissues and/or cultured cells from >800 patients of 253 disease types and normals		
DAIDS Specimen Repository			Collaboration required
<i>Multicenter AIDS Cohort Study</i>	Cells, serum, plasma, tissue (lymph node biopsies and autopsy tissues), semen, throat washings, fecal scrubs		
<i>Women and Infants Transmission Study</i>	Adult specimens include blood, urine, genital samples, Pediatric specimens include blood and urine		
<i>Women's Interagency Health Study</i>	Blood, oral/pharyngeal swabs, urine, vaginal and cervical swabs, cervicovaginal lavage fluids		

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
<i>HIV Network for Prevention Trials</i>	Serum, plasma, peripheral mononuclear cells, genital tract secretions, saliva (HIV strains isolated from these tissues also available)		
<i>Pediatric AIDS Clinical Trials Group</i>	Serum, plasma, peripheral mononuclear cells, culture supernatants, lymph node biopsies, tissues, urine, and other body fluids		
<i>Adult AIDS Clinical Trials Group</i>	Serum, plasma, peripheral blood mononuclear cells, culture supernatants, lymph node biopsies, tissues, urine, and other body fluids		
<i>AIDS Vaccine Evaluation Group</i>	Serum, plasma, peripheral mononuclear cells, genital tract secretions, saliva, and tears		
<i>Division of AIDS Treatment Research Initiative</i>	Serum, plasma, cells and cultured cells, supernatant from PBMC, plasma HIV cultures		
National Neurological Research Specimen Bank	Tissue specimens and CSF and blood collected from more than 11,000 cases Includes brain, spinal cord, pituitary glands, thymus, spleen, eyes, and lymph nodes	Confirmed diagnosis Demographic data	Tissue specimens distributed to approved investigators only Acknowledgment of the bank is required Shipping costs must be paid
UCSF AIDS Specimen Bank	>76,000 specimens Serum, tissue, saliva, CSF from HIV-infected individuals		

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Tissue Procurement Shared Resource at Ohio State University Comprehensive Cancer Center (CCC)	Handled >75,000 specimens (avg. 3,000/yr) Investigators can request remnant surgical or autopsy tissue by filling out request form	Pathology report	Application approval requires approved human subjects IRB Costs for CCC full members—\$5/specimen, CCC associate members—\$8/specimen, CCC non-members—\$10/specimen Single chart review—\$25 Histology Q.C.—\$7.85/tissue
Life-Span BioSciences, Inc.—Tissue and Disease Bank	1,000,000 normal and diseased human samples >175 different types of tissue from almost every organ, covering all ages >1,500 different pathologic disease categories	Pathologic report and result from requested test	LifeSpan does not sell its tissue per se but performs custom services using its tissue bank Cost varies according to services requested
PathServe—Autopsy and Tissue Bank	Collects all types of organs and tissues including specimens from placental and fetal origin Has ~300 specimens stored at any one time (does not maintain a central storage facility but instead stores samples in morgues in different hospitals) distributed ~30,000 specimens last year	Limited medical history	Tissue may be unsuitable for RNA isolation due to degradation Recipient will use tissue for scientific/medical research only No distribution of tissues to third parties Costs are adult brain—\$320, adult brain (cut)—\$90, spinal cord—\$240, heart—\$320, tissue section (internal organs)—\$240, artery—\$59, placenta—\$89, fetus—\$290, fetal brain—\$250, skin—\$270, pericardium—\$270, dura matter—\$79, eyes (pair)—\$240, temporal bones—\$100, formalin-fixed block—\$97

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Resource for Tumor Tissue and Data—NYU Medical Center	Tissue specimens are collected per investigator needs (tumor specimens may be stored and frozen if no immediate need exists) Specimens can be snap-frozen or fixed; tissue paraffin blocks also available	Specific clinical and/or demo- graphic data are made avail- able Pathology reports	Unused sections of paraffin blocks must be returned upon completion of the study
<b>Musculoskeletal</b>			
National Temporal Bone, Hearing and Balance Pathology Resource Registry	>12,000 temporal bone and brain tissue speci- mens from more than 6,300 cases of hearing and balance disorders	Demographic data Processing data Clinical and histopathological diagnosis	Only the 26 collaborating temporal bone laboratories have access to bone specimens Researchers wishing to use bone specimens must contact the lab director and discuss their intentions
<i>Baylor College of Medicine</i>	1,040 temporal bones from 1,040 cases		
<i>Bowman-Gray School of Medicine</i>	1,074 temporal bones from 1,075 cases		
<i>The Eye &amp; Ear Institute of Pittsburgh</i>	1,385 temporal bones from 826 cases		
<i>Goodhill Ear Center at UCLA School of Medicine</i>	1,000 temporal bones from 500 cases; 10 brain specimens		
<i>House Ear Institute</i>	1,256 temporal bones from 2,008 cases; 72 brain specimens		
<i>Kresge Hearing Research Institute-University of Michigan</i>	60 temporal bones from 65 cases; 4 brain specimens		
<i>Johns Hopkins University</i>	3,520 temporal bones from 3,522 cases; 2 brain specimens		

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
<i>Massachusetts Eye and Ear Infirmary</i>	1,518 temporal bones from 862 cases		
<i>Mount Sinai School of Medicine</i>	Not reported		
<i>New York University</i>	300 temporal bones from 300 cases		
<i>SUNY Health Science Center-Syracuse</i>	198 temporal bones from 162 cases		
<i>University of Chicago</i>	1,600 temporal bones from 771 cases; 293 brain specimens		
<i>University of Iowa Hospitals and Clinics</i>	818 temporal bones from 818 cases		
<i>University of Minnesota</i>	1,694 temporal bones from 946 cases		
<i>University of Texas South- western Medical Center</i>	Temporal bones from 137 cases		
<b>Other Biological Materials (Cells, DNA, RNA, protein)</b>			
NIH AIDS Research and Ref- erence Reagent Program (AIDS Reagent Program)	>1,400 reagents available, including HIV and related viruses, opportunistic infectious agents associated with HIV infections, DNA libraries, DNA clones, antibodies, purified proteins, synthetic peptides, and body fluids		Any commercial use requires written permission and compensation of reagent donor(s) and notification of the AIDS Reagent Program; investi- gators must register with NIH AIDS Research and Reference Reagent Pro- gram Investigator pays shipping costs

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
Indiana Alzheimer Disease Center National Cell Repository	Genetic material from more than 2,200 individuals from 440 families with histories of Alzheimer's disease (both lymphocytes and DNA are available from most participants)	Family pedigrees	Asked to cite IADC National Cell Repository Researchers may not transfer cells or DNA to third parties Materials received from IADC National Cell Repository may not be used for commercial purposes
Human Genetic Mutant Cell Repository (Coriell Cell Repositories)	Contains both DNA and cells from human and animal cultures, normal controls, inherited disorders and normal variants, NICMS extended family collections		Recipient agrees not to try to identify or contact submitter of sample or the donor subject from whom the cell line or DNA is derived; products derived from human cell cultures and DNA samples from HGMCR may not be sold or distributed with or without charge to third party Acknowledgment of repository in pub- lications is required Costs are cell cultures—\$75, human DNA—\$50, hybrid DNA—\$150

Table C.1- continued

Tissue Group/ Resource	Number of Specimens/ Tissue Type(s)	Other Data	Limitations
NIA Cell Repository (Coriell Cell Repositories)	Cell cultures from aging syndromes, Alzheimer's, normals, fibroblasts from aged sibling pairs, other cell types, animal cells	Each shipment includes a computer generated information sheet describing cell culture	Recipient agrees to obtain written permission of submitter and U.S. government before commercialization of cell lines or any products; cell cultures obtained cannot be resold, or distributed free of charge, but they may be replicated by a third party for the original purchaser  Costs are T25 flask—\$75 (for larger orders, first 75 are \$75 and each additional culture is \$25)
ADA Cell Repository Maturity Onset Diabetes Collection	DNA samples and phenotypic data from Phase I and II of the ADA's GENNID study—data on 170 pedigrees with a total of 650 affected individuals and approximately 1,200 subjects	Data set includes multiple metabolic factors as well as lifestyle variables	
American Tissue Culture Collection	Cell cultures from human, animal, and hybridomas	Basic description of cell culture (where derived, genotype, growth conditions)	Cost depends on type of cell culture (\$50-\$150) plus shipping and handling



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**ALPHABETICAL LISTING OF TISSUE BANKS/REPOSITORIES  
AND CONTACTS**


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Tissue Bank	Address and Web Site
Albert Einstein College of Medicine Dept. of Pathology and Neuroscience	1300 Morris Park Ave. Bronx, NY 10461 Phone: 212-430-2827
Alpers Neuropathology Laboratory	Dept. of Neurology Thomas Jefferson University 130 S. 9th St., Suite 400 Philadelphia, PA 19107 Phone: 215-955-6939
Alzheimer's Center—Case Western Reserve University	11100 Euclid Ave. Cleveland, OH 44106 Phone: 216-844-7360 Fax: 216-844-7239 <a href="http://www.ohioalzcenter.org">http://www.ohioalzcenter.org</a>
Alzheimer Disease Center—Indiana University	Indiana University School of Medicine 635 Barnhill Dr., MS-A142 Indianapolis, IN 46202 Phone: 317-274-7818 Fax: 317-274-4882 Indiana Alzheimer Disease Center National Cell Repository Fax: 317-274-2387 <a href="http://medgen.iupui.edu/research/alzheimer">http://medgen.iupui.edu/research/alzheimer</a>
Alzheimer's Disease Center—University of California, Los Angeles	Dept. of Neurology 710 Westwood Plaza Los Angeles, CA 90095 Phone: 310-206-5238 Fax: 310-206-5287
Alzheimer's Disease Center—Northwestern University	Northwestern University Medical School 320 E. Superior St. Searle 11-453 Chicago, IL 60611 Phone: 312-908-8789 Fax: 312-908-8789 <a href="http://www.brain.nwu.edu/core/index.htm">http://www.brain.nwu.edu/core/index.htm</a>

Tissue Bank	Address and Web Site
Alzheimer's Disease Center—University of Rochester	Dept. of Neurobiology & Anatomy Box 603 601 Elmwood Ave. Rochester, NY 14642 Phone: 716-275-2581 Fax: 716-273-1132
Alzheimer's Disease Center—University of Kansas Medical Center	Dept. of Neurology 3901 Rainbow Blvd. Kansas City, Kansas 66160 Phone: 913-588-6970 Fax: 913-588-6965 <a href="http://www.kumc.edu/instruction/medicine/neurology/resAD.html">http://www.kumc.edu/instruction/medicine/neurology/resAD.html</a>
Alzheimer's Disease Center—University of California, Davis	Northern California Alzheimer's Disease Center Alta Bates Medical Center 2001 Dwight Way Berkeley, CA 94704 Phone: 510-204-4530 Fax: 510-204-4524 <a href="http://alzheimer.ucdavis.edu/adc">http://alzheimer.ucdavis.edu/adc</a>
Alzheimer's Disease Core Center—Boston University	Geriatric, Education, and Clinical Center Bedford VA Medical Center 200 Springs Rd. Bedford, MA 01730 Phone: 781-687-2959 Fax: 781-687-3527 <a href="http://www.visn1.org/alzheimer/BrainBank.htm">http://www.visn1.org/alzheimer/BrainBank.htm</a>
Alzheimer's Disease Research Center—Baylor College of Medicine	ADRC 6560 Fannin St. Smith Tower, #1801 Houston, TX 77030 Phone: 713-798-6660 Fax: 713-798-5326 <a href="http://www.bcm.tmc.edu/neurol.struct/adrc/adrc1.html">http://www.bcm.tmc.edu/neurol.struct/adrc/adrc1.html</a>
Alzheimer's Disease Research Center—University of Southern California	2011 Zonal Ave. Los Angeles, CA 90033 Phone: 310-442-1601 Fax: 323-442-1808 <a href="http://www.usc.edu/dept/gero/ARDC">http://www.usc.edu/dept/gero/ARDC</a>
Alzheimer's Disease Research Center—Washington University	Campus Box 8111—ADRC 660 South Euclid Ave. St. Louis, MO 63110 Phone: 314-362-2881 Fax: 314-362-4763 <a href="http://www.adrc.wustl.edu/adrc/adrc2.html">http://www.adrc.wustl.edu/adrc/adrc2.html</a>

Alphabetical List of Tissue Banks 163

Tissue Bank	Address and Web Site
Alzheimer's Disease Research Center— University of Washington	Dept. of Pathology Box 357470 Seattle, WA 98195 Phone: 206-543-5088 Fax: 206-685-8356
Alzheimer's Tissue Repository I.R.U. in Brain Aging	University of California, Irvine Dept. of Psychobiology Irvine, CA 92717 Phone: 714-856-5032
Alzheimer's Treatment & Research Center	St. Paul-Ramsey Medical Ctr. 640 Jackson St. St. Paul, MN 48104-1687 Phone: 612-221-2743
Armed Forces Institute of Pathology	AFIP, Bldg. 54 Washington, D.C. 20306-6000 <a href="http://www.afip.org/">http://www.afip.org/</a>
Armed Forces DNA Laboratory	[Armed Forces DNA Laboratory— <a href="http://www.afip.org/homes/oafme/dna/afdil.html">http://www.afip.org/homes/oafme/dna/afdil.html</a> ]
National Pathology Repository	[National Pathology Repository— <a href="http://www.afip.org/Consultation/Standard_Consultation/Repository_and_Research_Servic/national_pathology_repository_.html">http://www.afip.org/Consultation/Standard_Consultation/Repository_and_Research_Servic/national_pathology_repository_.html</a> ]
Biologic Specimen Bank	Research Institute on Addictions 1021 Main St. Buffalo, NY 14203
Brain and Tissue Bank for Developmental Disorders—Children's Hospital of Orange County	455 South Main St. Orange, CA 92868 Phone: 1-800-992-2462 Fax: 714-532-8442 <a href="http://www.choc.com/btbmain.htm">http://www.choc.com/btbmain.htm</a>
Brain and Tissue Bank for Developmental Disorders—University of Maryland	Bressler Research Building #10-35 655 W. Baltimore St. Baltimore, MD 21201 Phone: 800-847-1539 Fax: 410-706-0020 <a href="http://www.som1.umaryland.edu/BTBank">http://www.som1.umaryland.edu/BTBank</a>
Brain and Tissue Bank for Developmental Disorders—University of Miami	Dept. of Pathology, 410 Pap Bldg. (R-5) 1550 N.W. 10th Ave. Miami, FL 33136 Phone: 800-592-7246 Fax: 305-243-6970 <a href="http://www.med.miami.edu/BTB">http://www.med.miami.edu/BTB</a>

Tissue Bank	Address and Web Site
Brain Bank—Medical College of Georgia	Medical College of Georgia Augusta, GA 30912 Phone: 706-721-2019 Fax: 706-721-6839 <a href="http://www.mcg.edu/Centers/Alz/arc.htm">http://www.mcg.edu/Centers/Alz/arc.htm</a>
Brain Tumor and Tissue Bank—University of Cincinnati College of Medicine; Dept. of Pathology and Laboratory Medicine	231 Bethesda Ave. Cincinnati, OH 45267-0524 Phone: 513-558-7109
CALGB Leukemia Tissue Bank	The Arthur G. James Cancer Hospital & Research Institute 320 West 10th Ave. Room 458A, Starling-Loving Hall Columbus, OH 43210 Phone: 614-293-7521 Fax: 614-293-7522 [Central Office— <a href="http://128.135.31.4">http://128.135.31.4</a> ]
California NeuroAIDS Tissue Network	University of California, San Diego Stein Research Bldg. 9500 Gilman Dr. San Diego, CA 92093
Center for Alzheimer's Disease and Related Disorders	PO Box 19230 Southern Illinois School of Medicine Springfield, IL 62794-9230 Phone: 217-524-6719
Center for Neurological Diseases	Brigham & Women's Hospital 75 Francis St. Boston, MA 02115 Phone: 617-732-6454
ECOG Solid Tumor Tissue Bank/Leukemia Tissue Bank	ECOG Coordinating Center FSTRF 303 Boylston St. Brookline, MA 02445 Phone: 617-632-3610 Fax: 617-632-2990
Emory University's Alzheimer's Disease Center	VA Medical Center 1670 Clairmont Rd. Decatur, GA 30033 Phone: 404-728-7714 Fax: 404-728-7771 <a href="http://www.emory.edu/WHSC/MED/ADC">http://www.emory.edu/WHSC/MED/ADC</a>
Geriatric Neurobehavior and Alzheimer's Center	University of Southern California 12838 Erickson Ave. Downey, CA 90342 Phone: 310-940-7094 Fax: 310-803-0921

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Tissue Bank	Address and Web Site
GOG Tissue Bank	Children's Hospital Research Foundation 700 Children's Dr. Columbus, OH 43205 Phone: 614-722-5302 Fax: 614-722-2897 <a href="http://www.gog.org">http://www.gog.org</a>
GOG/CHTN Ovarian Tissue Bank	Children's Hospital, J058 700 Children's Dr. Columbus, OH 43205 Phone: 614-722-2890 Fax: 614-722-2897 <a href="http://www.gog.org">http://www.gog.org</a>
Harvard Brain Tissue Resource Center	McLean Hospital 115 Mill St. Belmont, MA 02178 Phone: 617-855-2400 <a href="http://www.mcleanhospital.org/brainbank.html">http://www.mcleanhospital.org/brainbank.html</a>
HealthPartners Human Brain Bank	Alzheimer's Research Center Regions Hospital Foundation 640 Jackson St. St. Paul, MN 55101 Phone: 800-229-2872 Fax: 651-292-4040
Indiana University Medical Center Division of Neuropathology	635 Barnhill Dr., MS A142 Indianapolis, IN 46233 Phone: 317-274-7818
Inflammatory Bowel Disease Tissue Bank	Massachusetts General Hospital 55 Fruit St., Warren 256 Boston, MA 02114 Phone: 617-724-0277
Institute of Pathology	Case Western Reserve University 2085 Adelbert Rd. Cleveland, OH 44106 Phone: 216-844-1808
Kathleen Price Bryan Brain Bank	Dept. of Pathology, Box 3712 Duke University Medical Ctr. Durham, NC 27710 Phone: 919-684-5963 [Located within Duke's ADRC— <a href="http://www.medicine.mc.duke.edu/ADRC/INDEX.html">http://www.medicine.mc.duke.edu/ADRC/INDEX.html</a> ]
LifeSpan BioSciences, Inc.	700 Blanchard St. Seattle, WA 98121 Phone: 206-464-1554 Fax: 206-464-1723 <a href="http://www.lsbio.com">http://www.lsbio.com</a>

Tissue Bank	Address and Web Site
LSU Neuroscience Center Brain Tissue Bank	2020 Gravier LSU Medical Center New Orleans, LA 70112 Phone: 504-599-0916 <a href="http://neuroscience.lsumc.edu/BrainBank.html">http://neuroscience.lsumc.edu/BrainBank.html</a>
Manhattan HIV Brain Bank	Mt. Sinai School of Medicine New York, New York 10029
Massachusetts General Hospital Dept. of Neurology	Massachusetts General Hospital Dept. of Neurology, Warren 321 55 Fruit St. Boston, MA 02114 Phone: 617-726-5154
Massachusetts General Hospital Tumor Bank	Division of Hematology/Oncology Jackson 1021 MGH 55 Fruit St. Boston, MA 02114 Phone: 617-724-7081 Fax: 617-726-6974 <a href="http://cancer.mgh.harvard.edu/tumorbank">http://cancer.mgh.harvard.edu/tumorbank</a>
Mayo Clinic Dept. of Pathology	200 First St., S.W. Rochester, MN 55905 Phone: 507-284-6828
Mayo Clinic Jacksonville	4500 San Pablo Rd. Jacksonville, FL 32224 Phone: 904-223-2000
Michigan Alzheimer's Disease Research Center	Dept. of Neurology Michigan Alzheimer's Disease Research Ctr. University of Michigan 1103 E. Huron St. Ann Arbor, MI 48104-1687 Phone: 734-764-5479 Fax: 734-764-2189 <a href="http://www.med.umich.edu/madrc/MADRC.html">http://www.med.umich.edu/madrc/MADRC.html</a>
Missouri Lions Eye Research Foundation	404 Portland St. Columbia, MO 65201 Phone: 573-443-1471 <a href="http://www.rollanet.org/~rlions/mlerf">www.rollanet.org/~rlions/mlerf</a>
Mt. Sinai School of Medicine Dept. of Psychiatry	One Gustave L. Levy Pl. New York, NY 10029-6571 Phone: 212-584-9000, ext. 1789

Tissue Bank	Address and Web Site
Mucosal Immunology Core	11-934 Factor Building Box 951678 Los Angeles, CA 90095 Phone: 310-206-5797 Fax: 310-206-8824 <a href="http://www.medsch.ucla.edu/aidsinst/cfar/Mucosal.htm">http://www.medsch.ucla.edu/aidsinst/cfar/Mucosal.htm</a>
National Disease Research Interchange— Human Tissues and Organs for Research; Human Biological Data Interchange; Odyssey One	2401 Walnut St. Suite 408 Philadelphia, PA 19103 Phone: 800-222-NDRI <a href="http://www.ndri.com">http://www.ndri.com</a>
National Neurological AIDS Bank	W127 Neurology VAMC Los Angeles, CA 90073
National Neurological Research Bank	VA Wadsworth Medical Ctr. Wilshire and Sawtelle Blvds. Los Angeles, CA 90073 Phone: 213-824-4307
National Neurological Research Specimen Bank	VA Greater Los Angeles HealthCare System West Los Angeles VA Medical Center 11301 Wilshire Blvd. Los Angeles, CA 90073 Phone: 310-268-3536 Fax: 310-268-4768 <a href="http://www.loni.ucla.edu/~nnrsb/nnrsb">http://www.loni.ucla.edu/~nnrsb/nnrsb</a>
National Psoriasis Tissue Bank	Phone: 800-723-9166 ext. 13 Fax: 503-245-0626 <a href="http://www.psoriasis.org/tissuebank.html">http://www.psoriasis.org/tissuebank.html</a>
National Surgical Adjuvant Breast and Bowel Project (NSABP)	NSABP Operations Center East Commons Professional Bldg. Four Allegheny Center—5th Floor Pittsburgh, PA 15212 Phone: 412-330-4600 Fax: 412-330-4660 <a href="http://www.nsabp.pitt.edu/">http://www.nsabp.pitt.edu/</a>
National Wilms Tumor Study Group Tissue Bank	Dept. of Pediatrics Roswell Park Cancer Institute Elm and Carlton Sts. Buffalo, NY 14263 Phone: 716-845-2334 Fax: 716-845-8003
Neuropathology Autopsy Core	University of Southern California 2011 Zonal Ave. Los Angeles, CA 90033 Phone: 213-342-1602

Tissue Bank	Address and Web Site
New York University Medical Center Dept. of Pathology	550 First Ave. New York, NY 10016 Phone: 212-263-6449
Ohio St. University College of Medicine Division of Neuropathology	N-112B Upham Hall 473 W. 12th Ave. Columbus, OH 43210 Phone: 614-293-8254
Oregon Health Sciences University Division of Neuropathology	3181 S.W. Sam Jackson Park Rd., L113 Portland, OR 97201 Phone: 503-494-4654
PathServe Autopsy & Tissue Bank	PO Box 22023 San Francisco, CA 94122 Phone: 415-664-9686 Fax: 415-664-5861 <a href="http://www.tissuebank.com">http://www.tissuebank.com</a>
POG ALL Cell Bank	Stanford University School of Medicine Mail Code 5208 300 Pasteur Dr. Stanford, CA 94305 Phone: 650-723-5535 Fax: 650-498-6937
POG AML Cell Bank	St. Jude Children's Research Hospital 332 N. Lauderdale St. Memphis, TN 38105 Phone: 901-495-2799 Fax: 901-495-3100
POG CNS Tumor Bank	Duke University Pediatric Neuro-Oncology Division Box 3624 Duke South Hospital Room 2228 Durham, NC 27710 Phone: 919-684-5301 Fax: 919-684-6674
POG Germ Cell Tumor Bank	University of Alabama Pediatric/Hem/Onc 1600 7th Ave. S. Suite 651 Birmingham, AL 35266 Phone: 205-939-9285 Fax: 205-975-6377
POG Hepatoblastoma Biology Study and Tissue Bank	University of Texas Southwestern Medical Center 5323 Harry Hines Blvd. Dallas, TX 75235 Phone: 214-648-4907 Fax: 214-648-4940



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Tissue Bank	Address and Web Site
POG Hodgkin's Disease Bank	Wake Forest University School of Medicine Department of Pediatrics Medical Center Boulevard Winston-Salem, NC 27157 Phone: 336-716-4085 Fax: 336-716-3010
POG Lymphoid Relapse Cell Bank	MCSD Medical Center 200 W. Arbor Dr. San Diego, CA 92130 Phone: 619-543-6844 Fax: 619-543-5413
POG Neuroblastoma Bank	Division of Hematology/Oncology Box #30 Children's Memorial Hospital 2300 Children's Plaza Chicago, IL 60614 Phone: 773-880-4562 Fax: 773-880-3053
POG NHL Cell Bank	University of Massachusetts Medical School Pediatrics 55 Lake Ave. N. Worcester, MA 01655 Phone: 508-856-4225 Fax: 508-856-4282
POG Operations Office	645 N. Michigan Ave. Suite 910 Chicago, IL 60611 Phone: 312-482-9944 Fax: 312-482-9460 <a href="http://www.pog.ufl.edu">http://www.pog.ufl.edu</a>
Resource for Tumor Tissue and Data NYU School of Medicine	Kaplan Comprehensive Cancer Center 550 First Ave. New York, NY 10016 Phone: 212-263-6452 Fax: 212-263-7573 <a href="http://kccc-www.med.nyu.edu/RTTD.htm">http://kccc-www.med.nyu.edu/RTTD.htm</a>
RTOG Tissue Bank	LDS Hospital 8th Ave. and C St. Salt Lake City, UT 84143 Phone: 801-321-1929 Fax: 617-632-5710
Rush Alzheimer's Disease Center (Rush Brain Bank)	Rush-Presbyterian-St. Luke's Medical Center 1653 W. Congress Pkwy. Chicago, IL 60612 Phone: 312-942-3350 <a href="http://www.rush.edu/Departments/Alzheimers/Research.html">http://www.rush.edu/Departments/Alzheimers/Research.html</a>

Tissue Bank	Address and Web Site
Rush Presbyterian St. Luke's Medical Center Dept. of Pathology	1653 W. Congress Pkwy. Chicago, IL 60612-3864 Phone: 312-942-5254
S.L.U.M.C./Alzheimer's Association Brain Bank	Dept. of Psychiatry and Human Behavior St. Louis University Medical Ctr. 1221 S. Grand Blvd. St. Louis, MO 63104 Phone: 314-577-8726
Sanders-Brown Research Center on Aging University of Kentucky	101 Sanders-Brown Bldg. Lexington, KY 40536 Phone: 606-223-6040
St. Louis University Alzheimer's Brain Bank	Dept. of Geriatric Psychiatry Wohl Memorial Institute 2nd Floor 1221 South Grand Blvd. St. Louis, MO 63104 Phone: 314-577-8719
State of Florida Brain Bank	Mt. Sinai Medical Center 4300 Alton Rd. Miami Beach, FL 33140 Phone: 305-674-2543
Sun Health Research Institute —Institute for Biogerontological Research	PO Box 1278 Sun City, AZ 85372 Phone: 602-876-5328 Fax: 602-876-5461
SWOG National Tissue Repository	Operations Office Southwest Oncology Group 14980 Omicron Dr. San Antonio, TX 78245 Phone: 210-677-8808 Fax: 210-677-0006
Taub Center for Alzheimer's Disease Research—Columbia University	Columbia-Presbyterian Medical Center 630 W. 168th St. New York, NY 10032 Phone: 212-305-4531 Fax: 212-305-4548 <a href="http://pathology.cpmc.columbia.edu/ADNP.html">http://pathology.cpmc.columbia.edu/ ADNP.html</a>
Texas Repository for AIDS Neuropathogenesis Research	University of Texas Medical Branch, Galveston 301 University Blvd. Galveston, TX 77550
Tissue Accrual and In Situ Imaging Core	The Wistar Institute 3601 Spruce St. Philadelphia, PA 19104
Tissue Culture Core	Weill Medical College of Cornell University New York, New York 10021

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Tissue Bank	Address and Web Site
Tissue Procurement Core Facility	Dartmouth College Hanover, NH 03755
Tissue Procurement, Products, Bank, and Database—Yale University School of Medicine	
UCSD National Alzheimer's Disease Brain Bank	Dept. Pathology, M-012 BSB, Room 1004 University of California San Diego La Jolla, CA 92093 Phone: 619-534-6858 Fax: 619-534-8852
UCSF Cancer Center Tissue Core	Tissue Core UCSF Cancer Center Box 0808 San Francisco, CA 94143 Phone: 415-476-0435 <a href="http://cc.ucsf.edu/tissue/index.html">http://cc.ucsf.edu/tissue/index.html</a>
U.K.K.C. Neurodegeneration Autopsy Program	Dept. of Pathology U.K.K.C. Neurodegeneration Autopsy Program Truman Medical Ctr. 2301 Holmes St. Kansas City, MO 64108 Phone: 816-556-3212
University of California San Diego Dept. of Neuroscience and Pathology	UCSD 9500 Gilman Dr., Med. Tech. Bldg. 350 La Jolla, CA 92093 Phone: 619-534-6208 Fax: 619-534-6232
University of Florida Dept. of Neurology	1501 N.W. Ninth Ave. Miami, FL 33101 Phone: 305-547-6219
University of Iowa College of Medicine Dept. of Anatomy	650 Newton Rd. Iowa City, IA 52242 Phone: 319-335-7741
University of Massachusetts Dept. of Neurology	55 Lave Ave., North Worcester, MA 01655 Phone: 508-856-3323
University of Tennessee Medical Ctr.	1924 Alcoa Highway Knoxville, TN 37920 Phone: 615-544-9349
University of Texas at El Paso	206 Psychology Bldg. El Paso, TX 79968 Phone: 915-747-5551
University of Texas Southwestern Medical Ctr. Dept. of Pathology—Neuropathology Laboratory	5323 Harry Hines Blvd. Dallas, TX 75235-9072 Phone: 214-688-2148

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Tissue Bank	Address and Web Site
University of Washington Dept. of Pathology	Dept. of Pathology, SM-30 Seattle, WA 98195 Phone: 206-543-1871
Washington Univ. School of Medicine Dept. of Pathology, Autopsy Service	Dept. of Pathology, Box 8118 Washington Univ. School of Medicine 660 S. Euclid Ave. St. Louis, MO 63110 Phone: 314-362-7440 Fax: 314-362-4096
Western Psychiatric Institute and Clinic	3811 O'Hara St., Room E-1230 Pittsburgh, PA 15213 Phone: 412-624-5186
Wisconsin Alzheimer's Disease Brain Tissue Bank	Medical College of Wisconsin 9200 W. Wisconsin Ave. Milwaukee, WI 53226 Phone: 414-454-5200 Fax: 414-259-0469
Zablocki V.A. Medical Center	Research Service 151 Milwaukee, WI 53295 Phone: 414-259-2881

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**ALPHABETICAL LISTING BY STATE OF TISSUE BANKS  
DESCRIBED IN CHAPTER THREE**

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Alabama	Birmingham VA Medical Center—Early Detection Research Network: Tissue Bank for Matched Tissues to Screen for Markers of Neoplastic Progression
California	The International Skeletal Dysplasia Registry NCI AIDS Malignancy Bank UCLA Alzheimer's Disease Center University of Southern California—Environmental Health Sciences Center University of California, Davis—Institute of Toxicology and Environmental Health University of California, San Francisco—AIDS Specimen Bank Gift of Hope Brain Bank for AIDS Mucosal Immunology Core—UCLA Children's Hospital of Orange County—Brain and Tissue Bank for Developmental Disorders UCSF—Oral Cancer Research Center UCSF Cancer Center Tissue Core UCLA—Breast Tumor Bank Clontech Hereditary Disease Foundation National Neurological Research Specimen Bank PathServe Autopsy & Tissue Bank
Colorado	University of Colorado Cancer Center—SPORE in Lung Cancer Rocky Mountain Multiple Sclerosis Center Tissue Bank
Connecticut	Yale University—Program for Critical Technologies in Breast Oncology
District of Columbia	Armed Forces Institute of Pathology Georgetown University Medical Center and Lombardi Cancer Center— Breast Cancer Specimen Bank George Washington University—HIV-Related Malignancy Tissue/Biological Fluids Bank The Stanley Brain Collection and Neuropathology Consortium
Florida	University of Miami—Brain and Tissue Bank for Developmental Disorders State of Florida Brain Bank

Georgia	Emory University's Alzheimer's Disease Center Medical College of Georgia—Alzheimer's Research Center Brain Bank
Illinois	ECOG Solid Tumor Tissue Bank
Iowa	Iowa City VA Medical Center—Mental Health Clinic Research Center Brain Bank
Kansas	The University of Kansas Medical Center Alzheimer's Disease Center
Kentucky	Lexington VA Medical Center—Central Prostate Cancer Serum Repository
Louisiana	LSU's Stanley S. Scott Cancer Center—Tumor Bank for Solid Tumors LSU Neuroscience Center Brain Tissue Bank
Maryland	American Type Tissue Culture Collection Biomedical Research Institute Johns Hopkins University—SPORE in Gastrointestinal Cancer Johns Hopkins University—SPORE in Prostate Cancer Maryland Brain Collection McKesson BioServices National Biomonitoring Specimen Bank National Human Adipose Tissue Survey NCI Cooperative Breast Cancer Tissue Resource (CBCTR) NCI Prediagnostic Breast Cancer Serum Bank NCI Surveillance, Epidemiology, and End Results Program (SEER) NCI—Cooperative Central Nervous System Consortium Tissue Bank NCI—Biologic Specimen Bank for Early Lung Cancer Markers in Chinese Tin Miners NHLBI Blood Specimen Repository NIH National AIDS Research and Reference Reagent Program NIMH Brain Bank University of Maryland—Brain and Tissue Bank for Developmental Disorders
Massachusetts	Boston University's Alzheimer's Disease Center Dana Farber Cancer Institute — Breast Cancer Specimen Bank Harvard Brain Tissue Resource Center Harvard University—Kresge Center for Environmental Health Studies Inflammatory Bowel Disease Tissue Bank Massachusetts Eye and Ear Infirmary—National Temporal Bone, Hearing and Balance Pathology Resource Registry Massachusetts General Hospital Tumor Bank
Michigan	Michigan's Alzheimer's Disease Research Center Brain Bank University of Michigan Comprehensive Cancer Center—SPORE in Prostate Cancer University of Michigan—Breast Cell/Tissue Bank Data and Database University of Michigan—Tissue Procurement Core University of Michigan—Tissue/Pathology Core
Minnesota	North Central Cancer Treatment Group—Breast Cancer Specimen Bank HealthPartners Human Brain Bank Minneapolis VA Medical Center—Cancer Tissue Bank

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Missouri	Washington University Alzheimer Disease Research Center
Nebraska	University of Nebraska Medical Center—SPORE in Gastrointestinal Cancer
New Hampshire	Dartmouth College—Tissue Procurement Core Facility
New Jersey	Coriell Institute for Medical Research
New Mexico	Albuquerque VA Medical Center—Human Lung Cancer Tissue Resource Albuquerque VA Medical Center—Lung Cancer in Uranium Miners: A Tissue Resource
New York	Kaplan Comprehensive Cancer Center at NYU School of Medicine—Resource for Tumor Tissue and Data Mount Sinai School of Medicine—Manhattan HIV Bank Mount Sinai School of Medicine of CUNY—Brain Bank Core New York Multiple Sclerosis Consortium New York University Medical Center—Breast Cancer Specimen Bank The Research Institute on Addictions—Biologic Specimen Bank Sloan-Kettering Institute The Taub Center for Alzheimer's Disease Research Tissue Bank Tumor Bank Facility at Columbia-Presbyterian Medical Center's Herbert Irving Comprehensive Cancer Center University Center of Downstate Medical Center—Tissue Bank for Research on HIV-associated Malignancies University of Rochester Alzheimer's Disease Center Weill Medical College of Cornell University—Tissue Culture Core
North Carolina	Duke University—Breast Cancer Specimen Bank Duke University—Kathleen Price Bryan Brain Bank UNC Lineberger Comprehensive Cancer Center—SPORE in Breast Cancer
Ohio	GOG Tissue Bank Ohio State University Comprehensive Cancer Center—Tissue Procurement Shared Resource
Oklahoma	Oklahoma City VA Medical Center—Cell and Tissue Bank for Marker Studies of Diseases of the Bladder, Prostate, Kidney, Lung, and Breast
Oregon	Kaiser Permanente Center for Health Research
Pennsylvania	Fox Chase Network Breast Cancer Risk Registry National Disease Research Interchange National Surgical Adjuvant Breast and Bowel Project (NSABP) Pittsburgh VA Medical Center—Pittsburgh Cancer Institute Serum Bank and Tissue Bank Pittsburgh VA Medical Center—Tissue Banking for Early Detection Research Network RTOG Tumor Tissue Repository University of Pennsylvania, Dept. of Microbiology—Brain Tissue Bank University of Pennsylvania—Breast Cancer Specimen Bank University of Pittsburgh Medical Center—Western Genitourinary Tissue Bank University of Pittsburgh—Human Brain Bank
Tennessee	Nashville VA Medical Center—Human Gastrointestinal Tumor Bank

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Texas	Alzheimer's Disease Research Center at Baylor College of Medicine Baylor College of Medicine—Collection of DNA/RNA Tissue Repository for Neurodegenerative Disorders Baylor College of Medicine—Prostate SPORE National Psoriasis Tissue Bank San Antonio SPORE—Familial Breast Cancer Registry and Gene Bank San Antonio SPORE—National Breast Cancer Tissue Resource San Antonio VA Medical Center—Prostate Cancer Tumor Bank University of Texas M.D. Anderson Cancer Center—Tissue Core Facility at the Oral Cancer Research Center University of Texas M.D. Anderson Cancer Center—Tissue Procurement and Banking Facility University of Texas Southwestern's Medical Center—Tissue Procurement Core
Utah	Salt Lake City VA Medical Center—Regional Tumor Bank
Washington	LifeSpan BioSciences, Inc. University of Washington Alzheimer's Disease Research Center University of Washington—Center for Ecogenetics and Environmental Health University of Washington—Breast Cancer Database and Biologic Resource Bank University of Washington—International Registry of Werner Syndrome/Cell Bank
Wisconsin	Medical College of Wisconsin—Wisconsin's Alzheimer's Disease Brain Tissue Bank

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**TUMOR REGISTRIES BY STATE**

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California	<p>California Tumor Tissue Registry Loma Linda University School of Medicine Dept. of Pathology 11021 Campus Ave., AH 335 Loma Linda, CA 92350 Ph. 909-558-4788 Fax: 909-558-0188 <a href="http://www.llu.edu/llu.ctr">http://www.llu.edu/llu.ctr</a></p> <p>California Cancer Registry P.O. Box 942732, MS #592 Sacramento, CA 94234 Ph. 916-327-4663 Fax: 916-327-4657 <a href="http://www.ccrca.org">http://www.ccrca.org</a></p> <p>Cancer Registry of Central California 1625 E. Shaw Ave., Suite 155 Fresno, CA 93710 Ph. 559-274-4550 Fax: 559-221-1821</p> <p>Tri-Counties Regional Cancer Registry 345 Camino Del Remedio, Rm. M340 Santa Barbara, CA 93110 Ph. 805-681-5136 Fax: 805-681-5159</p> <p>Cancer Registry of Northern California 1560 Humboldt Rd., Suite 4 Chico, CA 95928 Ph. 530-345-2483 Fax: 530-345-3214</p>
Colorado	<p>Colorado Central Cancer Registry Colorado Dept. of Public Health and Environment Prevention Programs Division 4300 Cherry Creek Dr. South PPD-CR-A5 Denver, CO 80222 Ph. 303-692-2540 Fax: 303-782-0095 <a href="http://sedac.ciesin.org/ozone/regs/colorado.html">http://sedac.ciesin.org/ozone/regs/colorado.html</a></p>

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- Connecticut  
Tumor Registry Section  
Dept. of Public Health  
410-450 Capitol Ave.  
Hartford, CT 06134  
  
Hartford Hospital  
Cancer Registry  
80 Seymour St.  
Hartford, CT 06102  
Ph. 860-545-5555  
<http://www.harthosp.org/cancer/registry>
- Florida  
Florida Cancer Data System  
Division of Cancer Prevention and Control  
University of Miami School of Medicine  
P.O. Box 016960  
Miami, FL 33101  
Ph. 305-243-4600  
Fax: 305-243-4871  
<http://fcds.med.miami.edu/>
- Georgia  
Tumor Registry  
Phoebe Putney Memorial Hospital  
417 Third Ave.  
Albany, GA 31703  
Ph. 912-883-1800  
  
Georgia Comprehensive Cancer Registry  
Georgia Division of Public Health  
2 Peachtree St., N.W.  
Atlanta, GA 30303  
<http://www.ph.dhr.state.ga.us/org/cancercontrolsection.cancerregistry.htm>
- Hawaii  
The Hawaii Tumor Registry  
1236 Lauhala St.  
Honolulu, Hawaii 96813  
Ph. 808-586-9750  
Fax: 808-587-0024  
<http://www.planet-hawaii.com/htr>
- Idaho  
Cancer Data Registry of Idaho  
802 W. Bannock  
Suite 500  
P.O. Box 1278  
Boise, ID 83701  
<http://www.idcancer.org>
- Illinois  
Illinois State Cancer Registry  
Illinois Dept. of Public Health  
535 W. Jefferson St.  
Springfield, IL 62761  
Ph. 217-782-4977  
Fax: 217-782-3987  
<http://hometown.aol.com/epistudies/cancer/index.htm>

Tumor Registries by State 179

- Indiana** Tumor Registry at St. Joseph's  
Medical Center  
801 E. LaSalle  
South Bend, IN 46617  
Ph. 219-237-7111  
Fax: 219-239-4024
- Iowa** State Health Registry of Iowa  
University of Iowa  
Iowa City, Iowa 52242  
Ph. 319-335-8609  
<http://www.uiowa.edu/~vpr/research/organize/healthreg.htm>
- Kansas** Kansas Cancer Registry  
5028 Robinson Hall  
3901 Rainbow Blvd.  
Kansas City, KS 66160  
Ph. 913-588-4730  
<http://www.kumc.edu/som/kcr>
- Kentucky** Kentucky Cancer Registry  
306 Davis-Mills Building  
800 Rose St.  
Lexington, KY 40536  
Ph. 606-257-4582  
Fax: 305-243-4871  
<http://www.kcr.uky.edu>
- Louisiana** Louisiana Tumor Registry  
Dept. of Public Health & Preventive Medicine  
Louisiana Tumor Registry Suite 900  
Box 106  
1600 Canal St.  
New Orleans, LA 70112  
Ph. 504-568-4716  
Fax: 504-568-2493
- New Orleans Regional Tumor Registry  
P.O. Box 60630  
New Orleans, LA 70160  
Ph. 504-568-2616  
Fax: 504-599-1377
- Baton Rouge Regional Tumor Registry  
4950 Essen Lane  
Baton Rouge, LA 70809  
Ph. 225-767-0430  
Fax: 225-767-4742
- Southeast Louisiana Regional Cancer  
P.O. Box 60630  
New Orleans, LA 70160  
Ph. 504-568-2616  
Fax: 504-599-1377

Acadiana Tumor Registry  
705 E. Saint Mary Blvd.  
Lafayette, LA 70503  
Ph. 318-237-5398  
Fax: 318-235-9436

S.W. Louisiana Regional Tumor Registry  
524 South Ryan St.  
Lake Charles, LA 70601  
Ph. 318-491-7790  
Fax: 318-430-5471

Central Louisiana Regional Tumor Registry  
Northeast Louisiana University  
700 University Ave.  
CNSB Room 221  
Monroe, LA 71209  
Ph. 318-342-1820  
Fax: 318-342-1824

Northwest Louisiana Regional Cancer Registry  
LSU Medical Center—Shreveport  
Section Cancer Prevention & Control  
P.O. Box 33932  
Shreveport, LA 71130  
Ph. 318-675-7660  
Fax: 318-675-7600

North Louisiana Regional Tumor Registry  
Northeast Louisiana University  
700 University Ave.  
CNSB Room 226  
Monroe, LA 71209  
Ph. 318-342-1840  
Fax: 318-342-1824

Maine Central Maine Medical Center Cancer Registry  
300 Main St.  
Lewiston, ME 04240  
Ph. 207-795-2496  
<http://www2.cmmc.org/cmmc/cancercaare/registry.html>

Maryland National Familial Brain Tumor Registry  
The Johns Hopkins Oncology Center  
600 N. Wolfe St., Room 132  
Baltimore, MD 21287  
Ph. 410-955-0227  
  
National Familial Lung Cancer Registry  
The Johns Hopkins University School of Hygiene and Public Health  
615 N. Wolfe St., Room 6309  
Baltimore, MD 21205  
Ph. 410-614-1910  
Fax: 410-955-0863  
<http://www.path.jhu.edu/nfltr.html>

Massachusetts Massachusetts Cancer Registry  
250 Washington St.  
Boston, MA 02108

- MGH Cancer Data Registry  
32 Fruit St.  
Boston, MA 02114  
Ph. 617-726-8646  
Fax: 617-724-3013  
<http://cancer.mgh.harvard.edu/tumreg/tumreg.htm>
- New Hampshire Tumor Registry at the Cheshire  
Medical Center  
580 Court St.  
Keene, NH 03431  
Ph. 603-352-4111
- New Jersey New Jersey State Cancer Registry  
3635 Quaker Bridge Rd.  
CN 369  
Trenton, NJ 08625  
Ph. 609-588-3500  
Fax: 609-588-7431  
<http://www.ker.state.nj.us/health/cancer/njscri1b.htm>
- New York Metropolitan New York Registry  
NYU Medical Center, Dept. of Environmental Medicine  
341 E. 25th St., Room 209  
New York, NY 10010  
Ph. 212-263-5964  
Fax: 212-263-8570  
<http://www.med.nyu.edu/Biostat-Epi/mnyr.htm>
- North Carolina Tumor Registry at Duke University's Comprehensive Cancer Center  
3100 Tower Blvd., Suite 1602  
Box 3153 Medical Center  
Durham, NC 27710  
Ph. 919-419-7900
- North Carolina Cancer Registry  
State Center for Health Statistics  
1908 Mail Service Center  
Raleigh, NC 27699  
Ph. 919-715-9728  
<http://www.schs.state.nc.us/SCHS/about/branches/ccr.html>
- Ohio American Academy of Pediatrics  
Prepubertal Testicular Tumor Registry  
9500 Euclid Ave.  
Cleveland, OH 44195  
Fax: 216-444-0088
- Oregon Oregon State Cancer Registry  
Health Promotion and Chronic Disease Prevention  
800 N.E. Oregon St., Suite 368  
Portland, OR 97232  
Ph. 503-713-4858  
Fax: 503-713-4848  
<http://www.orcpr.org/oscar.html>

- Rhode Island**      Rhode Island Cancer Registry  
Rhode Island Dept. of Health  
3 Capitol Hill  
Providence, RI 02908  
Ph. 401-453-8424  
<http://www.health.state.ri.us/canrep.htm>
- South Carolina**      Savannah River Region Cancer Incidence Registry  
Medical University of South Carolina  
Biometry and Epidemiology  
550 MUSC Complex  
Suite 1133  
Charleston, SC 29425  
Ph. 843-876-1142  
Fax: 843-876-1143  
<http://www.musc.edu/srrhis/>
- Hollings Cancer Center  
High Risk Lung Cancer Registry  
Medical University of South Carolina  
171 Ashley Ave.  
Charleston, SC 29425  
Ph. 843-792-9074  
<http://hcc.musc.edu/lungreg>
- Tennessee**      International Pediatric Adrenocortical Tumor Registry  
Peds/Hem/Onc  
St. Jude Children's Research Hospital  
332 N. Lauderdale  
Memphis, TN 38105  
<http://www.stjude.org/ipactr/objectives.htm>
- Texas**      Familial Brain Tumor Registry  
University of Texas M.D. Anderson Cancer Center  
Dept. of Epidemiology, Box 189  
1515 Holcombe Blvd.  
Houston, TX 77340  
Ph. 800-248-4856  
Fax: 713-792-8261
- Medical Informatics—Tumor Registry  
University of Texas M.D. Anderson Cancer Center  
Dept. of Epidemiology, Box 189  
1515 Holcombe Blvd.  
Houston, TX 77030  
Ph. 713-792-6630  
Fax: 713-792-6401
- Texas Cancer Data Center  
1515 Holcombe Blvd.  
HMB 223  
Houston, TX 77030  
Ph. 713-792-2277  
Fax: 713-794-1951  
<http://www.txcancer.org>

<b>Vermont</b>	<b>Vermont Cancer Registry</b> Vermont Dept. of Health P.O. Box 70 Burlington, VT 05402 Ph. 802-865-7749 <a href="http://www.senate.gov/~leahy/bcreg.htm">http://www.senate.gov/~leahy/bcreg.htm</a>
<b>Virginia</b>	<b>Virginia Cancer Registry</b> Virginia Dept. of Health Office of Epidemiology Division of Surveillance and Investigation P.O. Box 2448, Rm. 114 Richmond, VA 23218 Ph. 804-786-1668 Fax: 804-371-4061 <a href="http://www.vdh.state.va.us/epi/ver.htm">http://www.vdh.state.va.us/epi/ver.htm</a>
<b>Washington</b>	<b>Washington State Cancer Registry</b> Washington State Dept. of Health 1112 S.E. Quince St. P.O. Box 47890 Olympia, WA 98504 <a href="http://www.doh.wa.gov/ehspl/epidemiology/wscr1.htm">http://www.doh.wa.gov/ehspl/epidemiology/wscr1.htm</a>
<b>Wisconsin</b>	<b>Wisconsin Cancer Reporting System</b> Dept. of Health and Family Services 1 W. Wilson St. Madison, WI 53702 Ph. 608-266-1865 <a href="http://www.dhfs.state.wi.us/wcrs/object.htm">http://www.dhfs.state.wi.us/wcrs/object.htm</a>
<b>Wyoming</b>	<b>Wyoming Cancer Surveillance Program</b> Wyoming Dept. of Health Hathaway Building Cheyenne, WY 82002 Ph. 307-777-7951 Fax: 307-777-5402 <a href="http://wdhfs.state.wy.us/cancer">http://wdhfs.state.wy.us/cancer</a>

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**ALPHABETICAL LISTING BY STATE OF LONGITUDINAL  
STUDIES AND RESEARCH PROJECTS THAT SIMULTANEOUSLY  
CREATE TISSUE BANKS**

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California	AIDS-Malignancy Clinical Trials Consortium (University of Southern California) Epidemiology of EBV-Defined Hodgkin's Disease (Northern California Cancer Center) Exogenous Toxicants and Genetic Susceptibility in Amyotrophic Lateral Sclerosis (Stanford University)
Colorado	Smoking Cessation Program for Patients Enrolled in SPORE Projects (Denver VAMC)
District of Columbia	Markers for Malignant Progression in Prostate Cancer (Georgetown University)
Georgia	National Health and Nutrition Examination Survey (CDC)
Kentucky	The Nun Study (University of Kentucky)
Louisiana	Bogalusa Heart Study (Louisiana State University Medical Center) <a href="http://www.mcl.tulane.edu/cardiohealth.bog.htm">http://www.mcl.tulane.edu/cardiohealth.bog.htm</a>
Maryland	Baltimore Longitudinal Study of Aging (National Institutes of Aging) National Institute of Child Health and Human Development (research projects on pregnancy, delivery, and child development-related issues) The National Institutes of Health Women's Health Initiative (Tissue samples stored in Maryland; Clinical Coordinating Center in Seattle, Washington)
Massachusetts	Framingham Heart Study Physicians' Health Study (Brigham and Women's Hospital) Women's Health Study (Brigham and Women's Hospital)
Minnesota	Prostate Cancer Intervention versus Observation Trial (Minneapolis VAMC)
New Jersey	Prospective Randomized Study of Adjuvant Chemotherapy versus Vinorelbine and Cisplatin in Completely Resected NSCLC with Comparison Tumor Marker Evaluation (East Orange VAMC)
New York	Blood Test to Predict Prognosis in Patients with Gynecologic Cancer: Plasma Assay of GLB and GLB:TIMP-1 Complexes (Northport VAMC) Lifetime Alcohol Exposure and Breast Cancer Risk (State University of New York at Buffalo)



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North Carolina	Molecular Basis of Split Hand/Foot Malformation (University of North Carolina)
Ohio	Molecular Epidemiology of Breast Cancer (Case Western Reserve University)
Pennsylvania	Case-Control Study of Hodgkin's Disease in Children (University of Pittsburgh) Genetics of Familial Polycystic Ovary Syndrome (Milton S. Hershey Medical Center) The Role of IL-1 Cytokines in Colorectal Cancer (Pittsburgh VAMC)
Tennessee	Pulmonary Hypertension—Mechanisms and Family Registry (Vanderbilt University Hospital)
Texas	Tissue and Biological Correlations of Soft Tissue Carcinoma (University of Texas M.D. Anderson Cancer Center)
Washington	Human Conceptual Tissue: Characterization for Transplantation Markers for Differentiated Diagnosis and Virulence of Prostate Cancer (Seattle VAMC)

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**TRANSPLANT ORGAN AND TISSUE BANKS BY STATE**

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Alabama	<p>Alabama Community Blood Bank (LifeSouth Community Blood Centers) 386 W. Orange Rd. Birmingham, AL 35209 Ph. 205-943-6000 Fax: 205-943-6003 <a href="http://www.crbs.org">http://www.crbs.org</a></p> <p>Alabama Eye Bank 500 Robert Jemison Rd. Birmingham, AL 35209 Ph. 800-423-78101 <a href="http://www.uab.edu/eye/eyebank3.html">http://www.uab.edu/eye/eyebank3.html</a></p> <p>Alabama Organ Center 301 S. 20th St., Suite 1001 Birmingham, AL 35233-2033 Ph. 800-252-3677 Fax: 205-731-9250 <a href="http://www.uab.edu/aoc/">http://www.uab.edu/aoc/</a></p> <p>Alabama Tissue Center 855 THT, 1900 University Blvd. Birmingham, AL 35294 Ph. 205-934-4314 Fax: 205-934-9219</p>
Alaska	<p>Blood Bank of Alaska, Inc. 400 Laurel St. Anchorage, Alaska 99508 Ph. 907-563-3110 <a href="http://www.customcpu.com/np/bba/default.htm">http://www.customcpu.com/np/bba/default.htm</a></p>
Arizona	<p>Donor Network of Arizona 3877 N. 7th St., Suite 200 Phoenix, AZ 85014 Ph. 602-222-2200 Fax: 602-222-2202 <a href="http://www.donor-network.org">http://www.donor-network.org</a></p>

United Blood Services  
6220 E. Oak St.  
P.O. Box 1541  
Scottsdale, AZ 85252  
Ph. 602-431-9500  
Fax: 602-675-5767  
<http://aztec.asu.edu/blood>

Arkansas Arkansas Regional Organ Recovery Agency  
1100 N. University, Suite 200  
Little Rock, AR 77207-6344  
Ph. 501-224-2623  
Fax: 501-372-6279

California American Red Cross Tissue Services  
Western Area  
3535 Hyland Ave.  
Costa Mesa, CA 92626  
Ph. 714-708-1300  
Fax: 714-708-1331

Blood Bank of the Redwoods  
2324 Bethards Dr.  
Santa Rosa, CA 95405  
Ph. 707-545-1222  
Fax: 707-575-8178  
<http://bbr.org>

Blood Centers of the Pacific  
270 Masonic Ave.  
San Francisco, CA 94118  
Ph. 415-567-6400  
Fax: 415-921-6430  
<http://www.citysearch.com/sfo/bloodcenter>

CA Transplant Donor Network  
55 Francisco St., Suite 510  
San Francisco, CA 94133  
Ph. 415-837-5888  
Fax: 415-837-5880

Central California Blood Center  
3445 N. First St.  
Fresno, CA 93726  
Ph. 559-224-2900  
Fax: 559-225-1602  
<http://www.cencalblood.org/default02.htm>

Community Tissue Service  
3445 N. First St.  
Fresno, CA 93726  
Ph. 800-201-8477  
Fax: 559-229-7217

Cord Blood Registry  
1200 Bayhill Dr.  
Suite 301  
San Bruno, CA 94066  
Ph. 888-267-3256  
<http://www.cordblood.com>

Transplant Organ and Tissue Banks by State 189

Delta Blood Bank  
65 N. Commerce St.  
P.O. Box 800  
Stockton, CA 95201  
Ph. 209-943-3830  
Fax: 209-462-0221

Doheny Eye and Tissue Transplant Bank  
1450 San Pablo St., Suite 3600  
Los Angeles, CA 90033  
Ph. 213-223-0333  
Fax: 213-342-7155

Doheny Eye and Tissue Transplant Bank of Central Coast  
5553 Hollister Ave., Suite 4  
Goleta, CA 93117  
Ph. 805-681-3224  
Fax: 805-681-3226

Golden State Donor Service  
1760 Creekside Oaks Dr., Suite 160  
Sacramento, CA 95833-3632  
Ph. 916-567-1600  
Fax: 916-567-8300

Houchin Community Blood Bank  
2600 G St.  
Eureka, CA 93301  
Ph. 805-327-8541  
Fax: 805-323-7304

Northern California Community Blood Bank  
2524 Harrison Ave.  
Eureka, CA 95501  
Ph. 707-443-8004  
Fax: 707-443-8007

Northern California Transplant Bank  
2593 Kerner Blvd.  
San Rafael, CA 94901  
Ph. 800-922-3100  
Fax: 415-455-9015

Orange County Eye & Tissue Bank  
801 N. Tustin Ave., #102  
Santa Ana, CA 92705  
Ph. 714-550-1022  
Fax: 714-550-9964

OTAC of Southern California  
3665 Ruffin Rd., Suite 120  
San Diego, CA 92123-1871  
Ph. 619-292-8750  
Fax: 619-560-5945

Regional OPA of Southern California  
10920 Wilshire Blvd., Suite 910  
Los Angeles, CA 90024  
Ph. 310-206-0222  
Fax: 310-825-5512

Sacramento Medical Foundation Blood Center  
1625 Stockton Blvd.  
Sacramento, CA 95816  
Ph. 916-456-1500  
Fax: 916-739-8219

San Diego Blood Bank  
440 Upas St.  
San Diego, CA 92103  
Ph. 619-296-6393  
Fax: 619-296-0126  
<http://www.sandiegobloodbank.org>

Sierra Eye and Tissue Donor Services  
1700 Alhambra Blvd., Suite 112  
Sacramento, CA 95816  
Ph. 916-456-1450  
Fax: 916-456-3731

Southern CA Organ Procurement Center  
2200 W. Third St., 2nd Floor  
Los Angeles, CA 90057  
Ph. 213-413-6219  
Fax: 213-413-5373

United Blood Services  
1756 Eastman Ave., Suite 104  
P.O. Box 760  
Ventura, CA 93002  
Ph. 805-654-1600  
Fax: 805-658-6527

Colorado

AlloSource  
8085 E. Harvard Ave.  
Denver, CO 80231  
Ph. 303-755-7775  
Fax: 303-755-7111

Bonfils Memorial Blood Center  
717 Yosemite Circle  
Denver, CO 80230  
Ph. 303-341-4000  
Fax: 303-340-2927

Donor Alliance, Inc. (Mile High Transplant Bank)  
3773 Cherry Creek N. Dr., Suite 601  
Denver, CO 80209  
Ph. 800-448-4644  
Fax: 303-321-0366

Rocky Mountain Lions Eye Bank  
695 S. Colorado Blvd., Suite 320  
Denver, CO 80246  
Ph. 800-444-7479  
Fax: 303-778-0428  
<http://www.corneas.org>

Rocky Mountain Multiple Sclerosis  
Center Tissue Bank  
701 E. Hampden Ave.  
Suite 420  
Englewood, CO 80110  
Ph. 303-788-7806  
<http://www.swedmc.com:80/msc/tissue.htm>

Rocky Mountain Tissue Bank  
2993 S. Peoria St., Suite 390  
Aurora, CO 80014  
Ph. 303-337-3330  
Fax: 303-337-9383

Connecticut

North East OPO and Tissue Bank  
P.O. Box 5037  
Hartford, CT 06102  
Ph. 800-545-2256  
Fax: 860-545-4153

Delaware

Blood Bank of Delaware  
100 Hygeia Dr.  
Newark, DE 19713  
Ph. 302-737-8406  
Fax: 302-737-8233

Florida

Central Florida Blood and Tissue Bank  
32 W. Gore St.  
Orlando, FL 32806  
Ph. 407-849-6100  
Fax: 407-649-8517  
<http://www.cffb.org>

Central Florida Lions Eye & Tissue Bank, Inc.  
5523 W. Cypress St., Suite 100  
Tampa, FL 33607  
Ph. 813-289-1200  
<http://www.lionseyebank.com/home.html>

Community Blood Centers of South Florida  
1700 N. State Rd. 7  
Ft. Lauderdale, FL 33313  
Ph. 954-735-9600  
Fax: 954-735-2839  
<http://www.cbcsf.org>

Florida Blood Services  
3602 Spectrum Blvd.  
P.O. Box 2125  
Tampa, FL 33601  
Ph. 813-632-5433  
Fax: 813-903-1177  
<http://www.fbsblood.org>

Florida Georgia Blood Alliance  
536 W. 10th St.  
Jacksonville, FL 32206  
Ph. 904-353-8263  
Fax: 904-358-7111  
<http://www.fgba.org>

LifeLink Tissue Bank

8510 Sunstate St.  
Tampa, FL 33634  
Ph. 800-683-2400  
Fax: 813-888-9419

Lifelink of Florida

2111 Swann Ave.  
Tampa, FL 33606-2423  
Ph. 813-253-2640  
Fax: 813-251-1819

Lifelink of Southwest Florida

12573 New Brittany Blvd., #10  
Fort Myers, FL 33907  
Ph. 813-936-2772

LifeSouth Community Blood Centers

1221 N.W. 13th St.  
Gainesville, FL 32601  
Ph. 352-334-1000  
Fax: 352-334-1066  
<http://www.crbs.org>

Manatee Community Blood Center

216 Manatee Ave., E.  
Bradenton, FL 34208  
Ph. 941-746-7195  
Fax: 941-748-1711

Medical Eye Bank of Florida

22 W. Lake Beauty Dr.  
Orlando, FL 32806  
Ph. 407-422-2020  
Fax: 407-425-7262  
<http://www.castlegate.net/MEBFL/index.htm>

North Florida Lions Eye Bank

1235 San Marco Blvd., Suite 201  
Jacksonville, FL 32207  
Ph. 800-822-4483  
Fax: 904-346-0444

Northwest Florida Blood Center

2201 N. 9th Ave.  
Pensacola, FL 32503  
Ph. 850-434-2535  
Fax: 850-469-9514

OPO at the University of Florida

Shands Hospital Dept. of Surgery  
Box 100286  
Gainesville, FL 32610  
Ph. 352-395-0632  
Fax: 352-338-9886

Sarasota Community Blood Bank

1760 Mound St.  
Sarasota, FL 34236  
Ph. 941-954-1600  
Fax: 941-951-2629  
<http://www.sarasota-online.com/scbb>

Southeastern Community Blood Center

1731 Riggins Rd.  
Tallahassee, FL 32503  
Ph. 850-877-7181  
Fax: 850-469-7435  
<http://scbcinfo.org>

Translife

2501 N. Orange Ave., Suite 40  
Orlando, FL 32804  
Ph. 407-897-5560

TransLife/Florida Hospital

2501 N. Orange Ave., Suite 40  
Orlando, FL 32804  
Ph. 407-897-5560  
Fax: 407-897-5574

University of Miami

Dept. of Ortho Rehab Tissue Bank  
P.O. Box 016960 (R-12)  
1600 N.W. 10th Ave.  
Miami, FL 33101  
Ph. 305-243-6786  
Fax: 305-243-4622

University of Miami OPO

1150 N.W. 14th St., Suite 208  
Miami, FL 33136  
Ph. 305-548-7622  
Fax: 305-243-7628

Georgia

Atlanta LifeSouth Community Blood Centers

2215 Cheshire Bridge Rd.  
Atlanta, GA 30324  
Ph. 404-329-1994  
Fax: 404-329-1465  
<http://www.crbs.org>

LifeLink of Georgia

3715 Northside Parkway Building 100  
Suite 300  
Atlanta, GA 30327  
Ph. 404-266-8884  
Fax: 404-266-0592

Shepard Community Blood Center

1533 Wrightsboro Rd.  
Augusta, GA 30904  
Ph. 706-737-4551  
Fax: 706-733-5214  
<http://www.shepardblood.com>



- South Georgia Branch of Southeastern Community Blood Center  
2705 E. Pinetree Blvd., Suite 4  
Thomasville, GA 31792  
Ph. 912-228-9980  
<http://www.scbcinfo.org>
- Hawaii
- Blood Bank of Hawaii  
2043 Dillingham Blvd.  
Honolulu, HI 96819  
Ph. 808-845-9966  
Fax: 808-848-4737
- Hawaii Lions Eye Bank  
P.O. Box 2783  
Honolulu, HI 96803  
Ph. 808-536-7416  
Fax: 808-528-5032  
<http://www.eyebank.org>
- Organ Donor Center of Hawaii  
1000 Bishop St., Suite 302  
Honolulu, HI 96813  
Ph. 808-599-7630  
Fax: 808-599-7631
- Illinois
- Bromenn Watson-Gailey Eye Bank  
Virginia at Franklin  
Normal, IL 61761  
Ph. 800-548-4703  
Fax: 309-454-3486
- Central Illinois Community Blood Bank  
1134 S. Seventh St.  
Springfield, IL 62703  
Ph. 217-753-1530  
Fax: 217-753-0689  
<http://www.fgi.net/~bloodbnk>
- Community Blood Services of Illinois  
1408 W. University Ave.  
Urbana, IL 61801  
Ph. 217-367-2202  
Fax: 217-367-6403
- Heartland Blood Centers  
1200 N. Highland Ave.  
Aurora, IL 60506  
Ph. 630-892-7055  
Fax: 630-892-4590
- Illinois Eye Bank  
800 S. Wells St., Suite 185  
Chicago, IL 60607  
Ph. 800-548-4703  
Fax: 312-431-3433

LifeSource  
1205 N. Milwaukee Ave.  
Glenview, IL 60025  
Ph. 847-803-7830  
Fax: 847-803-7685  
<http://www.itxm.org>

Regional Organ Bank of Illinois  
800 S. Wells, Suite 190  
Chicago, IL 60607-4529  
Ph. 312-431-3600  
Fax: 312-803-7643  
<http://www.robi.org>

Indiana

American Red Cross Tissue Services  
Central States Area  
1000 C Airport North Office  
Fort Wayne, IN 46825  
Ph. 219-497-7159  
Fax: 219-489-6994

Central Indiana Regional Blood Center Tissue Bank  
3450 N. Meridian St.  
Indianapolis, IN 46208  
Ph. 317-926-2381  
Fax: 317-927-1724  
<http://www.donor-link.org>

Clarion Health Eye and Tissue Bank  
1701 N. Senate Blvd.  
BG 54  
Indianapolis, IN 46206  
Ph. 317-929-2333  
Fax: 317-929-8216

Indiana Lions Eye Bank  
702 Rotary Circle, Room 146  
Indianapolis, IN 46202  
Ph. 317-274-8527  
Fax: 317-274-2180

Indiana OPO  
719 Indiana Ave., Suite 100  
Indianapolis, IN 46202  
Ph. 317-685-0389  
Fax: 317-685-1687

Iowa

Blood Center of Central Iowa  
1050 Seventh St.  
Des Moines, IA 50314  
Ph. 515-288-0276  
Fax: 515-288-0833  
<http://www.bloodonor.org>

Iowa Statewide OPO  
2732 Northgate Dr.  
Iowa City, IA 52245  
Ph. 800-831-4131  
Fax: 319-337-6105

Mercy Medical Center Surgical Bone Bank  
710 10th St. S.E.  
Cedar Rapids, IA 52403  
Ph. 319-398-6756  
Fax: 319-398-6229

Mississippi Valley Regional Blood Center  
3425 E. Locust St.  
Davenport, IA 52803  
Ph. 319-359-5401  
Fax: 319-359-8603

Siouxland Community Blood Bank  
1019 Jones St.  
P.O. Box 1566  
Sioux City, IA 51102  
Ph. 712-252-2534  
Fax: 606-233-4166

Southeast Iowa Blood Center  
1005 E. Pennsylvania  
Ottumwa, IA 52501  
Ph. 515-682-8149  
Fax: 515-682-6017

Kansas

Midwest Organ Bank  
1900 W. 47th Place, Suite 400  
Westwood, KS 66205  
Ph. 913-262-1666  
Fax: 913-262-5130

Wichita Eye Bank  
3306 E. Central Ave.  
Wichita, KS 67208  
Ph. 800-393-3008  
Fax: 316-688-7390  
<http://www2.southwind.net/~gsbryan>

Kentucky

Central Kentucky Blood Center  
330 Waller Ave.  
Lexington, KY 40504  
Ph. 606-276-2534  
Fax: 606-233-4166

Kentucky Lions Eye Bank  
301 E. Muhammad Ali Blvd.  
Louisville, KY 40202  
Ph. 502-852-5466  
Fax: 502-852-7298  
<http://athena.louisville.edu/medschool/ophthalmology/kleb.htm>

Kentucky Organ Donor Affiliates  
106 E. Broadway  
Louisville, KY 40202  
Ph. 502-581-9511  
Fax: 502-589-5157

- Western Kentucky Regional Blood Center  
3015 Hartford Rd.  
Owensboro, KY 42301  
Ph. 270-684-9296  
Fax: 270-684-4901
- Louisiana
- Blood Center for Southeast Louisiana  
312 S. Galvez St.  
New Orleans, LA 70119  
Ph. 504-524-1322  
Fax: 504-592-2694  
<http://www.thebloodcenter.org>
- Lifeshare Blood Centers  
1455 Wilkinson St.  
Shreveport, LA 71103  
Ph. 318-222-7770  
Fax: 318-222-8886
- Louisiana OPA  
3501 N. Causeway Blvd., Suite 940  
Metairie, LA 70002  
Ph. 504-837-3355  
Fax: 504-837-3587
- Southern Transplant Services, Inc.  
Houma Medical Center  
3901 Houma Blvd., Plaza 2, #405  
Metairie, LA 70006  
Ph. 504-454-7998  
Fax: 504-885-7873
- United Blood Services  
1503 Bertrand Dr.  
P.O. Box 3362  
Lafayette, LA 70502  
Ph. 318-235-5433  
Fax: 318-232-5352  
<http://aztec.asu.edu/blood>
- Maryland
- Blood Bank of Delaware  
1309 Mt. Hermon Rd.  
Salisbury, MD 21801  
Ph. 410-749-4161  
Fax: 410-749-7303
- Medical Eye Bank of Maryland  
Washington Eye Bank  
815 Park Ave.  
Baltimore, MD 21201  
Ph. 410-752-3800  
Fax: 410-545-4455
- Transplant Resource Center of Maryland  
1540 Caton Center Dr., Suite R  
Baltimore, MD 21227  
Ph. 410-242-7000  
Fax: 410-242-1871

- Massachusetts
- New England Cord Blood Bank  
665 Beacon St., Suite 302  
Boston, MA 02215  
Ph. 800-700-CORD  
<http://www.cordbloodbank.com/overview.htm>
- New England Eye & Tissue Transplant Bank  
50 Staniford St., 4th Floor  
Boston, MA 02114  
Ph. 617-523-3937  
Fax: 617-523-2364
- New England Organ Bank  
One Gateway Center  
Newton, MA 02158  
Ph. 800-446-6362  
Fax: 617-244-8755  
<http://www.neob.org>
- Michigan
- Michigan Community Blood Centers  
1036 Fuller Ave., N.E.  
P.O. Box 1704  
Grand Rapids, MI 49501  
Ph. 616-774-2300  
Fax: 616-776-1891  
<http://miblood.org>
- Michigan Eye Bank  
1000 Wall St.  
Ann Arbor, MI 48105  
Ph. 800-247-7250  
Fax: 734-936-0020  
<http://www.mebtc.org>
- Transplantation Society of Michigan  
2203 Platt Rd.  
Ann Arbor, MI 48104  
Ph. 313-973-1577  
Fax: 313-973-3133
- University of Michigan Skin Bank  
1500 E. Medical Center Dr.  
Rm. 1A435-UH, Box 0033  
Ann Arbor, MI 48109  
Ph. 313-936-9673  
Fax: 313-936-9657
- Minnesota
- American Red Cross Tissue Services  
North Central Region  
100 S. Robert St.  
St. Paul, MN 55107  
Ph. 800-847-7838  
Fax: 651-290-8925
- Lifeforce, Upper Midwest OPO, Inc.  
2550 University Ave. W.,  
Suite 315 S.  
St. Paul, MN 55114-1904  
Ph. 612-603-7800  
Fax: 612-603-7801

- Mississippi**
- Memorial Blood Centers of Minnesota**  
2304 Park Ave.  
Minneapolis, MN 55404  
Ph. 612-871-3300  
Fax: 612-871-1359  
<http://www.mbcm.org>
- Mississippi Blood Services**  
1995 Lakeland Dr.  
Jackson, MS 39216  
Ph. 601-981-3232  
Fax: 601-984-3783
- Mississippi Organ Recovery Agency**  
12 River Bend Place, Suite B  
Jackson, MS 39208  
Ph. 601-933-1000  
Fax: 601-933-1006
- United Blood Services**  
604 W. Eastern Blvd.  
P.O. Box 2577  
Tupelo, MS 38803  
Ph. 601-842-8871  
Fax: 601-680-9161  
<http://www.mississippi.net/~jrigdon/index.html>
- Missouri**
- Community Blood Center of Greater Kansas City**  
4040 Main St.  
Kansas City, MO 64111  
Ph. 816-753-4040  
Fax: 816-968-4047  
<http://kcblood.org>
- Mid-America Transplant Association**  
1139 Olivette Executive Parkway  
St. Louis, MO 63132-3205  
Ph. 314-991-1661  
Fax: 314-991-2805
- Missouri Lions Eye Research Foundation**  
404 Portland St.  
Columbia, MO 65201  
Ph. 573-443-1471
- St. Louis Cord Blood Bank**  
3662 Park Ave.  
St. Louis, MO 63110  
Ph. 314-268-2787  
Fax: 314-268-4081  
<http://www.slu.edu/colleges/med/departments/pediatrics/cordbank/moreinfo.html>
- Montana**
- United Blood Services**  
3000 7th Ave., N.  
P.O. Box 1672  
Billings, MT 64111  
Ph. 816-248-9168  
Fax: 406-248-1025  
<http://aztec.asu.edu/blood>

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200 Handbook of Human Tissue Sources

- Nebraska**
- Community Blood Bank of the Lancaster County Medical Society  
2966 O St.  
Lincoln, NE 68510  
Ph. 402-474-1781  
Fax: 402-474-5986  
<http://www.medlinc.com/lcms/bloodbnk>
- Nebraska Organ Retrieval System  
4060 Vinton St., Suite 200  
Omaha, NE 68105  
Ph. 402-553-7952  
Fax: 402-553-0933
- Nevada**
- Nevada Donor Network  
4580 S. Eastern Ave., Suite 33  
Las Vegas, NV 89119  
Ph. 702-796-9600  
Fax: 702-796-4225
- United Blood Services  
6930 W. Charleston Blvd.  
Las Vegas, NV 89117  
Ph. 702-228-4483  
Fax: 702-228-2374  
<http://www.unitedbloodservices.org>
- United Blood Services  
1125 Terminal Way  
Reno, NV 89502  
Ph. 702-329-6451  
Fax: 702-324-6480  
<http://aztec.asu.edu/blood>
- New Jersey**
- BioGenetics Corporation  
1130 Rte. 22W, P.O. Box 1290  
Mountainside, NJ 07092  
Ph. 908-654-8836  
Fax: 908-232-2114
- Blood Center of New Jersey  
45 S. Grove St.  
East Orange, NJ 07018  
Ph. 973-676-4700  
Fax: 973-676-4933  
<http://www.bloodnj.org>
- Central New Jersey Blood Center  
494 Sycamore Ave.  
Shrewsbury, NJ 07702  
Ph. 732-842-5750  
Fax: 732-842-1617  
<http://www.cjbc.org>
- Community Blood Services  
970 Linwood Ave. W.  
Paramus, NJ 07652  
Ph. 201-444-3900  
Fax: 201-670-6174

Transplant Organ and Tissue Banks by State 201

Lions Eye Bank of New Jersey  
DOC -1st Floor, 90 Bergen St.  
Newark, NJ 07103  
Ph. 973-972-2060  
Fax: 973-972-2093

Musculoskeletal Transplant Foundation  
Edison Corporate Center  
125 May St., Suite 300  
Edison, NJ 08837  
Ph. 732-661-0202  
Fax: 732-661-2297

New Jersey Organ and Tissue Sharing Network  
841 Mountain Ave.  
Springfield, NJ 07081  
Ph. 800-SHARE-NJ  
Fax: 201-379-5113  
<http://www.sharenj.org>

Osteotech, Inc.  
51 James Way  
Eatontown, NJ 07724  
Ph. 732-542-2800  
Fax: 732-542-2906

Tutogen Medical, Inc.  
1719 Route 10  
Parsippany, NJ 07054  
Ph. 973-359-8444  
Fax: 973-359-8410

New Mexico

New Mexico Donor Program  
2715 Broadbent Parkway, Suite J  
Albuquerque, NM 87107  
Ph. 505-843-7672  
Fax: 505-343-1828

New Mexico Lions Eye Bank  
303 San Mateo Blvd., Suite 103  
Albuquerque, NM 87108  
Ph. 505-266-3937  
Fax: 505-266-5560

United Blood Services  
1515 University Blvd., N.E.  
P.O. Box 25445  
Albuquerque, NM 87125  
Ph. 505-843-6227  
Fax: 505-247-8835  
<http://aztec.asu.edu/blood>

New York

American Red Cross Tissue Services  
Greater Northeast Region  
636 S. Warren St.  
Syracuse, NY 13202  
Ph. 315-464-1300  
Fax: 315-425-0471



**Center for Donation and Transplant**

218 Great Oaks Blvd.

Albany, NY 12208

Ph. 518-262-5606

Fax: 518-262-5427

**Eye Bank for Sight Restoration, Inc.**

120 Wall St., Fl. 3

New York, NY 10005

Ph. 212-742-9000

**Idant Laboratories**

350 5th Ave., Suite 7120

New York, NY 10118

Ph. 212-244-0555

Fax: 212-244-0806

**New York Blood Center**

150 Amsterdam Ave.

New York, NY 10023

Ph. 800-933-BLOOD

<http://www.nybloodcenter.org>

**New York Organ Donor Network**

475 Riverside Dr., Suite 1244

New York, NY 10115

Ph. 212-870-2240

Fax: 212-870-3299

**Rochester Eye and Human Parts Bank**

524 White Spruce Blvd.

Rochester, NY 14623

Ph. 800-568-4321

<http://www.rehpb.org>

**University of Rochester Organ Procurement Program**

Corporate Woods of Brighton

Bldg. 120, Suite 180

Rochester, NY 14623

Ph. 716-272-4930

Fax: 716-272-4956

**Upstate New York Transplant Services**

165 Genesee St., Suite 102

Buffalo, NY 14203

Ph. 716-853-6667

Fax: 716-853-6674

**North Carolina**

**Carolina LifeCare**

Medical Center Blvd.

Winston Salem, NC 27157

Ph. 910-777-3130

Fax: 910-777-3137

**Carolina OPA**

702 Johns Hopkins Dr.

Greenville, NC 27834

Ph. 919-957-0090

Fax: 919-757-0708

LifeShare of Carolinas  
101 W. T. Harris Blvd., Suite 5302  
P.O. Box 32861  
Charlotte, NC 28232  
Ph. 704-548-6850  
Fax: 704-548-6851

North Dakota

United Blood Services  
517 S. 7th St.  
P.O. Box 2052  
Bismarck, ND 58502  
Ph. 701-258-4512  
Fax: 701-223-0557  
<http://aztec.asu.edu/blood>

United Blood Services  
1320 1st Ave. N.  
P.O. Box 2462  
Fargo, ND 58108  
Ph. 701-293-9453  
Fax: 513-558-1300  
<http://aztec.asu.edu/blood>

Ohio

Community Tissue Services Community Blood Center  
349 S. Main St.  
Dayton, OH 45402  
Ph. 800-684-7783  
Fax: 937-461-4225

Hoxworth Blood Center  
University of Cincinnati Medical Ctr.  
3130 Highland Ave., ML0055  
Cincinnati, OH 45267  
Ph. 513-558-1200  
Fax: 513-558-1300  
<http://www.hoxworth.org>

Life Connection of Ohio  
1545 Holland Rd., Suite C  
Maumee, OH 43537  
Ph. 419-893-4891

LifeBand  
20600 Chagrin Blvd., Suite 350  
Cleveland, OH 44122-5343  
Ph. 216-752-5433  
Fax: 216-751-4204

Lifeline of Ohio Organ Procurement  
770 Kinnear Rd., Suite 200  
Columbus, OH 43212  
Ph. 614-291-5667  
Fax: 614-291-0660

Lifeshare  
105 Cleveland St.  
Dayton, OH 45402  
Ph. 440-322-5700  
Fax: 440-323-6240

Lions Eye Bank of West Central Ohio  
120 Ziegler St., Suite 100  
Dayton, OH 45402  
Ph. 937-223-4850  
Fax: 937-223-1541

Mid-America Tissue Center, Inc.  
2860 Lincoln Way E.  
Massillon, OH 44646  
Ph. 800-451-3587  
Fax: 330-830-0628

Northwest Ohio Tissue Bank  
2736 N. Holland-Sylvania Rd.  
Toledo, OH 43615  
Ph. 419-534-6930  
Fax: 419-534-6928

Ohio Valley LifeCenter  
2939 Vernon Place  
Cincinnati, OH 45219  
Ph. 513-558-5555  
Fax: 513-558-5556

Ohio Valley Tissue and Skin Center  
2939 Vernon Place  
Cincinnati, OH 45219  
Ph. 513-558-6400  
Fax: 513-558-6440

Toledo Life Connection of Ohio  
1545 Holland Rd., Suite C  
Maumee, OH 43537  
Ph. 419-893-4891  
Fax: 419-893-1827

Oklahoma

American Red Cross Tissue Services  
Southern Plains Area  
601 N.E. 6th St.  
Oklahoma City, OK 73104  
Ph. 405-815-6530  
Fax: 405-232-6819

McBride Clinic Bone Bank  
1111 N. Dewey Ave.  
Oklahoma City, OK 73103  
Ph. 405-272-9671, ext. 456  
Fax: 405-552-9355

Oklahoma Lions Eye Bank  
608 Stanton L. Young  
Oklahoma City, OK 73104  
Ph. 405-271-5691  
<http://www.ionet.net/~oleb/lionseye.html>

Oklahoma Organ Sharing Network  
5801 N. Broadway, Suite 100  
Oklahoma City, OK 73112  
Ph. 405-840-5551  
Fax: 405-840-9748

- Oregon
- Plasma Alliance, Inc.  
Oklahoma City, OK 73103  
Ph. 405-521-9204
- Sylvan N. Goldman Center Oklahoma Blood Institute  
1001 N. Lincoln Blvd.  
Oklahoma City, OK 73104  
Ph. 405-297-5700  
Fax: 405-297-5513
- Community Tissue Service  
16361 N.E. Cameron Blvd.  
Portland, OR 97230  
Ph. 503-408-9394  
Fax: 503-408-9395
- Lane Memorial Blood Bank  
2211 Willamette St.  
Eugene, OR 97405  
Ph. 541-484-9111  
Fax: 541-484-6976  
<http://www.lanecountyblood.org>
- Lions Eye Bank of Oregon  
1010 N.W. 22nd Ave, N144  
Portland, OR 97210  
Ph. 800-843-7793  
Fax: 800-798-9040  
<http://www.orlions.org/cover.htm>
- Pacific Northwest Transplant Bank  
2611 S.W. Third Ave., Suite 320  
Portland, OR 97201-4952  
Ph. 503-494-5560  
Fax: 503-494-4725
- Pennsylvania
- The Center for Organ Recovery and Education Ride Park  
204 Sigma Dr.  
Pittsburgh, PA 15238  
Ph. 412-963-3550  
Fax: 412-963-3563
- Central Pennsylvania Blood Bank  
Liberty Center Office Complex  
8170 Adams Dr., Suite 100  
Hummelstown, PA 17036  
Ph. 717-566-6161  
Fax: 717-566-7851
- Community Blood Bank of Erie County  
2646 Peach St.  
Erie, PA 16508  
Ph. 814-456-4206  
Fax: 814-452-3966  
<http://www.eriebloodbank.org>
- Delaware Valley Transplant Program  
2000 Hamilton St., Suite 201  
Philadelphia, PA 19130  
Ph. 610-543-6391  
Fax: 215-557-9359

Institute for Transfusion Medicine  
3636 Boulevard of the Allies  
Pittsburgh, PA 17036  
Ph. 800-310-9551  
Fax: 412-209-7335  
<http://www.itxm.org>

Lions Eye Bank of Northwest  
Pennsylvania  
5105 Richmond St.  
Erie, PA 16509  
Ph. 814-866-3545  
Fax: 814-864-1875  
<http://www.unitedwayerie.org/eyebank>

Miller Memorial Blood Center  
1465 Valley Center Parkway  
Bethlehem, PA 18017  
Ph. 610-691-5850  
Fax: 610-691-5423

Pennsylvania Regional Tissue Bank  
814 Cedar Ave.  
Scranton, PA 18505  
Ph. 570-343-5433  
Fax: 570-343-6993

University of Pennsylvania  
Medical Center  
Bone and Tissue Bank  
3508 Market St., Suite 490  
Philadelphia, PA 19104  
Ph. 215-662-7488  
Fax: 215-349-5083

Puerto Rico  
LifeLink of Puerto Rico  
Ponce de Leon Ave., Stop 36 1/2  
Hato Rey, PR 00919  
Ph. 809-758-2000

Rhode Island  
Rhode Island Blood Center  
405 Promenade St.  
Providence, RI 02908  
Ph. 401-453-8360  
Fax: 401-453-8557  
<http://www.ribc.org>

South Carolina  
American Red Cross Tissue Services  
Southeastern Area  
2751 Bull St.  
Columbia, SC 29201  
Ph. 803-251-6150  
Fax: 803-251-6105  
Carolina-Georgia Blood Center  
515 Grove Rd.  
Greenville, SC 29605  
Ph. 864-255-5000  
Fax: 864-255-9514

Transplant Organ and Tissue Banks by State 207

South Carolina OPA  
1064 Gardner Rd., #105  
Charleston, SC 29407  
Ph. 800-462-0755  
Fax: 803-763-6393  
<http://www.midnet.sc.edu/scopa/scopa.htm>

South Dakota

United Blood Services  
2209 W. Omaha  
P.O. Box 9608  
Rapid City, SD 29605  
Ph. 605-342-8585  
Fax: 605-342-6662  
<http://aztec.asu.edu/blood>

Tennessee

Blood Assurance, Inc.  
700 E. Third St.  
Chattanooga, TN 37709  
Ph. 423-756-0966  
Fax: 423-752-8460  
<http://www.bloodassurance.org>

East Tennessee Lions Eye Bank  
1924 Alcoa Highway, #U-26  
Knoxville, TN 37920  
Ph. 423-544-9625  
Fax: 423-523-4869  
<http://www.korrnet.org/eyebank/index.html>

Life Resources Regional Donor Center  
2812 McKinley Rd.  
Johnson City, TN 37604  
Ph. 423-929-1638  
Fax: 423-929-9598

Lifeblood/Mid-South Regional Blood Center  
1040 Madison Ave.  
Memphis, TN 38104  
Ph. 901-522-8585  
Fax: 901-529-6393  
<http://www.lifeblood.com>

Lifeline/West Tennessee Regional Blood Center  
828 N. Parkway  
Jackson, TN 38305  
Ph. 901-427-4431  
Fax: 901-422-4712

Mid-South Tissue Bank  
4719 Spottswood  
Memphis, TN 38117  
Ph. 901-683-6566  
Fax: 901-683-9910

Mid-South Transplant Foundation  
956 Court Ave., Suite G-228  
Memphis, TN 38163  
Ph. 901-448-5910  
Fax: 901-448-8126

Tennessee Donor Services  
5908-D Toole Dr.  
Knoxville, TN 37919  
Ph. 423-588-5903  
<http://www.korrnet.org/donors>

Tennessee Donor Services  
DCI Donor Services  
1714 Hayes St.  
Nashville, TN 37203  
Ph. 615-327-2247  
Fax: 619-320-1655

Texas

Blood and Tissue Center of Central Texas  
4300 N. Lamar Blvd.  
Austin, TX 78756  
Ph. 800-580-1121  
Fax: 512-458-3859  
<http://www.austin.citysearch.com/E/V/AUSTX/0004/52/93/11.html>

Carter Bloodcare  
9000 Harry Hines Blvd.  
Dallas, TX 75235  
Ph. 214-351-8111  
Fax: 214-351-9803

Coffee Memorial Blood Center  
1915 Coulter Dr.  
P.O. Box 3429  
Amarillo, TX 79106  
Ph. 806-358-4563  
Fax: 806-358-2982

Community Tissue Services  
708 S. Henderson St.  
Suite A  
Fort Worth, TX 76104  
Ph. 817-882-2556  
Fax: 817-882-2557

El Paso Regional Transplant Bank  
4505 Alberta  
El Paso, TX 79905  
Ph. 915-544-6714  
Fax: 915-544-5794

Great Plains Lions Eye Bank, Inc.  
Dept. of Ophthalmology & Visual Sciences  
School of Medicine  
Texas Tech University Health Sciences Center  
Lubbock, TX 79430  
Ph. 806-743-2400  
<http://www.ttuhs.edu/eye/defaultpage/main/EyeBank.htm>

Gulf Coast Regional Blood Center  
1400 La Concha Lane  
Houston, TX 77054  
Ph. 713-790-1200  
Fax: 713-790-1007  
<http://www.giveblood.org>

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Transplant Organ and Tissue Banks by State 209

LifeCell, Corp.  
3606 Research Forest Dr.  
The Woodlands, TX 77381  
Ph. 281-367-5368  
Fax: 281-363-3360

LifeGift Organ Donation Center  
5615 Kirby Dr., Suite 900  
Houston, TX 77005  
Ph. 713-523-4438  
Fax: 713-737-8100

Lions Eye Bank of Central Texas  
919 E. 32nd St.  
Austin, TX 78705  
Ph. 800-977-3937  
Fax: 512-457-0658  
<http://www.io.com/~garycox/LEBCT.html>

Nueces County Medical Society  
Community Blood Bank  
5025 Deepwood Circle  
Corpus Christi, TX 78415  
Ph. 361-855-4943  
Fax: 361-855-2641

Shriners Hospital for Children  
Burns Institute Galveston  
301 University Blvd.  
Galveston, TX 77555  
Ph. 409-621-1366  
Fax: 409-621-1390

South Texas Blood and Tissue Center  
6211 IH-10 W.  
San Antonio, TX 78201  
Ph. 210-731-5565  
Fax: 210-731-5505  
<http://www.bloodntissue.org>

South Texas Organ Bank  
8122 Datapoint Dr., Suite 1150  
San Antonio, TX 78229  
Ph. 210-614-7030  
Fax: 210-614-2129

Southwest Organ Bank  
3500 Maple Ave., Suite 800  
Dallas, TX 75219  
Ph. 214-821-1910  
<http://wg.dzn.com/swob/top.htm>

Southwest Transplant Alliance  
3710 Rawlins, #1100  
Dallas, TX 75219  
Ph. 800-788-8058  
Fax: 214-827-8352  
<http://www.organ.org>



Stewart Regional Blood Center  
815 S. Baxter Ave.  
Tyler, TX 75701  
Ph. 903-535-5400  
Fax: 903-535-5450

Texoma Regional Blood Center  
3911 N. Texoma Parkway  
Sherman, TX 75090  
Ph. 903-893-4314  
Fax: 903-893-8628

Transplant Services Center  
University of Texas  
Southwest Medical Center  
5323 Harry Hines Blvd. MC 9074  
Dallas, TX 75235  
Ph. 214-648-2609  
Fax: 214-648-2086

United Blood Services  
2325 Pershing Dr.  
P.O. Box 3547  
El Paso, TX 79923  
<http://aztec.asu.edu/blood>

United Blood Services  
1312 Pecan Blvd.  
McAllen, TX 78501  
Ph. 210-682-1314  
Fax: 210-682-7578  
<http://aztec.asu.edu/blood>

United Blood Services  
224 E. Harris Ave.  
P.O. Box 3206  
San Angelo, TX 76902  
Ph. 915-653-1308  
Fax: 915-658-3537  
<http://aztec.asu.edu/blood>

Utah

Intermountain Organ Recovery System  
230 S. 500 East, Suite 290  
Salt Lake City, UT 84102  
Ph. 801-521-1755  
Fax: 801-364-8815

Intermountain Tissue Center  
University of Utah Medical Center  
50 N. Medical Dr.  
Salt Lake City, UT 84132  
Ph. 801-581-4299  
Fax: 801-581-3271

Utah Lions Eye Bank  
John A. Moran Eye Center  
University of Utah Health Science Center  
75 N. Medical Dr.  
Salt Lake City, UT 84132  
<http://insight.med.utah.edu/lions/index.html>

Transplant Organ and Tissue Banks by State 211

Virginia

LifeNet Transplant Services

5809 Ward Court  
Virginia Beach, VA 23455  
Ph. 800-847-7831  
Fax: 757-464-5721

Lions Medical Eye Bank and Research

Center of Eastern Virginia, Inc.  
600 Gresham Dr.  
Norfolk, VA 23507  
Ph. 757-688-3937  
Fax: 757-688-3744

Old Dominion Eye Bank

1001 E. Marshall St.  
Richmond, VA 23219  
Ph. 800-832-0728  
Fax: 804-649-2879  
<http://www.odeb.org/default.htm>

Southeast Organ Procurement Foundation

5004 Monument Ave., Suite 101  
Richmond, VA 23230  
Ph. 804-342-1414

Virginia Blood Services/ASTRAEA

5002 Airport Rd.  
Roanoke, VA 24012  
Ph. 804-563-0300  
Fax: 804-563-8071

Virginia Blood Services/ASTRAEA

2201 Westwood Ave.  
Richmond, VA 23230  
Ph. 804-359-5100  
Fax: 804-359-5379

Virginia Blood Services/ASTRAEA

853 W. Milan St.  
Charlottesville, VA 22903  
Ph. 804-977-8956  
Fax: 804-979-4860

Virginia's OPA

1527 Huguenot Rd.  
Midlothian, VA 23113  
Ph. 804-794-4122  
Fax: 703-641-0211

Washington Regional Transplant Consortium

8110 Gatehouse Rd., Suite 101W  
Falls Church, VA 22042  
Ph. 703-641-0100  
<http://www.wrtc.org>

Washington

Cascade Regional Blood Services

220 S. I St.  
P.O. Box 2118  
Tacoma, WA 98401  
Ph. 253-383-2553  
Fax: 253-572-6340

Inland Northwest Blood Center  
507 S. Washington  
P.O. Box 1512  
Spokane, WA 99210  
Ph. 509-624-0151  
Fax: 509-624-5484  
<http://www.inbc2.org>

LifeCenter Northwest  
2553 76th Ave, S.E.  
Mercer Island, WA 98040-2758  
Ph. 888-543-3287  
Fax: 206-329-5433

Northwest Tissue Center  
921 Terry Ave.  
Seattle, WA 98104  
Ph. 206-292-1879  
Fax: 206-343-5043  
<http://www.nwtc.org>

Puget Sound Blood Center  
921 Terry Ave.  
Seattle, WA 98104  
Ph. 800-398-7888  
<http://www.psbcc.org>

Wisconsin

Blood Center of Southeastern Wisconsin  
638 N. 18th St.  
P.O. Box 2178  
Milwaukee, WI 53201  
Ph. 414-933-5000  
Fax: 414-933-6803  
<http://www.bloodctrwise.org>

Community Blood Bank  
4406 W. Spencer St.  
Appleton, WI 54915  
Ph. 920-738-3131  
Fax: 920-738-3139

The Eyebank of Wisconsin, Inc.  
2870 University Ave., Suite 103  
Madison, WI 53705-3611  
Ph. 877-233-2354  
Fax: 608-233-2895  
<http://www.eyebankwis.com/>

Marathon County Blood Bank  
404 S. Third Ave.  
Wausau, WI 54401  
Ph. 715-842-0761  
Fax: 715-845-6429

University of Wisconsin OPO  
600 Highland Ave.  
Madison, WI 53792  
Ph. 608-263-1341  
Fax: 608-262-9099

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Transplant Organ and Tissue Banks by State 213

Wisconsin Donor Network  
9200 W. Wisconsin Ave.  
Milwaukee, WI 53226  
Ph. 414-259-2024  
Fax: 206-259-8059

Wyoming

United Blood Services  
2021 Warren Ave.  
P.O. Box 1248  
Cheyenne, WY 82003  
Ph. 307-638-3326  
Fax: 307-638-1932  
<http://aztec.asu.edu/blood>

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**CRYOPRESERVATION STORAGE FACILITIES AND FERTILITY  
CLINICS BY STATE**

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The following is a partial list of cryopreservation storage facilities and fertility clinics (with egg, sperm, and embryo storage facilities) in the United States.

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|------------|--|
| Arizona    | Arizona Reproductive Medicine and Gynecology, Ltd.<br>2850 N. 24th St., Suite 503<br>Phoenix, AZ 85008<br>Ph. 602-468-3840<br>Fax: 602-468-2449<br><a href="http://www.conceive.com">http://www.conceive.com</a><br><br>IVF Phoenix<br>4626 E. Shea Blvd.<br>Building C, Suite C-230<br>Phoenix, AZ 85028<br>Ph. 602-996-2411<br>Fax: 602-996-5254<br><a href="http://www.ihr.com/ivfphoenix/index.html">http://www.ihr.com/ivfphoenix/index.html</a><br><br>West Valley Fertility Center<br>6525 West Sack Dr., Suite 208<br>Glendale, AZ 85308<br>Ph. 623-561-8636<br>Fax: 623-561-2522<br><a href="http://www.wvfc.com">http://www.wvfc.com</a> |
| California | Alta Bates In Vitro Fertilization Program<br>Stanford University Medical Ctr.<br>2999 Regent St. #101A<br>Berkeley, CA 94705<br>Ph. 510-649-0440<br>Fax: 510-649-8700<br><br>California Cryobank<br>1019 Gayley Ave.<br>Los Angeles, CA 90024<br>Ph. 310-443-5244<br>Fax: 310-443-5258   |

California Cryobank  
770 Welch Rd., Suite 170  
Palo Alto, CA 94304  
Ph. 650-324-1900  
Fax: 650-324-1946

California North Bay Fertility Association  
1111 Sonoma Ave., Suite 214  
Santa Rosa, CA 65405  
Ph. 707-575-5831  
Fax: 707-575-4379  
<http://www.ihf.com/cnbfa/>

The Fertility Institutes  
18370 Burbank Blvd., Suite 414  
Tarzana, CA 91356  
Ph. 818-776-8700  
Fax: 818-776-8700  
<http://www.fertility-docs.com>

IGO Medical Group of San Diego  
9339 Genesee Ave., Suite 220  
San Diego, CA 94305  
Ph. 619-455-7520  
Fax: 619-554-1312  
<http://www.ihf.com/igo/>

Northern California Fertility Center  
406 1/2 Sunrise Ave.  
Suite 3A  
Roseville, CA 95661  
Ph. 916-773-2229  
Fax: 916-773-8391  
<http://www.ncfmc.com>

NOVA In Vitro Fertilization Clinic  
1681 El Camino Real  
Palo Alto, CA 94306  
Ph. 650-322-0500  
Fax: 650-322-5404  
<http://www.novaivf.com>

Reproductive Endocrinology and Infertility Program  
Stanford Univ. Medical Ctr.  
300 Pasteur Dr.  
Stanford University  
Stanford, CA 94305  
Ph. 650-725-5983  
<http://www.stanford.edu/dept/GYNOB/rei>

The Sperm Bank of California  
Reproductive Technologies, Inc.  
2115 Milvia St., 2nd Floor  
Berkeley, CA 94704  
Ph. 510-841-1858  
Fax: 510-841-0332  
<http://www.thespermbankofca.org>

UCSF IVF Program  
350 Parnassus Ave.  
Suite 300  
San Francisco, CA 94117  
Ph. 415-476-2224  
Fax: 415-476-1811  
<http://www.ihr.com/ussfivf/index.html>  
West Coast Infertility Medical Center, Inc.  
250 N. Robertson Blvd., Suite 403  
Beverly Hills, CA 90211  
Ph. 310-285-0333  
Fax: 310-285-0334  
Zygen Laboratories  
18425 Burbank Blvd., Suite #411  
Tarzana, CA 91356  
Ph. 800-255-7242  
Fax: 818-705-3640

Colorado

CryoGam Colorado, Inc.  
1805 E. 18th St.  
Loveland, CO 80538  
Ph. 800-473-9601  
<http://www.cryogam.com>

Florida

Center for Advanced Reproductive Endocrinology  
6738 W. Sunrise Blvd.  
Suite 106  
Plantation, FL 33313  
Ph. 954-584-2273  
Fax: 954-587-9660  
<http://www.care-life.com/>  
Cryobanks International, Inc.  
270 S. Northlake Blvd., #1012  
Altamonte Springs, FL 32701  
Ph. 407-834-8333  
Fax: 407-834-3533  
<http://www.uscryo-cord.com/index.html>  
The Repository  
Sperm and Embryo Bank  
1930 N.E. 47th Street, Suite 105  
Ft. Lauderdale, FL 33308  
Ph. 954-351-7030  
Fax: 954-351-9060  
<http://www.safari.net/~sperm/index.html>

Georgia

Xytex  
1100 Emmett St.  
Augusta, GA 30904  
Ph. 706-733-0130  
Fax: 706-736-9720

Illinois

Advanced Fertility Center of Chicago  
6440 Grand Ave., Suite 102  
Gurnee, IL 60031  
Ph. 847-855-1818  
<http://www.advancedfertility.com>

- Reproductive Genetics Institute  
836 W. Wellington Ave.  
Chicago, IL 60657  
Ph. 773-296-7095  
Fax: 773-871-5221  
<http://www.globexnet.com/rgi/rgi7.htm>
- Iowa The Iowa Women's Health Center  
Advanced Reproductive Care  
2 Boyd Tower  
The University of Iowa Hospitals and Clinics  
200 Hawkins Dr.  
Iowa City, IA 52242  
Ph. 319-356-8483  
Fax: 319-353-6659  
<http://www.uihc.uiowa.edu/arc>
- Kansas Reproductive Resource Ctr. of Greater Kansas City  
12200 W. 106th, Suite 120  
Overland Park, KS 66215  
Ph. 913-894-2323  
Fax: 913-894-0841  
<http://www.rrcgkc.com>
- Maryland Fertility Center of Maryland  
110 West Rd., Suite 102  
Towson, MD 21204  
Ph. 410-296-6400  
Fax: 410-296-6405  
<http://www.erols.com/fcmivf/index.html>
- GBMC—Fertility Center  
6569 N. Charles St.  
Physicians Pavilion West  
Suite 406  
Baltimore, MD 21204  
Ph. 410-828-3109  
Fax: 410-828-3067  
[http://www.gbmc.org/services/fertility\\_center](http://www.gbmc.org/services/fertility_center)
- Shady Grove Fertility Center  
15001 Shady Grove Rd.  
Suite 400  
Rockville, MD 20850  
Ph. 301-340-1188  
Fax: 301-340-1612  
<http://www2.shadygrovefertility.com/sgfc>
- Massachusetts California Cryobank, Inc.  
955 Massachusetts Ave.  
Cambridge, MA 02139  
Ph. 617-497-8646  
Fax: 617-497-6531



Fertility Ctr. of New England, Inc.  
20 Pond Meadow Dr.  
Suite 101  
Reading, MA 01867  
Ph. 781-942-7000  
Fax: 781-942-7200  
<http://www.fertilitycenter.com>  
Reproductive Science Center of Boston  
Deaconess Waltham Hospital  
Hope Ave.  
Waltham, MA 02254  
Ph. 617-647-6263  
Fax: 617-647-6323  
<http://www.cris.com/~rscboston/>

Minnesota

Cryogenic Laboratories, Inc.  
1944 Lexington Ave. N.  
Roseville, MN 55113  
Ph. 800-466-2796  
Fax: 651-489-8989  
<http://www.cryolab.com>

Montana

Northwest Andrology & Cryobank, Inc.  
2825 Fort Missoula Rd.  
Physicians Center #1, Suite 121  
Missoula, MT 59804  
Ph. 406-549-0958  
<http://www.nwcryobank.com>

New Jersey

Sperm & Embryo Bank of New Jersey  
1130 Rte. 22W, P.O. Box 1290  
Mountainside, NJ 07092  
Ph. 800-637-7776  
Fax: 908-232-2114

North Carolina

North Carolina Center for Reproductive Medicine  
400 Ashville Ave., Suite 200  
Cary, NC 27511  
Ph. 919-233-1680  
Fax: 919-233-1685  
<http://www.nccrm.com/nccrm/>

Ohio

Andrology Laboratory & Sperm Bank  
The Cleveland Clinic Foundation  
9500 Euclid Ave., Desk A19.1  
Cleveland, OH 44195  
Ph. 800-223-2273, ext. 48182  
Fax: 216-445-6049  
Cryobiology, Inc.  
4830D Knightsville Blvd.  
Columbus, OH 43214  
Ph. 614-451-4375  
Fax: 614-451-5284

- Genetics and IVF Institute of Ohio  
369 W. First Street, Suite 120  
Dayton, OH 45402  
Ph. 937-418-GIVF  
<http://www.erienet.com/givf>
- Oregon OHSU Fertility Consultants  
1750 S.W. Harbor Way, Suite 100  
Portland, OR 97201  
Ph. 503-418-3750  
Fax: 503-418-3767  
<http://www.ihr.com/oregon/>
- Pennsylvania Fertility Center  
Geisinger Medical Center  
Danville, PA 17821  
Ph. 570-271-5620  
Fax: 570-271-5629  
<http://www.hslc.org/~rshabanowitz/index.htm>
- Reproductive Science Institute  
950 West Valley Rd.  
Suite 2401  
Wayne, PA 19087  
Ph. 610-964-9663  
Fax: 610-964-0536
- Women's Institute for Fertility, Endocrinology, and Menopause  
815 Locust St.  
Philadelphia, PA 19107  
Ph. 215-922-2206  
Fax: 215-922-3777  
<http://www.womensinstitute.org>
- Tennessee The Center for Applied Reproductive Science  
Johnson City Medical Ctr. Office Bldg  
408 State of Franklin Rd.  
Johnson City, TN 37604  
Ph. 423-461-8880  
Fax: 423-461-8887  
<http://www.ivf-et.com>
- The Center for Reproductive Health  
326 21st Ave. N.  
Nashville, TN 37203  
Ph. 615-321-8899  
Fax: 615-321-8877  
<http://www.reproductivehealthctr.com/>
- Texas Fertility Center of San Antonio  
4499 Medical Dr., Suite 360  
San Antonio, TX 78229  
Ph. 210-692-0577  
Fax: 210-692-1210  
<http://www.fertilityusa.com>

Virginia

North Houston Center for Reproductive Medicine  
530 Wells Fargo Dr., Suite 116  
Houston, TX 77090  
Ph. 281-444-4784  
Fax: 281-444-0429  
<http://www.ihr.com/nhcrm/>

Dominion Fertility and Endocrinology  
46 S. Glebe Rd., Suite 301  
Arlington, VA 22204  
Ph. 703-920-3890  
Fax: 703-892-6037  
<http://www2.dominionfertility.com/df/>

Genetics and IVF Institute  
Fairfax Cryobank  
3015 Williams Dr., #110  
Fairfax, VA 22301  
Ph. 800-338-8407  
Fax: 703-698-3933  
<http://www.givf.com>  
<http://fairfaxcryobank.com>

Jones Institute for Reproductive Medicine  
601 Colley Ave.  
Norfolk, VA 23507  
Ph. 757-446-7100

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**STORED TISSUE SAMPLE WEB SITES**


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Advanced Fertility Center of Chicago	<a href="http://www.advancedfertility.com">http://www.advancedfertility.com</a>
Alabama Community Blood Bank	<a href="http://www.crbs.org">http://www.crbs.org</a>
Alabama Eye Bank	<a href="http://www.uab.edu/eye/eyebank3.html">http://www.uab.edu/eye/eyebank3.html</a>
Alabama Organ Center	<a href="http://www.uab.edu/aoc/">http://www.uab.edu/aoc/</a>
Alzheimer Center—Case Western Reserve University	<a href="http://www.ohioalzcenter.org">http://www.ohioalzcenter.org</a>
Alzheimer's Disease Center—Northwestern University	<a href="http://www.brain.nwu.edu/core/index.htm">http://www.brain.nwu.edu/core/index.htm</a>
Alzheimer's Disease Center—University of Kansas Medical Center	<a href="http://www.kumc.edu/instruction/medicine/neurology/resAD.htm">http://www.kumc.edu/instruction/medicine/neurology/resAD.htm</a>
Alzheimer's Disease Center—University of California, Davis	<a href="http://alzheimer.ucdavis.edu/adc">http://alzheimer.ucdavis.edu/adc</a>
Alzheimer's Disease Core Center	<a href="http://www.visn1.org/alzheimer/BrainBank.htm">http://www.visn1.org/alzheimer/BrainBank.htm</a>
Alzheimer's Disease Research Center—Baylor College of Medicine	<a href="http://www.bcm.tmc.edu/neurol.struct/adcrc/adcrc1.html">http://www.bcm.tmc.edu/neurol.struct/adcrc/adcrc1.html</a>
Alzheimer's Disease Research Center—University of Southern California	<a href="http://www.usc.edu/dept/gero/ADRC">http://www.usc.edu/dept/gero/ADRC</a>
Alzheimer's Disease Research Center—Washington University	<a href="http://www.adrc.wustl.edu/adrc/adcrc2.html">http://www.adrc.wustl.edu/adrc/adcrc2.html</a>
American Association of Tissue Banks	<a href="http://www.aatb.org/aatbac.htm">http://www.aatb.org/aatbac.htm</a>
American Red Cross	<a href="http://www.redcross.org">http://www.redcross.org</a>
Arizona Reproductive Medicine and Gynecology, Ltd.	<a href="http://www.conceive.com">http://www.conceive.com</a>
Armed Forces DNA Laboratory	<a href="http://www.afip.org/homes/oafme/dna/afdil.html">http://www.afip.org/homes/oafme/dna/afdil.html</a>
Atlanta LifeSouth Community Blood Centers	<a href="http://www.crbs.org">http://www.crbs.org</a>
Blood Assurance, Inc.	<a href="http://www.bloodassurance.org">http://www.bloodassurance.org</a>
Blood and Tissue Center of Central Texas	<a href="http://www.austin.citysearch.com/E/V/AUSTX/0004/52/93/11.html">http://www.austin.citysearch.com/E/V/AUSTX/0004/52/93/11.html</a>
Blood Bank of Alaska, Inc.	<a href="http://www.customcpu.com/np/bba/default.htm">http://www.customcpu.com/np/bba/default.htm</a>
Blood Bank of the Redwoods	<a href="http://bbr.org">http://bbr.org</a>
Blood Center for Southeast Louisiana	<a href="http://www.thebloodcenter.org">http://www.thebloodcenter.org</a>
Blood Center of Central Iowa	<a href="http://www.bloodonor.org">http://www.bloodonor.org</a>
Blood Center of New Jersey	<a href="http://www.bloodnj.org">http://www.bloodnj.org</a>

Blood Center of Southeastern Wisconsin	<a href="http://www.bloodctrwise.org">http://www.bloodctrwise.org</a>
Blood Centers of the Pacific	<a href="http://www.citysearch.com/sfo/bloodcenter">http://www.citysearch.com/sfo/bloodcenter</a>
Brain and Tissues Bank for Developmental Disorders—Children's Hospital of Orange County	<a href="http://www.choc.com/btbmain.htm">http://www.choc.com/btbmain.htm</a>
Brain and Tissues Bank for Developmental Disorders—University of Maryland	<a href="http://www.som1.umaryland.edu/BTBank">http://www.som1.umaryland.edu/BTBank</a>
Brain and Tissues Bank for Developmental Disorders—University of Miami	<a href="http://www.med.miami.edu/BTB">http://www.med.miami.edu/BTB</a>
Brain Bank—Medical College of Georgia	<a href="http://www.mcg.edu/Centers/Alz/arc.htm">http://www.mcg.edu/Centers/Alz/arc.htm</a>
CALGB Central Office	<a href="http://128.135.31.4">http://128.135.31.4</a>
California Cancer Registry	<a href="http://www.ccrca.org">http://www.ccrca.org</a>
California North Bay Fertility Association	<a href="http://www.ihr.com/cnbfa/">http://www.ihr.com/cnbfa/</a>
California Tumor Registry	<a href="http://www.llu.edu/llu.ctr">http://www.llu.edu/llu.ctr</a>
Cancer Data Registry of Idaho	<a href="http://www.idcancer.org">http://www.idcancer.org</a>
Center for Advanced Reproductive Endocrinology	<a href="http://www.care-life.com/">http://www.care-life.com/</a>
Centers for Disease Control and Prevention (CDC)	<a href="http://www.cdc.gov/">http://www.cdc.gov/</a>
Central California Blood Center	<a href="http://www.cencalblood.org/default02.htm">http://www.cencalblood.org/default02.htm</a>
Central Florida Lions Eye and Tissue Bank, Inc.	<a href="http://www.lionseyebank.com/home.html">http://www.lionseyebank.com/home.html</a>
Central Illinois Community Blood Bank	<a href="http://www.fgi.net/~bloodbnk">http://www.fgi.net/~bloodbnk</a>
Central Indiana Regional Blood Center Tissue Bank	<a href="http://www.donor-link.org">http://www.donor-link.org</a>
Central Maine Medical Center	<a href="http://www2.cmmc.org/cmmc/cancerare/registry.html">http://www2.cmmc.org/cmmc/cancerare/registry.html</a>
Central New Jersey Blood Center	<a href="http://www.cjbc.org">http://www.cjbc.org</a>
Colorado Central Cancer Registry	<a href="http://sedac.ciesin.org/ozone/regs/colorado.html">http://sedac.ciesin.org/ozone/regs/colorado.html</a>
Community Blood Bank of Erie County	<a href="http://www.eriebloodbank.org">http://www.eriebloodbank.org</a>
Community Blood Center of Greater Kansas City	<a href="http://kcblood.org">http://kcblood.org</a>
Cord Blood Registry	<a href="http://www.cordblood.com">http://www.cordblood.com</a>
Coriell Institute for Medical Research	<a href="http://arginine.umdnj.edu/info.html">http://arginine.umdnj.edu/info.html</a>
CryoBanks International, Inc.	<a href="http://www.uscryo-cord.com/index.html">http://www.uscryo-cord.com/index.html</a>
CryoGam Colorado, Inc.	<a href="http://www.cryogam.com">http://www.cryogam.com</a>
Cryogenics Laboratories, Inc.	<a href="http://www.cryolab.com">http://www.cryolab.com</a>
Dominion Fertility and Endocrinology	<a href="http://www2.dominionfertility.com/df/">http://www2.dominionfertility.com/df/</a>
Donor Network of Arizona	<a href="http://www.donor-network.org">http://www.donor-network.org</a>
East Tennessee Lions Eye Bank	<a href="http://www.kornet.org/eyebank/index.html">http://www.kornet.org/eyebank/index.html</a>
Emory University's Alzheimer's Disease Center	<a href="http://www.emory.edu/WHSC/MED/ADC">http://www.emory.edu/WHSC/MED/ADC</a>

Fairfax Cryobank	<a href="http://fairfaxcryobank.com">http://fairfaxcryobank.com</a>
Federal Bureau of Investigations (FBI)	<a href="http://www.fbi.gov/">http://www.fbi.gov/</a>
Fertility Center—Geisinger Medical Center	<a href="http://www.hslc.org/~rshabanowitz/index.htm">http://www.hslc.org/~rshabanowitz/index.htm</a>
Fertility Center of Maryland	<a href="http://www.erols.com/fcmivf/index.html">http://www.erols.com/fcmivf/index.html</a>
Fertility Center of New England, Inc.	<a href="http://www.fertilitycenter.com">http://www.fertilitycenter.com</a>
Fertility Center of San Antonio	<a href="http://www.fertilityusa.com">http://www.fertilityusa.com</a>
Florida Blood Services	<a href="http://www.fbsblood.org">http://www.fbsblood.org</a>
Florida Cancer Data System	<a href="http://fdcs.med.miami.edu/">http://fdcs.med.miami.edu/</a>
Florida Georgia Blood Alliance	<a href="http://www.fgba.org">http://www.fgba.org</a>
Forensic Science Research and Training Center	<a href="http://www.fbi.gov/lab/report/research.htm">http://www.fbi.gov/lab/report/research.htm</a>
Genetics and IVF Institute	<a href="http://www.givf.com">http://www.givf.com</a>
Genetics and IVF Institute of Ohio	<a href="http://www.erienet.com/givf">http://www.erienet.com/givf</a>
Georgia Comprehensive Cancer Registry	<a href="http://www.ph.dhr.state.ga.us/org/cancercontrolsection.cancerregistry.htm">http://www.ph.dhr.state.ga.us/org/cancercontrolsection.cancerregistry.htm</a>
GOG Tissue Bank	<a href="http://www.gog.org">http://www.gog.org</a>
Great Plains Eye Bank, Inc.	<a href="http://www.ttuhscc.edu/eye/defaultpage/main/EyeBank.htm">http://www.ttuhscc.edu/eye/defaultpage/main/EyeBank.htm</a>
Greater Baltimore Medical Center—Fertility Center	<a href="http://www.gbmc.org/services/fertility_center">http://www.gbmc.org/services/fertility_center</a>
Gulf Coast Regional Blood Center	<a href="http://www.giveblood.org">http://www.giveblood.org</a>
Hartford Hospital Cancer Registry	<a href="http://www.harthosp.org/cancer/registry">http://www.harthosp.org/cancer/registry</a>
Harvard Brain Tissue Resource Center	<a href="http://www.mcleanhospital.org/brainbank.html">http://www.mcleanhospital.org/brainbank.html</a>
Hawaii Lions Eye Bank	<a href="http://www.eyebank.org">http://www.eyebank.org</a>
Hawaii Tumor Registry	<a href="http://www.planet-hawaii.com/htr">http://www.planet-hawaii.com/htr</a>
Hollings Cancer Center—High Risk Lung Cancer Registry	<a href="http://hcc.musc.edu/lungreg">http://hcc.musc.edu/lungreg</a>
Hoxworth Blood Center—University of Cincinnati Medical Center	<a href="http://www.hoxworth.org">http://www.hoxworth.org</a>
IGO Medical Group of San Diego	<a href="http://www.ihr.com/igo">http://www.ihr.com/igo</a>
Illinois State Cancer Registry	<a href="http://hometown.aol.com/epistudies/cancer/index/htm">http://hometown.aol.com/epistudies/cancer/index/htm</a>
Indiana Alzheimer Disease Center National Cell Repository	<a href="http://medgen.iupui.edu/research/alzheimer">http://medgen.iupui.edu/research/alzheimer</a>
Inland Northwest Blood Center	<a href="http://www.inbc2.org">http://www.inbc2.org</a>
International Pediatric Adrenocortical Tumor Registry	<a href="http://www.stjude.org/ipactr/objectives.htm">http://www.stjude.org/ipactr/objectives.htm</a>
IVF Phoenix	<a href="http://www.ihr.com/ivfphoenix/index.html">http://www.ihr.com/ivfphoenix/index.html</a>
Kansas Cancer Registry	<a href="http://www.kumc.edu/som/kcr">http://www.kumc.edu/som/kcr</a>
Kathleen Price Bryan Brain Bank	<a href="http://www.medicine.mc.duke.edu/ADRC/INDEX.html">http://www.medicine.mc.duke.edu/ADRC/INDEX.html</a>
Kentucky Lions Eye Bank	<a href="http://athena.louisville.edu/medschool/ophthalmology/kleb.htm">http://athena.louisville.edu/medschool/ophthalmology/kleb.htm</a>
Kentucky Cancer Registry	<a href="http://www.kcr.uky.edu">http://www.kcr.uky.edu</a>
Lane Memorial Blood Bank	<a href="http://www.lanecountyblood.org">http://www.lanecountyblood.org</a>
Lifeblood/Mid-South Regional Blood Center	<a href="http://www.lifeblood.com">http://www.lifeblood.com</a>
LifeSouth Community Blood Centers	<a href="http://www.crbs.org">http://www.crbs.org</a>
LifeSpan BioSciences, Inc.	<a href="http://www.lsbio.com">http://www.lsbio.com</a>

Lions Eye Bank of Central Texas	<a href="http://www.io.com/~garycox/LEBCT.html">http://www.io.com/~garycox/LEBCT.html</a>
Lions Eye Bank of Northwest Pennsylvania	<a href="http://www.unitedwayerie.org/eyebank">http://www.unitedwayerie.org/eyebank</a>
Lions Eye Bank of Oregon	<a href="http://www.orlions.org/cover.htm">http://www.orlions.org/cover.htm</a>
Longitudinal Studies Branch of the National Institute on Aging (NIA)	<a href="http://www.grc.nia.nih.gov/Branches/lisb/lisb.htm">http://www.grc.nia.nih.gov/Branches/lisb/lisb.htm</a>
Massachusetts General Hospital Cancer Data Registry	<a href="http://cancer.mgh.harvard.edu/tumreg/tumreg.htm">http://cancer.mgh.harvard.edu/tumreg/tumreg.htm</a>
Massachusetts General Hospital Tumor Bank	<a href="http://cancer.mgh.harvard.edu/tumorbank">http://cancer.mgh.harvard.edu/tumorbank</a>
Medical Eye Bank of Florida	<a href="http://www.castlegate.net/MEBFL/index.htm">http://www.castlegate.net/MEBFL/index.htm</a>
Memorial Blood Centers of Minnesota	<a href="http://www.mbcm.org">http://www.mbcm.org</a>
Metropolitan New York Registry	<a href="http://www.med.nyu.edu/Biostat-Epl/mnyr.htm">http://www.med.nyu.edu/Biostat-Epl/mnyr.htm</a>
Michigan Alzheimer's Disease Research Center	<a href="http://www.med.umich.edu/madrc/MADRC.html">http://www.med.umich.edu/madrc/MADRC.html</a>
Michigan Community Blood Centers	<a href="http://miblood.org">http://miblood.org</a>
Michigan Eye Bank	<a href="http://www.mebtc.org">http://www.mebtc.org</a>
Missouri Lions Eye Research Foundation	<a href="http://www.rollanet.org/~rlions/mlerf">http://www.rollanet.org/~rlions/mlerf</a>
Mucosal Immunology Core—UCLA	<a href="http://www.medsch.ucla.edu/aidsinst/cfar/Mucosal.htm">http://www.medsch.ucla.edu/aidsinst/cfar/Mucosal.htm</a>
National Cancer Institute (NCI)	<a href="http://www.nci.nih.gov">http://www.nci.nih.gov</a>
National Center for Environmental Health (NCEH)	<a href="http://www.cdc.gov/nceh/ncehome.htm">http://www.cdc.gov/nceh/ncehome.htm</a>
National Center for Infectious Diseases (NCID)	<a href="http://www.cdc.gov/ncidod/ncid.htm">http://www.cdc.gov/ncidod/ncid.htm</a>
National Disease Research Interchange	<a href="http://www.ndri.com">http://www.ndri.com</a>
National Familial Lung Cancer Registry	<a href="http://www.path.jhu.edu/nfltr.html">http://www.path.jhu.edu/nfltr.html</a>
National Health and Nutrition Examination Survey (NHANES)	<a href="http://www.cdc.gov/nchswww/about/major/nhanes/nhanes.htm">http://www.cdc.gov/nchswww/about/major/nhanes/nhanes.htm</a>
National Heart, Lung, and Blood Institute (NHLBI)	<a href="http://www.nhlbi.nih.gov/nhlbi/nhlbi.htm">http://www.nhlbi.nih.gov/nhlbi/nhlbi.htm</a>
National Institute of Environmental Health Sciences	<a href="http://www.niehs.nih.gov">http://www.niehs.nih.gov</a>
National Institute of Allergy and Infectious Disease (NIAID)	<a href="http://www.niaid.nih.gov/">http://www.niaid.nih.gov/</a>
National Institutes of Health (NIH)	<a href="http://www.nih.gov/index.html">http://www.nih.gov/index.html</a>
National Institute of Mental Health (NIMH)	<a href="http://www.nimh.nih.gov/">http://www.nimh.nih.gov/</a>
National Institute on Aging	<a href="http://www.nih.gov/nia">http://www.nih.gov/nia</a>
National NeuroAIDS Tissue Consortium	<a href="http://www.nimh.nih.gov/oa/nntnhome.htm">http://www.nimh.nih.gov/oa/nntnhome.htm</a>
National Neurological Research Specimen Bank	<a href="http://loni.ucla.edu/~nrsb/nrsb">http://loni.ucla.edu/~nrsb/nrsb</a>
National Pathology Repository	<a href="http://www.afip.mil/repository/welcome.html">http://www.afip.mil/repository/welcome.html</a>
National Psoriasis Tissue Bank	<a href="http://www.psoriasis.org/tissuebank.html">http://www.psoriasis.org/tissuebank.html</a>

National Temporal Bone, Hearing, and Balance Pathology Resource Registry	<a href="http://www.tbregistry.org">http://www.tbregistry.org</a>
National Wilms Tumor Study Group	<a href="http://www.nwtsg.org">http://www.nwtsg.org</a>
NCI AIDS Malignancy Bank	<a href="http://cancernet.nci.nih.gov/amb/amb.html">http://cancernet.nci.nih.gov/amb/amb.html</a>
NCI Breast Cancer Specimen and Data Information System	<a href="http://www.napbc.ims.nci.nih.gov/">http://www.napbc.ims.nci.nih.gov/</a>
NCI Cooperative Breast Cancer Tissue Resource (CBCTR)	<a href="http://www-cbctr.ims.nci.nih.gov">http://www-cbctr.ims.nci.nih.gov</a>
NCI Cooperative Family Registry for Breast Cancer Studies (CFRBCS)	<a href="http://www-dceg.ims.nci.nih.gov/cfrbcs">http://www-dceg.ims.nci.nih.gov/cfrbcs</a>
NCI Cooperative Human Tissue Network (CHTN)	<a href="http://www-chn.ims.nci.nih.gov/">http://www-chn.ims.nci.nih.gov/</a>
NCI Clinical Trials Cooperative Group	<a href="http://www.specimens.ims.nci.nih.gov/about.html">http://www.specimens.ims.nci.nih.gov/about.html</a>
NCI Surveillance, Epidemiology, and End Results Program	<a href="http://www-seer.ims.nci.nih.gov">http://www-seer.ims.nci.nih.gov</a>
New England Cord Blood Bank	<a href="http://www.cordbloodbank.com/overview.htm">http://www.cordbloodbank.com/overview.htm</a>
New England Organ Bank	<a href="http://www.neob.org">http://www.neob.org</a>
New Jersey Organ and Tissue Sharing Network	<a href="http://www.sharenj.org">http://www.sharenj.org</a>
New Jersey State Cancer Registry	<a href="http://www.ker.state.nj.us/health/cancer/njscr1b.htm">http://www.ker.state.nj.us/health/cancer/njscr1b.htm</a>
New York Blood Center	<a href="http://www.nybloodcenter.org">http://www.nybloodcenter.org</a>
NIH Women's Health Initiative (WHI)	<a href="http://odp.ld.nih.gov/whi/">http://odp.ld.nih.gov/whi/</a>
North Carolina Cancer Registry	<a href="http://www.schs.state.nc.us/SCHS/about/branches/ccr.html">http://www.schs.state.nc.us/SCHS/about/branches/ccr.html</a>
North Carolina Center for Reproductive Medicine	<a href="http://www.nccrm.com/nccrm/">http://www.nccrm.com/nccrm/</a>
North Houston Center for Reproductive Medicine	<a href="http://www.ihr.com/nhcrm">http://www.ihr.com/nhcrm</a>
Northern California Fertility Center	<a href="http://www.ncfmc.com">http://www.ncfmc.com</a>
Northwest Andrology and Cryobank, Inc.	<a href="http://www.nwcryobank.com">http://www.nwcryobank.com</a>
Northwest Tissue Center	<a href="http://www.nwtc.org">http://www.nwtc.org</a>
NOVA In Vitro Fertilization Clinic	<a href="http://www.novalvf.com">http://www.novalvf.com</a>
Old Dominion Eye Bank	<a href="http://www.odeb.org/default.htm">http://www.odeb.org/default.htm</a>
Oklahoma Lions Eye Bank	<a href="http://www.ionet.net/~oleb/lionseye.html">http://www.ionet.net/~oleb/lionseye.html</a>
Oregon Health Sciences University Fertility Consultants	<a href="http://www.ihr.com/oregon">http://www.ihr.com/oregon</a>
Oregon State Cancer Registry	<a href="http://www.orcpr.org/oscar.html">http://www.orcpr.org/oscar.html</a>
PathServe Autopsy and Tissue Bank	<a href="http://www.tissuebank.com">http://www.tissuebank.com</a>
POG Operations Office	<a href="http://www.pog.ufl.edu">http://www.pog.ufl.edu</a>
Puget Sound Blood Center	<a href="http://www.psbcc.org">http://www.psbcc.org</a>
Regional Organ Bank of Illinois	<a href="http://www.robi.org">http://www.robi.org</a>
Reproductive Endocrinology and Infertility Program	<a href="http://www.stanford.edu/dept/GYNOB/rei">http://www.stanford.edu/dept/GYNOB/rei</a>
Reproductive Genetics Institute	<a href="http://www.globexnet.com/rgi/rgi7.htm">http://www.globexnet.com/rgi/rgi7.htm</a>
Reproductive Resource Center of Greater Kansas City	<a href="http://www.rrcgkc.com">http://www.rrcgkc.com</a>



Reproductive Science Center of Boston	<a href="http://www.cris.com/~rscboston/">http://www.cris.com/~rscboston/</a>
Resource for Tumor Tissue and Data—NYU School of Medicine	<a href="http://kccc-www.med.nyu.edu/RTTD.htm">http://kccc-www.med.nyu.edu/RTTD.htm</a>
Rhode Island Blood Center	<a href="http://www.ribc.org">http://www.ribc.org</a>
Rhode Island Cancer Registry	<a href="http://www.health.state.ri.us/canrep.htm">http://www.health.state.ri.us/canrep.htm</a>
Rochester Eye and Human Parts Bank	<a href="http://www.rehpb.org">http://www.rehpb.org</a>
Rocky Mountain Lions Eye Bank	<a href="http://www.corneas.org">http://www.corneas.org</a>
Rocky Mountain Multiple Sclerosis Center Tissue Bank	<a href="http://www.swedmc.com:80/msc/tissue.htm">http://www.swedmc.com:80/msc/tissue.htm</a>
Rush Alzheimer's Disease Center (Rush Brain Bank)	<a href="http://www.rush.edu/Departments/Alzheimers/Research.html">http://www.rush.edu/Departments/Alzheimers/Research.html</a>
San Diego Blood Bank	<a href="http://www.sandiegobloodbank.org">http://www.sandiegobloodbank.org</a>
Sarasota Community Blood Bank	<a href="http://www.sarasota-online.com/scbb">http://www.sarasota-online.com/scbb</a>
Savannah River Region Cancer Incidence Registry	<a href="http://www.musc.edu/srrhis/">http://www.musc.edu/srrhis/</a>
Shady Grove Fertility Center	<a href="http://www2.shadygrovefertility.com/sgfc">http://www2.shadygrovefertility.com/sgfc</a>
Shepard Community Blood Center	<a href="http://www.shepardblood.com">http://www.shepardblood.com</a>
South Carolina OPA	<a href="http://www.midnet.sc.edu/scopa/scopa.htm">http://www.midnet.sc.edu/scopa/scopa.htm</a>
South Georgia Branch of Southeastern Community Blood Center	<a href="http://www.scbcinfo.org">http://www.scbcinfo.org</a>
South Texas Blood and Tissue Center	<a href="http://www.bloodntissue.org">http://www.bloodntissue.org</a>
Southeastern Community Blood Center	<a href="http://www.scbcinfo.org">http://www.scbcinfo.org</a>
Southwest Organ Bank	<a href="http://wg.dzn.com/swob/top.htm">http://wg.dzn.com/swob/top.htm</a>
Southwest Transplant Alliance	<a href="http://www.organ.org">http://www.organ.org</a>
St. Louis Cord Blood Bank	<a href="http://www.slu.edu/colleges/med/departments/pediatrics/cordbank/moreinfo.html">http://www.slu.edu/colleges/med/departments/pediatrics/cordbank/moreinfo.html</a>
State Health Registry of Iowa	<a href="http://www.uiowa.edu/~vpr/research/organize/healthreg.htm">http://www.uiowa.edu/~vpr/research/organize/healthreg.htm</a>
Taub Center for Alzheimer's Disease Research—Columbia University	<a href="http://pathology.cpmc.columbia.edu/ADNP.html">http://pathology.cpmc.columbia.edu/ADNP.html</a>
Tennessee Donor Services	<a href="http://www.kornet.org/donors">http://www.kornet.org/donors</a>
Texas Cancer Data Center	<a href="http://www.txcancer.org">http://www.txcancer.org</a>
The Center for Applied Reproductive Science	<a href="http://www.ivf-et.com">http://www.ivf-et.com</a>
The Center for Reproductive Health	<a href="http://www.reproductivehealthctr.com/">http://www.reproductivehealthctr.com/</a>
The Eyebank of Wisconsin, Inc.	<a href="http://www.eyebankwis.com">http://www.eyebankwis.com</a>
The Fertility Institutes	<a href="http://www.fertility-docs.com">http://www.fertility-docs.com</a>
The Iowa Women's Health Center Advanced Reproductive Care	<a href="http://www.uihc.uiowa.edu/arc">http://www.uihc.uiowa.edu/arc</a>
The Repository Sperm and Embryo Bank	<a href="http://www.safari.net/~sperm/index.html">http://www.safari.net/~sperm/index.html</a>
The Sperm Bank of California	<a href="http://www.thespermbankofca.org">http://www.thespermbankofca.org</a>
United Blood Services	<a href="http://aztec.asu.edu/blood">http://aztec.asu.edu/blood</a>
University of California, San Francisco, IVF Program	<a href="http://www.ihr.com/ucsfivf/index.html">http://www.ihr.com/ucsfivf/index.html</a>
University of California, San Francisco, Cancer Center Tissue Core	<a href="http://cc.ucsf.edu/tissue/index.html">http://cc.ucsf.edu/tissue/index.html</a>

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Utah Lions Eye Bank	<a href="http://www.insight.med.utah.edu/lions/index.html">http://www.insight.med.utah.edu/lions/index.html</a>
Vermont Cancer Registry	<a href="http://www.senate.gov/~leahy/bcreg.htm">http://www.senate.gov/~leahy/bcreg.htm</a>
Virginia Cancer Registry	<a href="http://www.vdh.state.va.us/epi/ver.htm">http://www.vdh.state.va.us/epi/ver.htm</a>
Washington Regional Transplant Consortium	<a href="http://www.wrtc.org">http://www.wrtc.org</a>
Washington State Cancer Registry	<a href="http://www.doh.wa.gov/ehspl/epidemiology/wscr1.htm">http://www.doh.wa.gov/ehspl/epidemiology/wscr1.htm</a>
West Valley Fertility Center	<a href="http://www.wvfc.com">http://www.wvfc.com</a>
Wichita Eye Bank	<a href="http://www2.southwind.net/~gsbryan">http://www2.southwind.net/~gsbryan</a>
Wisconsin Cancer Reporting System	<a href="http://www.dhfs.state.wi.us/wcrs/object.htm">http://www.dhfs.state.wi.us/wcrs/object.htm</a>
Women's Institute for Fertility, Endocrinology, and Menopause	<a href="http://www.womensinstitute.org">http://www.womensinstitute.org</a>
Wyoming Cancer Surveillance	<a href="http://wdhfs.state.wy.us/cancer">http://wdhfs.state.wy.us/cancer</a>

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# Handbook of Human Tissue Sources

## A National Resource of Human Tissue Samples

Human tissues have been stored for a long time. Some institutions in the United States have archived specimens of human tissues that are more than 100 years old. Historically, these stored tissue samples have been used by the biomedical community for educational and research purposes. More recently, stored tissues have played a major role in the understanding and treatment of such diseases as cancer, HIV/AIDS, and heart disease. The use and storage of human tissues, however, raises several legal, ethical, and social issues. Furthermore, as recent and rapid advances in biological and medical research have made it possible to analyze DNA from almost any minuscule sample of human tissue, concerns about privacy and informed consent have been raised. Complicating these issues is the paucity of information addressing tissue acquisition, use, and storage.

To date, no central database captures information about stored tissue samples. This handbook serves as a national resource, to bring together for the first time, in a single document, information about tissue storage in the United States. It also provides information about several aspects of stored tissue samples, such as how many stored tissue samples exist in the United States, where they are, who has them, and for what purposes they are used. A conservative estimate from the tissue collections described in this book is that more than 307 million tissue specimens from more than 178 million cases are stored in the United States, accumulating at a rate of more than 20 million per year. This handbook will be a valuable resource for researchers who require tissue samples for studies in genetics, cancer, immunology, physiology, and cell biology, among many other disciplines. In addition, this handbook may be useful to policymakers, physicians, and other professions related to health care.

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