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13. ABSTRACT *(Maximum 200 words)*

We have placed two innovative cancer information resources on the World Wide Web (www.askcnet.org). In our Cancer Data Query site, we provide public access to California and NCI SEER cancer case information, allowing anyone on the Web to propose data queries and receive tables of counts from their query. Information available on our web site include:

- Cancer types, stages, and treatment for all California cancer cases diagnosed 1988-1993 (N=780,804)
- Preliminary results of 1995 study fields on cancer screening, protocol use, and clinical indicators
- SEER's 10% of national cancer cases 1973-1993 (N~2 million)

We also have completed our Clinical Trials Matching System, allowing the general public and healthcare professionals to obtain consumer-oriented summaries of current IRB-approved clinical trials that specifically match the requested patient characteristics. Analysis is provided of the age, stage, and previous treatment characteristics of the requests.

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Introduction

Background

The California Cancer reporting system has been collecting data on all breast cancer cases (~20,000/year) for over nine years statewide, and for more than 25 years in some geographic areas. This pioneering system is built around mandatory electronic cancer case reporting, coupled with software specifically designed to carry out this mandatory reporting.

Hospital-based tumor registry software (C/NET) was developed by the California Public Health Foundation (now known as the Public Health Institute, or PHI) to achieve high-quality and efficient data collection. PHI has distributed C/NET to 250+ hospitals and other cancer reporting facilities throughout the state. C/NET is also used on portable computers to collect cases from the remaining, smaller hospitals around California. C/NET currently handles autocoding, data entry, interfield edits, and the preparation of periodic transmit files for conveying new case reports and later case modifications or corrections to California's central cancer registry. Cases are first sent to one of eight regional intrastate registries, which carry out further editing, case matching, and quality control before sending the cases on to the California Cancer Registry.

The C/NET hospital software is widely used and appreciated, as it carries out functions essential to hospital registries and their clinician staffs beyond case collection and reporting. Various versions of C/NET are in use in over 650 other hospitals outside of California. These versions have been distributed by the American College of Surgeons (ACoS), and, more recently, by the PHI, our parent organization. C/NET software gathers data on cancer diagnoses, stage, treatment, and follow-up in national standard format. It includes all fields necessary for the National Cancer Institute (NCI)'s SEER Program and ACoS's National Cancer Database. However, not all data items gathered at the hospitals have been uploaded to the California central registry at present.

As the number of years of complete statewide data collection has increased, the California Cancer Registry has used its statewide database in numerous studies and publications.

Statement of the Problem

Several factors have hindered wide usage of registry data for clinical and epidemiological studies in breast cancer. These problems include: lack of easy access to the data, built-in delays in the reporting system, difficulty in pilot testing or adding new data fields targeted for breast cancer studies, and lack of rapid case ascertainment to support special studies. Many investigators have noted the imbalance in registry focus, with more attention being given to data collection than data usage. Also, analytical tables and reports are not available through a single, uniform access method. Instead they are scattered across many locally produced

publications. This has limited access to statewide cancer registry data to a few sophisticated users, who are largely within the cancer reporting system.

The current cancer reporting systems are slow in their ability to revise data collection to match changing clinical practices. Potential new methods of detection, staging, and treatment are constantly appearing and require evaluation. Although computers should facilitate the rapid deployment of new fields and codes for pilot testing, this is not occurring. Rapid turnaround studies require both faster methods for distributing data item revisions, as well as faster methods for reviewing early results.

Efforts to improve breast cancer treatment have suffered from other problems caused by the lack of information reaching the gatekeepers and the patients. One is the difficulty obtaining the optimum numbers and variety of patients enrolled in clinical trials. The need for consumer access to clinical trial information is now recognized, but convenient methods are not yet available. The PDQ system, for example, provides consumers either oversimplified summaries or, at extra cost, an overwhelming amount of information through an interface that is not organized for consumers asking what trials might be available for them.

Purpose and Technical Objectives

We have been adding new functions to the computerized reporting system now in place in order to solve these problems. We want to make the data available in highly useable form and foster studies not before possible on such a large and ethnically diverse population. Examples include testing whether access to care for breast cancer and quality of care are related to patient insurance status, ethnic, type of provider, or geographic factors.

Specific goals of the system enhancements include:

1. Provide a **dial-in user query system** open to all investigators, allowing user-defined tabulations, plots, and offline maps on a wide variety of breast case data. Databases open to queries would come from three sources: California statewide data from 1988 to the current year, and NCI SEER data from 1973 forward.

2. Facilitate the rapid, electronic communication of case-related information by adding **integrated telecommunications** to the C/NET hospital-based registry software. This would allow all 250 hospitals in California to easily submit case data, receive shared data, query the central statistical databases, carry out e-mail communication with their peers and their technical support personnel, and load comparison data counts which parallel their own in-house queries, in order to produce tables and graphs with direct comparisons.

3. Encourage cost-effective targeted patient interview studies by adding a flexible **rule-based rapid case reporting** channel for cases discovered in hospitals that potentially

meet special patient interview study criteria, so the regional registries can conduct these studies at a much reduced cost.

4. **Monitor and encourage enrollment in treatment protocols** by adding rule-based criteria to hospital registry software. The rules would flag cases meeting current criteria for one or more national treatment protocols. This helps track the rate of use of these protocols in the target patient population, and may facilitate the recruitment of patients.

5. Help **solve at the hospital level the problem of incomplete treatment reporting** by adding Physician Data Query (PDQ) recommended treatment plans to the software. This will identify the most commonly recommended treatment for patients of a particular age, stage, and disease type. The software will also support the automatic mailing of physician letters to inquire whether this therapy has been carried out, if the medical record is incomplete.

6. Assure that a large cohort of breast cases has crucial staging and follow-up information by carrying out a one-time catch-up data upload of **AJCC stage and followup data** from California hospitals to the regional and central registry. These data are mostly available in the hospital systems, but have not been fully communicated to the central registry. They will be transmitted on a regular basis thereafter.

7. Facilitate the timely flow of case-related data by setting up **regional registry bulletin board systems** in California to handle all communications with hospitals and other treatment facilities in eight regional centers. These bulletin board systems (BBS's) will manage automatic information uploads and downloads, as well as e-mail, and will be tied together into a statewide network. They can also be used to update data collection software.

8. Broaden the kinds of research questions that can be studied statewide by **adding new fields** to the recommended state data set, and by adding rapid turnaround study fields that would change every year. To study protocol enrollment, protocol number or reason for no protocol would be coded. To study financial limitations on care for breast patients, insurance status/source of payment will be tracked. In order to study treatment success, disease free interval would be calculated. Fields will also be added to collect co-morbid conditions, and to pass on the clinical indicators for breast cancer required by the JCAHO beginning in 1995. To encourage hospital studies in more detail, optional fields will include procedures performed and their costs, and details of radiation and chemotherapy performed or the reason none was given. These fields will be evaluated and revised yearly.

Several more related goals were added to the project through a supplemental grant to this one that was awarded by the U.S. Public Health Service National Action Plan on Breast Cancer. The mission of the supplemental project (called Breast Cancer Answers) is to empower women with online clinical trial and support information in an effort to both improve breast cancer treatment research and to support breast cancer survivors and their families (*http://www.canceranswers.org/ See Appendix V*).

The **added objectives** were as follows:

9. Form a **Consumer Advisory Panel** comprised of a variety of community breast cancer organizations to review the content and presentation of the breast cancer information presented.

10. Add confidential online **matching of breast cancer patients to potential clinical trials,** translating medical protocol language for consumer understanding. Consumers will be given Internet access to the current list of potential clinical trials through an easy-to-use lookup based on details of their diagnoses. Where needed, we will translate the trial information into a more consumer-oriented format.

11. **Evaluate the web site additions.** Feedback is solicited from all users, as to the helpfulness of the information and the convenience of the interface.

12. With the advice of our Consumer Advisory Panel, we also undertook to provide **psychosocial support** to breast cancer survivors and their families through a unique on-line art gallery and personal story collection, and through online links to breast cancer support groups and hotlines.

✦ ✦ ✦

Work Accomplished

Online Cancer Data Query System.

To provide access to the large cancer registry datasets available, we created a web site *(www.askcnet.org)* with a query engine which could accept user requests of the selection criteria and data items. Within seconds, a two-way table of the resulting counts is presented to the user for review and downloading. Because any two data items from a substantial list can be chosen for analysis, a very large number of different analyses can be run, depending on the needs of the inquirer. We developed a custom interface to the HIRS software developed at CDC in order to place the power of its query engine into a convenient web-based system. The sequence of steps to perform a web-based query are as follows *(see Appendix -1 for an example):*

1. Go to the *www.askcnet.org* web site and choose 'Cancer Statistics on Demand.'

2. Log in. New users are asked to provide any login ID and password they choose. They have the option of including their email address and name, as well as category of user *(see below)*.

3. Choose the data source. Currently the choices are California statewide data and SEER data. They also may review a description of each.

4. Agree to the use agreement terms after reading them. California and SEER have supplied us specific language for these agreements.

5. Choose a subfile to study. For California data, users can chose to analyze all cancer cases 1988-1993, or chose specific subfiles of breast, prostate, or lung cases where a more detailed set of data items is available.

6. Choose the row and column data items for tabulation. For the all-sites California subfile, they can choose age at diagnosis, California region, year of diagnosis, stage, cancer site, race, or sex. For the California female breast subfile, they also can choose to tabulate on histology, subsite, type of surgery, and reason for no surgery.

7. Choose whether to compute and display row, column, and table percentages.

8. Choose selection criteria, if desired, to narrow down the cases tabulated. The same data items can be used as selection criteria as are available for tabulation.

9. Click on the Query button to execute it. The tabulation is displayed in table format, and can be saved to the local computer.

10. Appended to the table are suggested citation language along with specific caveats concerning the use of the data.

Appendix A-1 displays the series of web screens encountered to prepare and run a query on cancer stage versus year of diagnosis across all California cancer cases.

Large Datasets Online

We currently make available two large databases: all California cancer cases diagnosed 1988-1993 (780,804 cases) and NCI's SEER data for 1973-1993 (872,944 breast, lung, prostate, and colon cases). Another example of the printed output from a query on California cases 1988-93 by site is shown in *Appendix A-2* Examples of queries on NCI SEER data are shown in *Appendices B-1 and B-2.*

Availability of the California and SEER 1994 case data has been delayed. We anticipate receiving and loading 1994 and 1995 data from both sources by the end of 1998.

Confidentiality

It is crucial to protect the confidentiality of individual cases. Even though only tabulations are performed, and no names or other identifiers are used, we had to guard against the possibility that special characteristics of an individual could be revealed through a tabulation that has just 1 or 2 individuals in a single cell. For example, if a tabulation identified a very young person living in a low population geographic area who had a rare form of cancer site and cell type, that individual might possibly be identifiable. To prevent this, any cell in the row/column tabulation that has a count under ten is suppressed (marked with an asterisk), signifying that the count could be anywhere between 1 and 9. As a further refinement, some companion cells must also be suppressed so that the small cell counts cannot be obtained by computation from row and column totals. This methodology has assured the data providers at the California Cancer Registry and NCI that confidentiality will be preserved. (See *Appendix A-3* for an example query with suppressed cells, obtained by requesting race versus stage at diagnoses counts for 1993 California cases.)

Site Use Monitoring

We wanted to know not just how many people were using the query site, but also how they are using the data. To that end we added a log-in system, asking a few questions of first-time users. Personal identification is completely optional. Users are asked to identify themselves as a researcher, patient, friend, etc., with multiple choices allowed. The most commonly chosen category was researcher, closely followed by family member. *(See Appendix C).*

Users can comment or ask questions via email as well, and a full-time statistician is available to help with the use of the site.

Analysis of the web server logs *(Appendix D)* show that the Cancer Data Query web site has been well received. Over the calendar year 1997, an average of 100 visitors logged into the system each month, generating nearly 400 queries per month. We also track each query, so we can later analyze what specific kinds of queries are of most interest. If the agencies supplying the data wish, we can provide lists of the queries run against their data. *(See Appendix E for an example.)*

Special Study Data Items

As part of this study, a number of data items relating to cancer treatment were added to the cancer reporting system in California for 1995 and 1996 cases, and have been subsequently loaded into the query engine. The added items include: treatment, screening, JCAHO clinical indicators, and protocol used. *(See Appendix F)* These items were identified by a representative group of hospital cancer registry personnel as data of considerable interest to their research users, but which were currently not collected by the State. Adding them to the dataset collected provided a valuable source of comparison data.

The new data items were not required by California or national organizations. To assure enough data for analyses, cancer registrars were encouraged to participate. We attended regional meetings and trained regional personnel to help get the word out and answer questions about the new fields.

Special Study Data Items Analysis

When plans for a one-time batch submission of follow-up and staging information began to be formulated, we added a one-time submission of the new data fields as well. This software was available to the hospital registries by the beginning of 1997, and we began receiving case files from the regions shortly thereafter. Eventually we received files containing over 41,000 cases, or approximately one third of the 1995 cancer cases diagnosed in California.

The preliminary analysis of the early files for levels of utilization of the new fields had shown that there had been a very low level of utilization of the new data fields. This was to be expected since participation in the study was optional. Nevertheless, we encouraged registrars to take the time to code the new fields.

With the new sample of cases covering the entire calendar year, the results looked much better. Utilization of the fields still showed a wide range, but there were consistently more cases coded than seen in the early samples. Nevertheless, we still created analysis files based on coding within a group *(see Appendix G-1 for a list of the fields grouped)* such that any

record with a code in any field in the group was included. For an example of a special study field, *Appendix G-2* shows the results of the utilization of multichannel chemistry as part of the workup for breast cancer, by stage at diagnosis.

We had anticipated that we would revise the list of special items collected based on feedback from data users for year three. However, the advisory group requested that we continue with the same set of data items.

Networking All California Regional Registries

Since the rapid collection of cancer data in California depends on efficient electronic reporting between agencies, we set up consistent email and BBS systems at each region. This allows hospital registries to use either the Internet or dialup Bulletin Board System to report cases. The Wildcat BBS system has been installed in all seven California regions. Overall, most of California's 250+ reporting hospitals now have efficient and straightforward access to our electronic reporting system.

In addition, the regional BBS's have been configured to share email to allow communication between users in different regions.

One-time Upload of Follow-up and Staging Data

Not all data collected in hospitals in California were sent to the central registry, due to various historical problems. In particular, information on the current patient status (follow-up), which is crucial to perform studies of survival rates, was not consistently transmitted in the past. Also, the AJCC staging of cancer cases that physicians perform in order to plan treatment was not always sent in with the cases. To correct these problems, we programmed and distributed software that produced one-time upload files with the missing follow-up and staging information. The hospital software was distributed to the registrars in December, 1996, and the upload process began immediately thereafter. These data have all been transferred from hospitals to the regional registries.

Integrate Telecommunications Functions into C/NET

This task has changed substantially in concept since our proposal. The growth of the Internet has led to a rapid change in the communications methods available to registries. In keeping with this, we shifted to a method that allows either dial-up BBS or Internet-based communications. To achieve this we disseminated copies of Wildcat Navigator to all California hospital registries that had the computer resources to make use of it. The

requirements were a Windows system on their desktop and either a modem or Internet connection. This deployment has been successful. In the region encompassing Orange County, for example, 40 hospitals currently use Wildcat to send in their data. Our registry software currently automatically prepares files of cancer case submissions, including compressing them. Then Wildcat is used to send them in. *(See Appendix H for sample screen.)*

The proposed integration of comparison data into the hospital software's analysis rountines had to be postponed. It awaits completion of our transition from a DOS-based to a Windows-based system. Our DOS application has reached its limits in terms of the ability to add new functionality. Windows programming is currently moving forward, with delivery over the next year.

Program Rule-based Recommended Treatment System

We have chosen a different approach to the problem of tracking recommended treatments than originally proposed. The California Cancer Registry decided to carry out implementation of a rule-based treatment monitoring system at the regional level rather than at the hospitals. There were several reasons for this decision. The problem of incomplete treatment information had become a high-priority concern for researchers at the regional and state level, and they wished to put in place a system that would ascertain completeness across all cases, not just those seen in hospitals with active cancer registries. There was also the problem that if letters were sent to physicians by computer systems at both the hospital and the region, triggered by missing information, there would be a good deal of duplication of effort.

Under separate funding, regional software is now being developed. It uses PDQ rules to flag cases where data indicate that standard treatment practices have not been completely carried out. Often this is caused by a failure in the reporting system rather than by an incomplete treatment implementation. The software automatically produces letters to the physicians involved asking whether treatment was in fact completed, and if not, what the reason was for discontinuing it. It is hoped that this will not only lead to improvements in the quality of the database but also a better understanding of the reasons for the discontinuance of treatment. The software has been successfully implemented in the San Francisco Bay Area SEER registry, and shortly will be implemented in the rest of the state. It will be used instead of the hospital-based system we had originally proposed.

Program rule-based flagging system to indicate when hospital registry cases may be eligible for existing treatment protocols

This is another area where changes in the technology since we submitted our proposal are allowing an improvement in the deployment methods. Our original intent was to provide updatable rules in the hospital software that would signal which cancer cases might be subjects for current treatment protocols. However, the task of keeping the hospital-based rules system up-to-date in hundreds of locations was somewhat daunting. With the increased use of the Internet, another solution has become available. We decided to publish a clinical trials matching system as part of our Web site. This could more easily be kept up to date, and could provide links to NCI's trial descriptions, as well as to sites where patients are being recruited into trials. Thus cancer registrars, clinicians, and the general public could locate open trials that are relevant to their situation.

The web matching system has been in operation for the past year-and-a-half. The matching is carried out by asking the inquirer anonymously to fill in certain data on her or his age group, type of cancer, stage, and demographics. She or he then sees a list of the trials which match on these criteria. A patient can take this list to her or his physician for more detailed discussion. Cancer registrars can use the matching to check whether the case they are reporting might be suitable for a clinical trial.

We currently have 91 active trials in the database *(see Appendix I for the list)*. The site is further described below, under the work accomplished as part of our supplemental grant. The patterns of usage are also described.

Our long-term goal is to integrate the hospital-based desktop cancer registry application with web-based lookup of current information. We plan to add the ability to query our clinical trials web system during cancer case coding, in an effort to flag potential candidates for trials. Work continues on other funding.

Work Accomplished on National Action Plan on Breast Cancer Supplemental Grant

Formation of Consumer Advisory Panel

The Breast Cancer Answers Project received feedback on the web site from a Consumer Advisory Panel comprised of a diverse group of breast cancer health educators, activists, nurses, a physician, a lawyer, and a bioethicist from the following organizations: National Women's Health Network, Women's Cancer Resource Center, Northern California Cancer Center, American Cancer Society, The Ethics Practice, Better Health Foundation, The Breast Cancer Fund, Stanford University Medical Center, California Department of Health Services,

Community Breast Health Project, Alta Bates Comprehensive Breast Center, Public Health Institute, Y-ME, Clinical Trials Information Project, California Pacific Medical Center, John Muir Medical Center, National Latina Health Organization, and Wilson, Sonsini, Goodrich & Rosati.

The Consumer Advisory Panel met for an all-day meeting in May 1996 and reviewed grant deliverables, identified potential problems, proposed ideas *(see Technical Objectives 3 and 4)*, and identified online formats for online presentation that would encourage consumer use). Overall, panel participants were quite enthusiastic about our web site. They were pleased with the content, the graphics, and the user-friendly format. More specifically, they were pleased with our objective of broadening consumer access to clinical trials information. One panel member noted "I've been waiting a long time for this."

Implement Web-based Clinical Trials Matching System

Based on feedback from our Consumer Advisory Panel and extensive pilot testing, we designed and launched The Breast Cancer Answers Clinical Trials Matching System (CTMS) *(http://www.canceranswers.org/treat.htm)*. The CTMS offers a unique online resource for women seeking breast cancer treatment. When using the system, a breast cancer survivor anonymously fills out a simple and graphically attractive online patient profile that asks her about her treatment history, stage of disease, and other specific disease criteria *(see Appendix J-1)*. Based on her profile, the system then matches her to a comprehensive database of over 90 clinical trials in California for which she may be eligible to participate *(see Appendix J-2)*. All of the trials are IRB-approved and have been translated for easier consumer understanding.

Our translated summaries, written by our nurse educator consultant, are simple one-to-two-page summaries that include essential trial information, including the purpose and relevance of the trial, a clear explanation of the protocol, eligibility requirements, risk factors, payment and insurance information (where applicable), sponsorship (where applicable), and contact information *(See Appendix K)*. Technical terms in trial summaries that need further clarification are underlined and defined in a glossary of clinical terms produced by the National Cancer Institute. Attractive graphics designed by our graphic artist consultant soften the summaries and make them friendly and non-threatening.

We collaborated with two organizations, the National Cancer Institute and Clinical Trials Information Project, in producing online translated clinical trial summaries. In March, 1997, the National Cancer Institute converted all National Cancer Institute (NCI) sponsored clinical trials from their Physician Data Query (PDQ) database into non-technical language and listed the trials on their web site, Cancernet. Women using the CTMS who are eligible for PDQ trials are matched through the system to Cancernet's summaries *(see Appendix L)*. We also collaborated with Clinical Trials Information Project (CTIP) to translate trial summaries *(see Appendix M for memo of collaboration and project description)*. CTIP translates breast

cancer clinical trials in the San Francisco Bay Area and publishes the trials on their web site and in a printed guide. We conserved resources by linking to their summaries *(see Appendix N)*. In exchange for use of their summaries, we served as the hosting site for their web site.

Our staff devoted considerable time each month to maintaining and updating the CTMS with a comprehensive database of clinical trials. Our project director established relationships with clinical trial coordinators at University of California at San Francisco, University of California at San Diego, University of California at Los Angeles, University of California at Irvine, University of Southern California, Stanford University, and several California hospitals to ensure that the CTMS contained updated and accurate trial information. In addition, once we established ourselves as an important internet service, clinical trial investigators approached us with trial information to add to our database. The relationships we established with clinical researchers resulted in the development of an extremely comprehensive and diverse database of IRB-approved trials reflecting both government-funded and privately-funded treatment, prevention and supportive protocols.

Significantly, as the only online resource linking a breast cancer survivor, based on her specific disease profile, with clinical trials for which she may be eligible to participate, we have provided women with tailored, quick, and friendly information that they can discuss with their families and health care provider.

Provide Psychosocial Support via the Web

Based on feedback from Consumer Advisory Panel Members, we concluded it was essential to provide online support to breast cancer survivors. We provided support through a unique online art gallery and personal story collection, and through online links to breast cancer support groups and hotlines.

***Artwork*:** Through advertisements in art centers, hospitals, and breast cancer consumer group newsletters, we collected artwork from over 50 women and men touched by breast cancer *(http://www.canceranswers.org/gallery/index.htm)*. We are currently unaware of any other web site that contains an online art gallery specific to breast cancer.

The artwork collection portrays many different emotions, ranging from fear, mourning, and anger, to strength, healing, recovery and survivorship. These emotions are arranged in categories on the web site so that the viewer can easily navigate to sections of the gallery that closely match her/his life experience. Our definition of art is open-ended. The gallery includes personal sculptures, paintings, photography and poetry *(see Appendix O)*. Most pieces are accompanied by a personal statement from the artist that helps the viewer understand the message the artist intends to convey.

Through the art gallery, we hope to support, empathize with, and empower those touched by breast cancer. We also hope to promote art as an effective coping and healing mechanism.

Personal Stories: We also collected personal accounts from breast cancer survivors that describe their unique experiences with breast cancer *(http://www.canceranswers.org/stories/index.htm)*. The stories focus on the treatment process, including the emotions surrounding treatment decisions, the criteria considered in making treatment choices, and the coping and healing mechanisms used in recovery from treatment. The stories reflect a variety of treatment decisions, ranging from surgery and chemotherapy to macrobiotics and acupressure *(see Appendix P)*. Through the personal story collection, we hope to provide emotional support and empathy to breast cancer survivors and their families.

Links: Through collaboration with other breast cancer web sites and breast cancer organizations, we link viewers to a comprehensive listing of online resources, local support groups and hotline numbers. *(http://www.canceranswers.org/links.htm) (See Appendix Q).*

We also collaborated with the National Cancer Institute's Cancer Information Service by referring all web site inquiries from users seeking breast cancer treatment information to NCI's hotline (1-800-4-CANCER). This collaboration enabled us to provide effective response management to those in need of further information about breast cancer.

Broadening utilization of Breast Cancer Answers web site:

Based on feedback from consumer advisory panel members, we felt it was important to devote time to marketing the site to potential Internet users who could take advantage of the web site's unique resources. We relied on two methods to market the site: online marketing and marketing mailings.

Through online marketing, we successfully marketed the web site to other popular cancer web sites and search engines who link to our site, including Oncolink, Breast Cancer Network, National Breast Cancer Coalition, Breast Cancer Compendium, National Coalition of Cancer Survivors, Steve Dunn's CancerGuide, Clinical Solutions, Yahoo, Excite, Alta Vista, Infoseek, and Web Crawler. Through marketing mailings, we informed over 300 breast cancer organizations, support groups, hospitals, clinics, and libraries located in both Northern and Southern California about our web site. In addition, we published information about the site in three issues of C/NOTES, C/NET's quarterly newsletter which reaches cancer registrars in over 250 hospitals in California.

Evaluation of Breast Cancer Answers Web Site

We relied on multiple methods to both qualitatively and quantitatively evaluate the web site. First, we relied on our IRB-approved email survey *(see Appendix R)* to assess satisfaction with the web site components, health behavior related to clinical trials, basic demographics, and methods used to learn about the web site and to access the site. These variables not only allowed us to make modifications to our site based on users' suggestions, but gave us a better

understanding of our target population which led to more effective marketing and outreach efforts. Second, we relied on our IRB-approved patient profile survey to assess the disease characteristics and demographics of our users. Our statistician analyzed the results from these two surveys on a regular basis. Third, our statistician analyzed web site accesses and patterns of use on a weekly basis through collection of data on log files. This data collection method measured the level of web site activity as well as the popularity of each web site component. Fourth, we contacted members of our Consumer Advisory Panel to obtain feedback about specific components of our web site before going public. Fifth, we relied on qualitative email feedback from our users on a regular basis to modify and enhance the web site.

All evaluation methods maintained the confidentiality of those who used our site. We made every effort to preserve the confidentiality of those who filled out the clinical trials profile form, and/or the email survey, and of those who provided us with email feedback on the site. First, we obtained IRB-approval from the Public Health Institute's Institutional Review Board to ensure that our instruments met human subjects approval. Second, we used web server technology that permits encrypted transmission (scrambling) of information across the Internet for collecting personal data from respondents. Third, once the data were received at our site, personal identifiers, such as names and email addresses, were separated from the rest of survey responses and both files were stored in separate, encrypted database files. For additional security, these files were moved off the web server on a regular basis. Fourth, staff who had access to the personal data files signed a Certification of Confidentiality.

Qualitative Results: We received over seventy email responses from web site users. Many of the responses reflect inquiries about specific breast cancer treatments. We referred such inquiries to the National Cancer Institute's Cancer Information Service. Other responses reflect qualitative comments about our web site, the majority of which are positive. As shown below, many of the responses illustrate how the stories and artwork presented on the web site provided empathy to women experiencing similar life circumstances. Moreover, the responses reflect user satisfaction with the clinical trial matching system and the web site graphics. *(See Appendix S for examples of responses.)*

Quantitative Results: The number of clinical trials queries processed by the Breast Cancer Answers web site averaged about 200 per month in 1998 *(See Appendices T1 and T2).* Since a query often produced more than one trial that fit the parameters of the request, the number of potential trials presented was more like 1200 per month, as is shown. An analysis of the specific characteristics entered by requestor sheds some light on the type of patient for whom potential trials are being requested *(see Appendix U)*. The most common age group was 40-49 (34%), and the most common stage was recurrent breast cancer (24%). Only 4% declined to state an age, and 22% did not select a cancer stage. With 61% noting current or previous chemotherapy, it is clear that interest is highest among patients who have already received considerable treatment and are looking for more options.

Although the web site received considerable use, very few users filled out the email survey. Due to the small sample size, we decided not to send a follow-up survey at this time. Work is continuing under other funding.

✦ ✦ ✦

Summary of Performance on Deliverables

Year One

Install the HIRS query system. Reformat and load California registry data from 1988-1992 into it. Pilot test and revise as needed. **Completed in Year One.**

Load NCI SEER 1972-1992 data into HIRS and test. **Completed in Year Three.**

Set up bulletin board hardware and LAN for the central registry node, and install BBS software. **Completed in Year One.**

Announce new query bulletin board, provide user documentation, and demonstrate its use to groups of potential users. Start statistical assistance hotline. **Completed in Year One.**

Implement e-mail and case transmit bulletin boards in the seven regional registries, and link through nightly mail exchange with the central board. **Completed in Year Three.**

Add proposed new data items to C/NET hospital registry software and distribute to all registry hospitals in California. **Completed in Year One.**

Program and carry out a one-time data upload of patient follow-up and AJCC staging data from registry hospitals to the regional registries. **Completed in Year Three.**

Load 1993 case data into the query system when it becomes available **Completed in Year Two.**

Year Two

Add 1994 cases from state and SEER program to HIRS database when available. **1994 data was not available in Year Two; delayed to December 1998.**

Prepare new query system database of hospital breast case reports, from 1988-1994, including preliminary data on the new fields added in year 1. **Completed in Year Three.**

Revise new data items, deleting, modifying, or adding, depending on results of review of previous year's testing, and new research needs. **Completed in Year Two.**

Integrate telecommunications functions into C/NET registry software. **Completed in Year Three.**

Implement rule-based rapid case reporting in C/NET and use it in at least one region to facilitate a case-control study. **Not Completed**

Program rule-based recommended treatment system and install rules based on current PDQ guidelines. Add function to mail physician query letters when insufficient information on treatment is found. Monitor success rates. **Completed in one region in Year Three.**

Program rule-based flagging system to indicate when hospital registry cases may be eligible for existing treatment protocols. **Substituted Web-based Clinical Trials Matching, Completed in Year Three.**

Year Three

Add function to C/NET to integrate the hospitals own data tabulations with comparison data received from statewide query system, for side-by-side comparison. **Not Completed.**

Add 1994 cases from state and SEER program to HIRS database when available. **In progress, for December 1998 completion.**

Revise new data items, deleting, modifying, or adding, depending on results of review of previous year's testing and new research needs. **Review Completed in Year Three, no changes required.**

Analyze success of PDQ-based treatment queries by examining trends in treatment completeness over time, and success rates of receiving added information. **Not Completed.**

Analyze success of protocol identification system in terms of user acceptance and data consistency. Revise as needed, maintaining a current rule list of protocols. **Completed in Year Three.**

Review successes/failures of the query system by analyzing its patterns of use, the studies or reports that may have resulted from it, and the results from user feedback questionnaires. **Completed in Year Three.**

National Action Plan on Breast Cancer Supplement Deliverables

1. Form a Consumer Advisory Panel comprised of a variety of community breast cancer organizations to review the content and presentation of the breast cancer information presented. **Completed.**

2. Add confidential online matching of breast cancer patients to potential clinical trials, translating medical protocol language for consumer understanding. **Completed.**

3. **Evaluate the web site additions.** Feedback is solicited from all users, as to the helpfulness of the information and the convenience of the interface. **Completed.**

Conclusions

1. We have successfully implemented online Web-based queries using cancer case datasets of substantial size. For example, we loaded twenty years of data based on 10% of the US in a few hours. Queries against this database then take about one second to complete. This speed fits nicely with the Web environment, and proves there is no technical barrier to opening public access to very large public health datasets.

2. We find the detailed logging of incoming user queries to be feasible and useful in monitoring the kinds of uses the query site is being asked to provide. Users are willing to identify themselves by general category (e.g. researcher), making that information available for analysis as well.

3. It takes careful planning and cooperation with data suppliers in order to publish meaningful data queries on the web. Each agency, such as the California Cancer Registry and SEER, have their own concerns regarding case confidentiality, disclaimers, descriptions, and the monitoring of use. However, once we solved these problems, we were able to move ahead.

4. The Web appears to be a better delivery system for clinical trials information lookups than adding software to hospital registry systems. It gives the general public as well as the healthcare professional access to current trial selections that match specific criteria. Also, we find it easier to update the trials list and support links to other trials information sites through a central web server than through individual desktop software.

5. We are pleased that telecommunications options are now becoming more integrated. Bulletin board software suppliers such as Wildcat are now offering solutions that integrate the more traditional dialup model with the benefits of Internet connections and web browser-like screens. This makes it much easier for us to provide a single software package to the eight California regions which can encompass the variety of user access methods. It also means we can develop a smooth interface between our hospital registry software and our Internet web content, such as clinical trials matching.

6. Rapid turnaround of registry data is still not easily accomplished. The major problem in California comes from the fact that a number of organizations are involved in the data flow, including regional registries with different software systems. These agencies have their own sets of priorities.

7. Implementing new optional data items takes more training resources than we thought. Each registrar must be convinced of the value of the extended dataset, and decentralized training meetings are needed to make the coding consistent and answer the inevitable questions that arise when using new data items.

Appendix A-1:
Accessing the California Cancer Registry Public Use File

California Cancer Registry
Public Use Dataset

The California Cancer Registry is a legally mandated, population-based cancer reporting system and has collected information on cancer cases diagnosed throughout the state since 1988. The Statewide Cancer Reporting Law (Section 210, 211.3, and 211.5 of the California Health and Safety Code) prohibits use of these data for purposes other than research and statistical analysis.

Users of these data must agree that they will not attempt to learn the identity of any person or establishment through manipulation of these data.

Do you agree to these terms?

Yes, I agree to these terms

No, I do not agree

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, California Public Health Foundation

Select database subfile to query: California Cancer Incidence, 1988-1993

- California Cancer Incidence, 1988-1993
- Calif Female Breast Cancer, 1988-93
- Calif Prostate Cancer, 1988-93
- Calif Lung Cancer, 1988-93
- Calif Breast Cancer, 1995, Summary & Treatmen
- Calif Breast Cancer, 1995, #1 Guidelines
- Calif Breast Cancer, 1995, #2 Guidelines
- Calif Breast Cancer, 1995, JCAHO Indicators
- Calif Prostate Cancer, 1995, Summary & Treatm
- Calif Prostate Cancer, 1995, #1 Guidelines
- Calif Prostate Cancer, 1995, #2 Guidelines

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, Public Health Institute

Select field for ROWS: Stage

Select field for COLUMNS: Year of Dx

Age at Dx
Primary Site
Race
Region
Sex
Stage
Year of Dx

Show percentages for:

Columns?

Rows?

Tables? Yes ◉ No ○

Query All Data | Select Data to Query | Reset

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, Public Health Institute

Select Age at Dx: [All]

Select Primary Site: [All]

Select Race: [All]

Select Region: [All]

Select Sex: [All]

Select Stage: [All]

Select Year of Dx: [All]

Query Selected Data | Reset

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, Public Health Institute

California Cancer Incidence, 1988-1993

	Year of Dx						
Stage	**Total**	**1988**	**1989**	**1990**	**1991**	**1992**	**1993**
In situ	82897	********	12364	14035	********	********	********
Localized	283088	42576	42829	45506	49167	52354	50656
Regional	155479	24758	24773	25778	26437	27381	26352
Distant	161815	25221	26116	27273	28319	27927	26959
Blank	11	********	0	0	********	********	********
Unstaged	97514	16171	16024	16716	15990	16103	16510
Total	780804	120697	122106	129308	134117	139068	135508

NOTE: Because of the influence on cancer incidence of the age and the size of the population at risk, these case counts cannot be used to assess cancer risk, but may be helpful in assessing the public health impacts of cancer.

The preceding table represents cases of cancer diagnosed during the indicated time period. Unless the file was subdivided by race or stage, the data represent all racial and ethnic groups and both invasive and *in situ* cases, respectively.

Suggested Citation

Any person or group using this data shall include the following citations in any publication, presentation, or printed report using data from the State-funded cancer reporting program and the Ask C/NET query engine:

1988-1993 Public Use File	California Cancer Registry public use tape, 1988-1993. Sacramento (CA): California Department of Health Services, Cancer Surveillance Section; 1996 March. Available from: *http://www.askcnet.org/dataq/index.htm*
1995 Early Reporting File	California Cancer Registry preliminary data, 1995. Sacramento (CA): California Department of Health Services, Cancer Surveillance Section; 1996 September. Available from: *http://www.askcnet.org/dataq/index.htm*
Program	Cancer statistics on demand. Berkeley (CA): Public Health Institute, C/NET Solutions; 1997 July. Available from: *http://www.askcnet.org/dataq/index.htm*

- Display information about the California database.
- Perform another query using the California database.
- Perform a query using a different database.
- Return to the Ask C/NET Home Page.

Appendix A-2:

California Data: Site by Year

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, Public Health Institute

California Cancer Incidence, 1988-1993

	Year of Dx						
Primary Site	**Total**	**1988**	**1989**	**1990**	**1991**	**1992**	**1993**
Oral Cavity	18439	3026	3107	3111	3051	3069	3075
Stomach	14656	2393	2462	2433	2434	2466	2468
Colorectal	86159	14411	14290	14370	14547	14412	14129
Liver	6487	920	914	1068	1125	1210	1250
Pancreas	16377	2708	2663	2727	2776	2748	2755
Larynx	7229	1236	1292	1292	1174	1165	1070
Lung & Bronchus	101795	16698	16673	17287	17089	17255	16793
Bone	1637	257	241	282	279	306	272
Leukemias	18124	2888	3024	3092	3068	3039	3013
Melanoma of Skin	27862	4156	4557	4682	4704	4865	4898
Brain & Nervous System	10833	1708	1752	1827	1806	1865	1875
Soft Tissues	3991	621	647	649	697	690	687
Breast	118242	19002	18451	19650	20081	20797	20261
Cervix uteri	49525	7523	7693	8844	8258	8693	8514
Corpus uteri	20135	3422	3201	3332	3352	3396	3432
Ovary	14594	2350	2337	2453	2430	2515	2509
Prostate	103560	12047	12880	15321	19690	22716	20906
Testis	4965	755	809	855	833	855	858
Kidney	12804	2018	1978	2132	2204	2241	2231
Bladder	30022	4903	4818	5044	5113	5057	5087
Eye	1595	249	270	258	290	277	251
Thyroid	8822	1335	1428	1448	1457	1624	1530
Kaposi's Sarcoma	10158	1582	1744	1785	1896	1706	1445
Non-Hodgkin's Lymphoma	26422	3909	4196	4428	4570	4694	4625
Hodgkin's Disease	4656	748	777	797	778	796	760
Other	61715	9832	9902	10141	10415	10611	10814
Total	780804	120697	122106	129308	134117	139068	135508

NOTE: Because of the influence on cancer incidence of the age and the size of the population at risk, these case counts cannot be used to assess cancer risk, but may be helpful in assessing the public health impacts of cancer.

Appendix A-3:
California Data: Race by Stage

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, Public Health Institute

California Cancer Incidence, 1988-1993

Year of Dx : 1993

	Stage						
Race	**Total**	**In situ**	**Localized**	**Regional**	**Distant**	**Blank**	**Unstaged**
White, Non-Hispanic	99638	*********	39218	19528	19546	*********	11325
Row%	100.0	*********	39.4	19.6	19.6	*********	11.4
Black, Non-Hispanic	8513	827	2838	1741	2108	0	999
Row%	100.0	9.7	33.3	20.5	24.8	0.0	11.7
Hispanic	15492	*********	4965	3087	3337	*********	1666
Row%	100.0	*********	32.0	19.9	21.5	*********	10.8
Asian/Other, Non-Hispanic	7990	799	2705	1838	1763	0	885
Row%	100.0	10.0	33.9	23.0	22.1	0.0	11.1
Unknown	3875	947	930	158	205	0	1635
Row%	100.0	24.4	24.0	4.1	5.3	0.0	42.2
Total	135508	*********	50656	26352	26959	*********	16510
Row%	100.0	*********	37.4	19.4	19.9	*********	12.2

NOTE: Because of the influence on cancer incidence of the age and the size of the population at risk, these case counts cannot be used to assess cancer risk, but may be helpful in assessing the public health impacts of cancer.

The preceding table represents cases of cancer diagnosed during the indicated time period. Unless the file was subdivided by race or stage, the data represent all racial and ethnic groups and both invasive and *in situ* cases, respectively.

Appendix B-1:
Accessing the SEER Public Use File

Ask C/NET

CANCER STATISTICS ONLINE

An information service of C/NET Solutions, Public Health Institute

SEER Prostate 1973-93

	Race					
Stage	**Total**	**White**	**Black**	**Hispanic**	**Asian/Other**	**Unknown**
In situ Col%	354 0.2	301 0.2	20 0.1	12 0.2	********** **********	********** **********
Local Col%	122147 58.7	101969 59.3	11180 54.6	3455 63.3	4251 58.9	1292 40.4
Regional Col%	31494 15.1	26910 15.7	2432 11.9	765 14.0	1155 16.0	232 7.3
Distant Col%	29736 14.3	23133 13.5	4468 21.8	771 14.1	1263 17.5	101 3.2
Unknown Col%	24503 11.8	19578 11.4	2359 11.5	458 8.4	********** **********	********** **********
Total Col%	208234 100.0	171891 100.0	20459 100.0	5461 100.0	7223 100.0	3200 100.0

Because of the influence on cancer incidence of the age and the size of the population at risk, these case counts cannot be used to assess cancer risk, but may be helpful in assessing the public health impacts of cancer.

The preceding table represents cases of cancer diagnosed during the indicated time period. Unless the file was subdivided by race or stage, the data represent all racial and ethnic groups and both invasive and in situ cases, respectively.

Suggested Citation

Any person or group using these data shall include the following citations in any publication, presentation, or printed report using data from the SEER Program and the Ask C/NET query engine:

1973-1992 Public Use File	Surveillance, Epidemiology, and End Results (SEER) Program public use CD-ROM (1973-1992), National Cancer Institute, DCPC, Surveillance Program, Cancer Statistics Branch, July 1995. Available from: *http://www.askcnet.org/dataq/index.htm*
Program	Cancer statistics on demand. Berkeley (CA): Public Health Institute, C/NET Solutions; 1997 July. Available from: *http://www.askcnet.org/dataq/index.htm*

- Display information about the SEER database.
- Perform another query using the SEER database.
- Perform a query using a different database.
- Return to the Ask C/NET Home Page.

Appendix B-2:
Accessing the SEER Public Use File

SEER Public Use File

There are specific laws which insure the confidentiality of individuals diagnosed with cancer when information about their cancer is entered into a data base for the purpose of establishing a research resource. In utilizing data on such individuals for research purposes, it is absolutely necessary to insure, to the extent possible, that uses of any such data will be limited to research and that uses for any other reason, particularly those resulting in personal disclosure, will be prosecuted to the full extent of the law.

In order for the Surveillance, Epidemiology, and End Results Program to provide a public use data file to you, it is necessary that you agree to the following provisions:

1. You will not use nor permit others to use the data in any way other than for statistical reporting and analysis.

2. You will not attempt to link nor permit others to link the data with individually identified records in another data base.

3. No one having access to the data will attempt to learn the identity of any person whose cancer data is in the data base.

4. If the identity of any person is discovered inadvertantly, then the following should be done:

   - no use will be made of this knowledge,
   - the Cancer Statistics Branch will be notified of the incident,
   - no one else will be informed of the discovered identity.

5. You will not release nor permit others to release the datasets or any part of them to any person who is not a member of your organization except with the written approval of NCI.

Clicking the **"I agree"** button below indicates that you agree to comply with the above provisions. Deliberately making a false statement regarding any matter within the jurisdiction of any department or agency of the Federal Government violates 18 USC 1001 and is punishable by a fine up to $10,000 or up to five years in prison.

Do you agree to these terms?

Yes, I agree to these terms

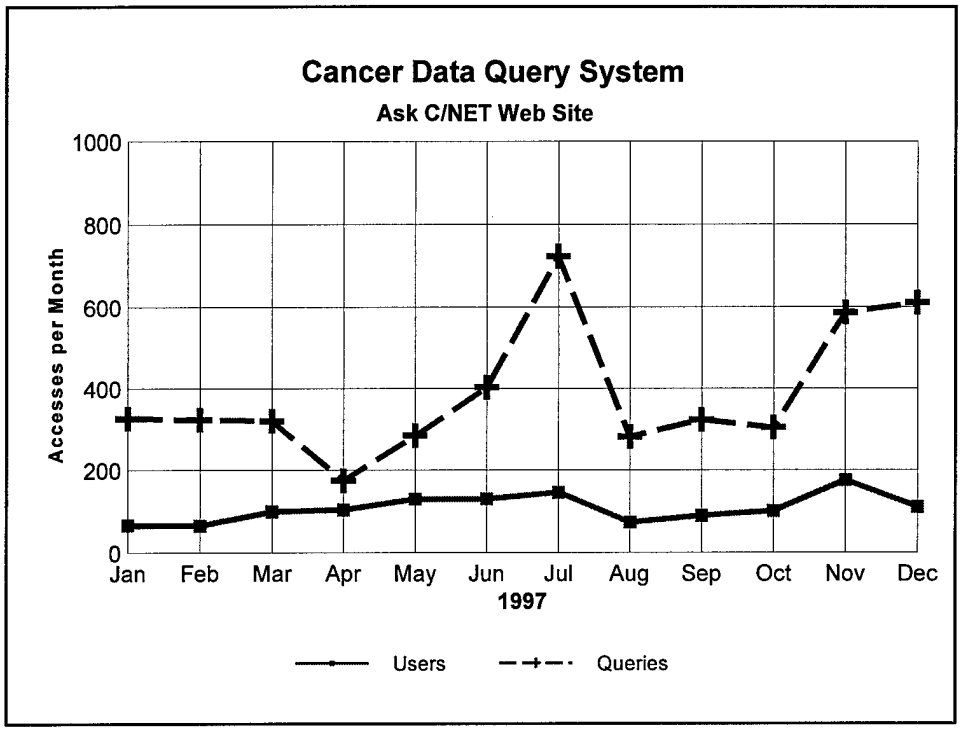
No, I do not agree

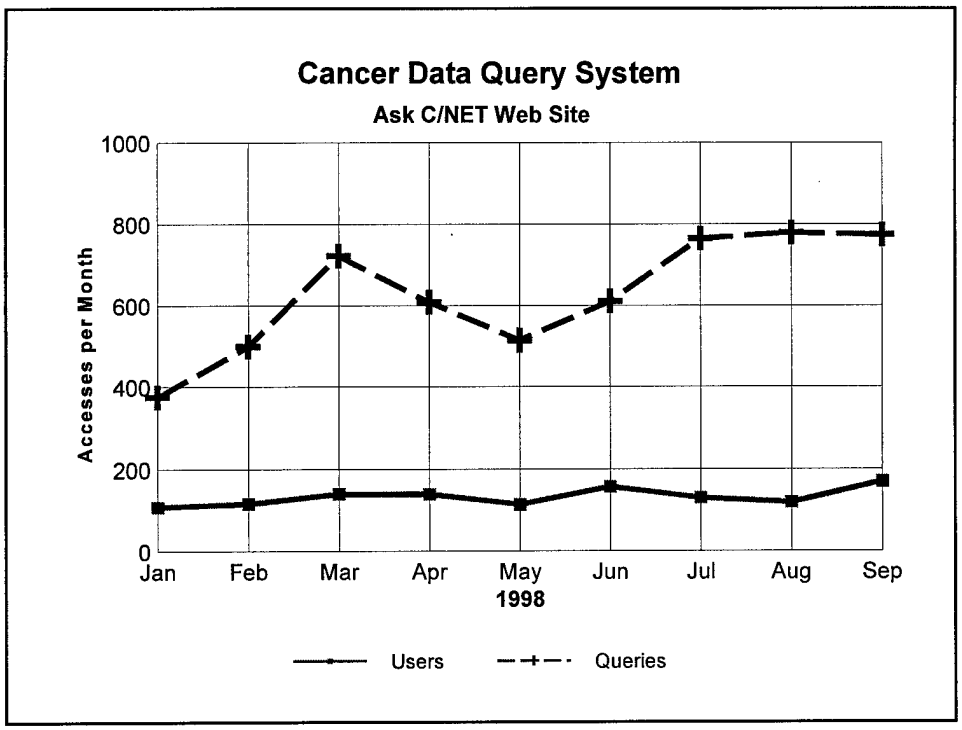
Appendix C:
Self-described Characteristics of Cancer Query Data System Users

Category	Number	Percent
Patients	84	8%
Family members	300	29%
Providers	144	14%
Researchers	437	42%
Registrars	70	7%
Analysts	184	18%
Other Professional	97	9%
Other	167	16%
Total	1050	

Note: Users may identify themselves in more than one category.

Appendix D:
Users and Queries by Month, Cancer Query Data System





Appendix E:

Sample Askcnet Query Log

Dateset	Row	Column	Selection	
California Cancer Incidence, 1988-199	**Primary Site**	**Year of Dx**	Sex	: Female
Date: 8/19/96 18:23:41			Race	: White, N
User Type: Provider			Stage	: Localize
			Primary Site	: Cervix u
			Age at Dx	: 30-34
Calif Lung Cancer, 1988-93	**Sex**	**Year of Dx**		
Date: 8/20/96 15:22:31				
User Type: Unknown				
Calif Lung Cancer, 1988-93	**Histology**	**Reason No Surger**		
Date: 8/20/96 15:53:46				
User Type: Unknown				
California Cancer Incidence, 1988-199	**Primary Site**	**Year of Dx**	Sex	: Female
Date: 8/20/96 21:25:54			Stage	: In situ
User Type: Registrar			Region	: San Fran
			Primary Site	: Breast
Calif Prostate Cancer, 1988-93	**Year of Dx**	**Stage**		
Date: 8/20/96 23:38:52				
User Type: Researcher				

Appendix F: New Data Items, CCR 1995 Early Reporting File

New Data Items for 1995 Cases

JCAHO Clinical Indicators (Breast, Lung, & Colorectal)	Treatment (All Sites)	Global Clinical Guidelines (All Sites)	Other
T &N Staging Documented	Surgical Approach	Surgical Consult	Discovd by Screening
Margin Status Documented	Reason for No Radiation	Radiation Oncology Consult	Family History of Cancer
Histology Documented	Reason for No Chemotherapy	Medical Oncology Consult	Personal History of Cancer
Extension Documented	Reason for No Hormone Therapy	CBC	Support Services
Tumor Size Documented	Chemotherapy Completion Status	Multichannel Chemistry	S-Phase (Breast)
Lymph Node Examination Documented	Protocol Eligibility	Chest X-Ray	DNA Level (Breast)
Surgical Path Consult Documented		MRI of Primary	PSA Value (Prostate)
Staged by Managing Physician		CT Chest/Lung	PSA Level (Prostate)
ER Analysis Documented (Breast)		CT Abdomen/Pelvis	
Complete Resection (Lung)		CT Liver/Spleen	
Barium Enema (Colorectal)		Imaging Bone	
Colonoscopy (Colorectal)		Imaging Brain	
Obstructed or Perforated (Colorectal)			
Proctosigmoidoscopy (Colorectal)			

Appendix G-1
Special Study Data Fields in Cancer Data Query Subfiles

New data fields are shown in bold face.

File 1 (Breast Cancer):

Region, Age at Diagnosis, Subsite, Histologic Type, Stage, Surgery, Radiation, Chemotherapy, Hormone Therapy, **Surgical Approach**, **Screening**, ER Analysis, and PR Analysis

File 2 (Breast Cancer):

Region, Age at Diagnosis, Subsite, Stage, Surgery, Radiation, **Surgical Approach**, **Screening**, ER Analysis, and PR Analysis, **Surgical Consult, Radiation Consult, Oncology Consult**

File 3 (Breast Cancer):

Region, Subsite, Stage, **CBC, CT Abdomen/Pelvis, CT Chest/Lung, CT Liver/Spleen, Chest Xray, Imaging - Bone, Imaging - Brain, MRI, Multichannel Chemistry**

File 4 (Breast Cancer):

Region, Age at Diagnosis, Subsite, Stage, **Staged by MD, ERA Documented, Extension in Path Report, Histology in Path Report, Lymph Node Examination Documented, Surgical Margins Documented, Path T & N Documented, Tumor Size Documented, Surgical Path Consult**

Appendix G-2:
Example of Special Study Data Item

Ask C/NET

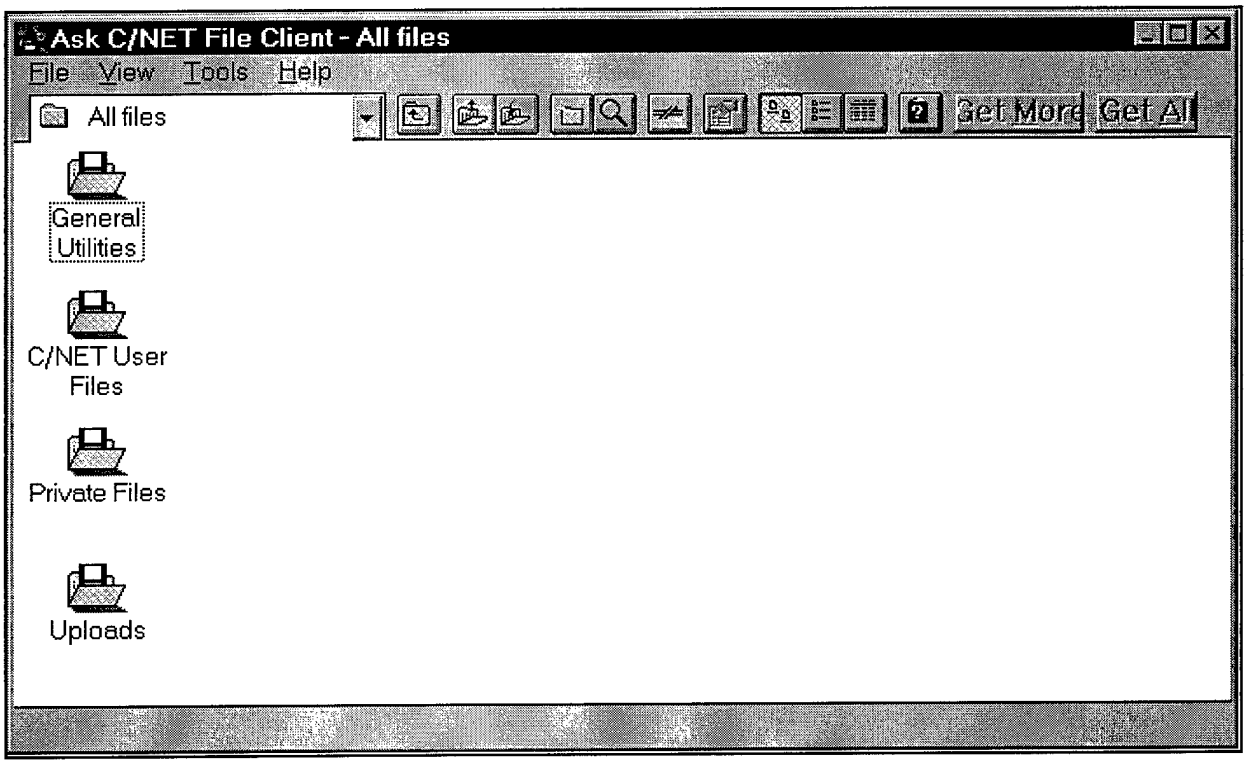
CANCER STATISTICS ONLINE

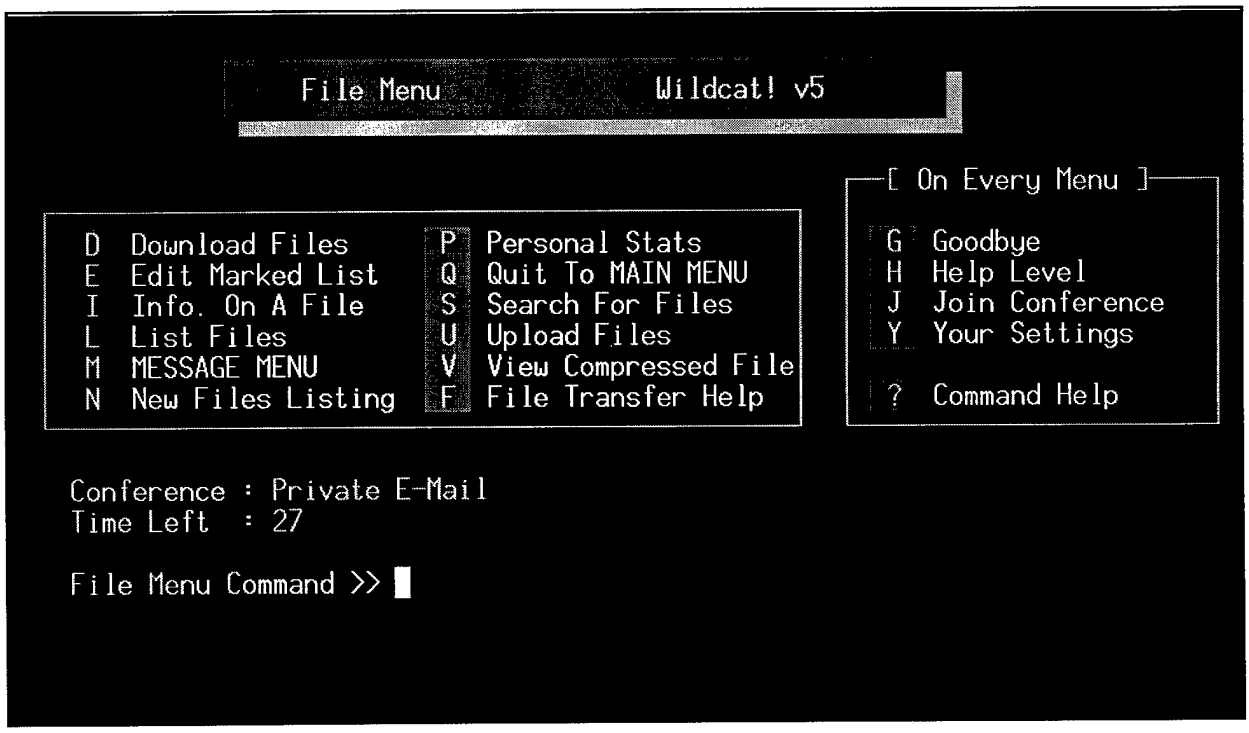
An information service of C/NET Solutions, Public Health Institute

Calif Breast Cancer, 1995, Guidelines #2 of 2

	Multichannel chemistry				
Stage	**Total**	**No**	**Yes**	**Unknown**	**Uncoded**
In situ	165	52	80	21	12
Localized	975	144	649	130	52
Regional	538	67	356	78	37
Distant	82	*******	64	*******	*******
Unstaged	102	*******	52	*******	*******
Total	1862	300	1201	250	111

Appendix H
BBS File Menu as Seen via the Internet





Appendix I
Clinical Trials Matching System

The following clinical trials are in the CTMS database:

CALGB9082: High Dose Chemotherapy with ABMT versus Standard Combination Chemotherapy for High-Risk Breast Cancer

CHNMC-96139: Chemotherapy and Stem Cell Transplantation in Patients with Stage IIIB Breast Cancer

CHNMC-PHI-08: Docetaxel in Patients with Solid Tumors and Abnormal Liver Function

CLB-9343: Tamoxifen With or Without Radiation Therapy for Node-Negative Breast Cancer in Elderly Women

CLB-9661: Interleukin-2 Plus Monoclonal Antibody Therapy in Treating Patients with Solid Tumors

CLB-9741: Chemotherapy Versus Combination Chemotherapy in Patients with Breast Cancer

CLB-9840: Phase III Randomized Study of Paclitaxel Administered as a One Hour Versus Three Hour Infusion for Advanced Breast Cancer

CWSTU1260: Study of an investigational biologic agent to treat Depletion of Blood Platelets

CWSTU736: Study of an anti-depressant medication for women with breast cancer

E-1195: Drug Resistance Inhibition in Patients with Recurrent or Metastatic Breast Cancer

E-5194: Evaluation of Breast Cancer Recurrence Rates Following Surgery for Ductal Carcinoma in Situ

E-EB193: Adjuvant Hormonal Therapy in Node-Positive, Receptor-Positive Breast Cancer

E1Y97: Identification of Genes Associated with Cancer in Patients and Siblings Who Have Cancer

E2196: Marimastat or No Further Therapy in Treating Patients with Metastatic Breast Cancer That is Responding or Stable Following Chemotherapy

ECOGE3193: Adjuvant Tamoxifen and Ovarian Ablation in Node-Negative, Receptor-Positive Breast Cancer

ELIB92MC1123: A Phase I Study of the Intratumoral Metabolism of Gemcitabine with F Nuclear Magnetic Resonance Spectroscopy

EST-2190: Standard Adjuvant Chemotherapy vs. High-Dose Combination Chemotherapy and Autologous Stem Cell Rescue in Women with Stage 2/3 Breast Cancer

LAC-USC-1B972: Radiation Therapy Plus Paclitaxel in Patients with Stage IIB or III Breast Cancer

MRS381: A F-Nuclear Magnetic Resonance Spectroscopy Study to Access 5-Fluorouracil Trapping Following A Test Bolus in Patients Treated with Continuous 5-Fluorouracil Infusion

NCCTG-N9431: Correlation of Menstrual Cycle Phase At Time of Primary Surgery with 5-Year Disease Free Survival in Women with Stage I or Stage II Breast Cancer

NCI-G98-1434: Phase I Study of CEA Peptide Pulsed Dendritic Cell Vaccine in Patients with

	Metastic or Gastrointestinal Cancer
NCI-G98-1446:	Phase II Study of Multiple Courses of High Dose Chemotherapy Supported with Filgrastim (G-CSF) and Peripheral Blood Progenitor Cells in Patients with Metastatic Breast Cancer
NCI-H94-0001:	Nutritional Intervention in Patients with Breast Cancer
NCI-H96-1053:	Combination Chemotherapy in Advanced Breast Cancer
NCI-H97-1137:	Paclitaxel Versus Paclitaxel Plus PSC 833 For Metastatic Breast Cancer
NCI-P93-0042:	Quit-Smoking Strategies for Cancer Patients
NCI-P93-0052:	Weight Loss Program for Overweight Women with Stage I/II Breast Cancer
NCI-P97-0124:	Radiation Therapy in Treating Patients With Bone Metastases From Breast or Prostate Cancer
NCI-P97-0125:	Comparison of Biafine Cream With Standard Care for Treating Skin Irritation in Women Receiving Radiation Therapy for Breast Cancer
NCI-T90-0180D:	CMF vs. High-Dose Combination Chemotherapy for Metastatic Breast Cancer
NCI-T92-0171O:	Edatrexate for Advanced Breast Cancer and other Malignancies
NCI-T95-0081H:	Hydroxyurea and Fluorouracil in Advanced Solid Tumors
NCI-T97-0061:	Vaccine Therapy in Treating Patients with Metastatic Breast or Gastrointestinal Cancer
NCI-V92-0155:	Autologous Tumor Cell Vaccine in Patients with Advanced Cancer
NCI-V93-0342:	Biologic Therapy plus High-Dose Cimetidine in Patients with Metastatic Cancer
NCI-V95-0658:	Monoclonal Antibody 520C9xH22 with G-CSF for Metastatic Cancer that Overexpresses HER2/neu
NCI-V96-0934:	Combination Chemotherapy for Metastatic or Recurrent Breast Cancer
NCI-V96-0940:	Low-Fat Diet, Fish Oil, and Soy Supplements for the Treatment of Breast Cancer
NCI-V96-0947:	Monoclonal Antibody HER2 for Metastatic Breast Cancer That Overexpresses the HER2/neu Oncogene
NCI-V96-1033:	High-Dose Combination Chemotherapy and Peripheral Stem Cell Transplantation for Advanced Cancer
NCI-V96-1042:	High-Dose Combination Chemotherapy with Peripheral Stem Cell Transplantation for Advanced Cancers
NCI-V96-1043:	Oral Thymidine for the Prevention of Mucositis in Patients with Breast Cancer and Other Malignancies Treated with Fluorouracil-Based Chemotherapy
NCI-V96-1054:	Combination Chemotherapy Followed by Peripheral Stem Cell Transplantation in High-Risk Breast Cancer
NCI-V97-1258:	Doxorubicin in Treating Patients With Locally Advanced or Metastatic Breast Cancer
NCI-V97-1314:	PhotodynamicTherapy in Treating Women With Recurrent Breast Cancer That Has Not Responded to Previous Radiation Therapy
NCI-V97-1315:	Lutetium Texaphyrin Prior to Phototherapy in Treating Women with Recurrent or Metastatic Breast Cancer Who Are Receiving Hormone Therapy
NCI-V98-1388:	Phase III Randomized Comparison Study of Letrozole Versus Tamoxifen as First-Line Therapy in Postmenopausal Women with Stage IIIB, Metastatic, or Recurrent Breast Cancer

NCI-V98-1391: Phase II Study of the Predictive Value of the Extreme Drug Resistance Assay in Patients Receiving Paclitaxel for Metastatic Breast Cancer

NSABP-B-23-QOL: Companion Study to Evaluate Quality of Life of Women With Primary Invasive Breast Cancer Enrolled in Protocol NSABP-B-23

NSABP-B-29: Octreotide, Tamoxifen, and Chemotherapy in Treating Women with Breast Cancer

NSABP-BP-57: Doxorubicin and Docetaxel in Treating Women with Locally Advanced or Metastatic Breast Cancer

NSABP-BP-58: Phase II Study of Doxorubicin, Docetaxel, and Cyclophosphamide (ATC) in Patients with Metastatic or Locally Advanced Breast Cancer

NSABP-P-1: Tamoxifen as a Preventive Agent for Invasive Breast Cancer

NSABPB21: Radiation Therapy and Tamoxifen in Very Early Stage Breast Cancer

NSABPB23: Conventional versus Intensive Adjuvant Combination Chemotherapy, with versus without Hormone Therapy, for Poor Risk Breast Cancer

NSABPB27: Docetaxel Before or After Surgery or No Docetaxel for Women with Operable Breast Cancer

NSABPB28: Addition of Paclitaxel to Adjuvant Chemotherapy in Locoregional Breast Cancer

RP56976TAX311: Paclitaxel or Docetaxel for Women with Advanced Breast Cancer

RTOG-9517: Adjuvant Isotope Therapy for Stage I/II Breast Cancer

SB-223030/010: Idoxifene Compared with Tamoxifen in Treating Postmenopausal women with Metastatic Breast Cancer

SCRF-98014: Amifostine Followed by High-Dose Chemotherapy in Treating Patients with Hematologic Cancer and Solid Tumors

SD950099: A Randomized Controlled Trial of Plant-Based Diet in Breast Cancer Recurrence

SD970569: A Phase II Study of BP1-7-KLH for Antigen-Specific Immunotherapy (ASI) of Metastatic Breast Cancer in Conjunction with Stem Cell Transplantation

SD980095: Evaluation of an RT-PCR Assay for HER2/neu as a Marker for the Presence of Circulating Breast Cancer Cells in Peripheral Blood: Determination of the Sensitivity, Specificity, Positive and Negative Predictive Value of an Assay to identify Circulating Tumor Cells

STAN833: A Phase I Trial of Doxorubicin, PacLitaxel and PSC-833

SVMCONC222: Autologous Tumor Cell Vaccine for Advanced Cancers

SVMCV890296: High-Dose Megestrol for Metastatic Breast Cancer, Endometrial Cancer, or Mesothelioma

SWOG-S9625: FAC in Patients With Locally Advanced and Inflammatory Breast Cancer

SWOG9342: Long-Term Effects of Adjuvant Chemotherapy on the Heart in Women Treated in the SWOG-8897 Clinical Trial

SWOG9623: Standard-Dose Chemotherapy versus High-Dose Chemotherapy with Stem Cell or Bone Marrow Rescue for Breast Cancer at High Risk for Relapse

THERADEX-B97-1250: Paclitaxel in Treating Women with Refractory Metastatic Breast Cancer

UCLA-HSPC-960629301: Radiolabeled Tracer in Treating Patients with Breast Cancer

UCSF8904: Intensification Therapy with Bone Marrow Rescue for Breast Cancer

UCSF957512:	Anastrozole with Tamoxifen Citrate for Advanced Breast Cancer in Postmenopausal Women
UCSF957513:	Recombinant Humanized Anti-p185 HER2 Monoclonal Antibody in Patients with HER2/neu Overexpression Who Have Relapsed Following Multiple Cytotoxic Chemotherapy Regimens for Metastatic Breast Cancer
UCSF95758:	Recombinant Humanized Anti-p185 HER2 Monoclonal Antibody for Patients Whose Metastatic Breast Cancer Progressed During Treatment on Protocol H0648g
UCSF97751:	A Multicenter Trial of CAELYX/DOXIL as Monotherapy vs. a Comparative Salvage Regimen for the Treatment of Patients with Advanced Breast Cancer Who Have Failed a Prior Taxane-Containing Regimen
UCSF97754:	An Open Label Trial to Determine Safety of Cyclophosphamide and DOXIL in Recently Diagnosed Patients with Metastatic or Recurrent Breast Cancer
UCSF97755:	A Randomized, Double Blind, Placebo Controlled Study to Assess the Feasibility, Toxicity and Efficacy (Phase I/II) of A Chinese Herbal Therapy (CHT) for Symptom Management in Women Undergoing Chemotherapy for Stage I/II Breast Cancer
UPCC-ACR-6883:	MRI to Detect Breast Tumors in Women
USBIOTMTX:	A Pilot Study of The Potential Effect of Neutrexin on the Pharmacokinetics of 5-Fluorouracil and Leucovorin in Cancer Patients
USC1B933:	Continuous 5-FU Infusion and Concomitant Radiation for Locally Advanced Breast Cancer
USC1B953:	Radiosurgery For T1 Breast Cancers: Clinical, Physical and Radiobiological Correlates
USC1B961:	Single Dose Tin Ethyl Etiopurpurin Photodynamic Therapy in Patients with Advanced Breast Cancer
USC1B963:	Intralesional Human Chorionic Gonadotropin in Metastatic Breast Cancer Skin Lesions
USC1B971:	Pilot Study of Primary Chemotherapy in T2 Breast Cancers: Biological Correlates and Pathological Response
USC1B975:	Clinical Study of the Screening of Breasts for Identification of Suspicious Tissue Using Clinical Examination and Mammography With and Without the TMI Computerized Thermal Imaging System
USCIB951:	19F-Nuclear Magnetic Resonance Spectroscopy to Evaluate 5-Fluorouracil Metabolism in Carcinoma of the Breast
VMRC6366:	Radioimmunotherapy for Advanced Cancers
VX-96-710-004:	VX-710 Plus Paclitaxel in Treating Women with Metastatic or Locally Advanced Breast Cancer that has not Responded to Paclitaxel
YALEHIC7676:	Paclitaxel and Growth Factor Prior to Peripheral Stem Cell Transplantation for Metastatic Breast, Ovarian, and Testicular Cancer

Appendix J-1
Clinical Trials Matching System

Breast Cancer Answers
New Treatment

Clinical Trials Matching System

Welcome to the Breast Cancer Answers California Clinical Trials Matching System.

A short profile will ask you a few questions about the characteristics of you and your breast cancer, including your stage of disease and your prior treatment. When you complete the profile, we will match your information to a database of current Institutional Review Board-approved clinical trials in California to see if there are any trials for which you may be eligible. Please try and be as accurate as possible so that the system can make the best matches possible.

Your answers to the profile are strictly confidential and voluntary. All of your responses will only be reported as a summary in combination with the responses from other web site users. None of the information will be used or released in any way that could identify you. Any possible identifiers, such as your name, address, and email address, will be separated from your profile responses and will not be identified in project files and reports. If there are any questions which you do not wish to answer, please feel free to skip them.

Completing this profile will benefit you by helping you learn about the clinical trials taking place in California. Increased knowledge of breast cancer treatment may lead to more scientific research into the cause, prevention, and cure of breast cancer. The primary risk to completing this profile is the slight possibility of a breach of confidentiality. Several precautions (as described above), however, will be taken to reduce this risk.

For additional information about the profile questions, you may contact us, at the Breast Cancer Answers Project, Public Health Institute. You may also contact the Public Health Institute Institutional Review Board if you have questions. They can be reached at 510-644-8200 between the hours of 9:00 a.m. and 5:00 p.m. (Pacific Time).

Go to the Profile

For best results, you should be using a frames-compatible browser such as Netscape 3.0 or Microsoft Internet Explorer 3.0.

Information for Principal Investigators

BCA Home

Breast Cancer Answers
New Treatment

Clinical Trials Matching System

Your Profile

After you complete the questionnaire below, the CTMS will match the information to its database of current clinical trials to see if there are any trials for which you may be eligible. Please try to be as accurate as you can in answering the questions so that the system can make the best match possible.

What is your age?

What stage disease were you diagnosed with?
(If you have a recurrence, please click on "Recurrent" instead of the stage.)

Don't Know
- Don't Know
- In situ
- 0
- 1
- 2
- 2A
- 2B
- 3
- 3A
- 3B
- 4
- Inflammatory
- Recurrent

Were there any positive lymph nodes?

Were there metastases to the bone?
- Yes
- No

Were there metastases to the brain or nervous system?
- Don't Know
- Yes
- No

Have you received or will you undergo surgery?
- Don't Know
- Yes
- No

Have you received or will you undergo radiation therapy?
- Don't Know
- Yes
- No

Have you received or will you undergo chemotherapy?
- Don't Know
- Yes
- No

Have you received or will you undergo hormone or endocrine therapy?
- Don't Know
- Yes
- No

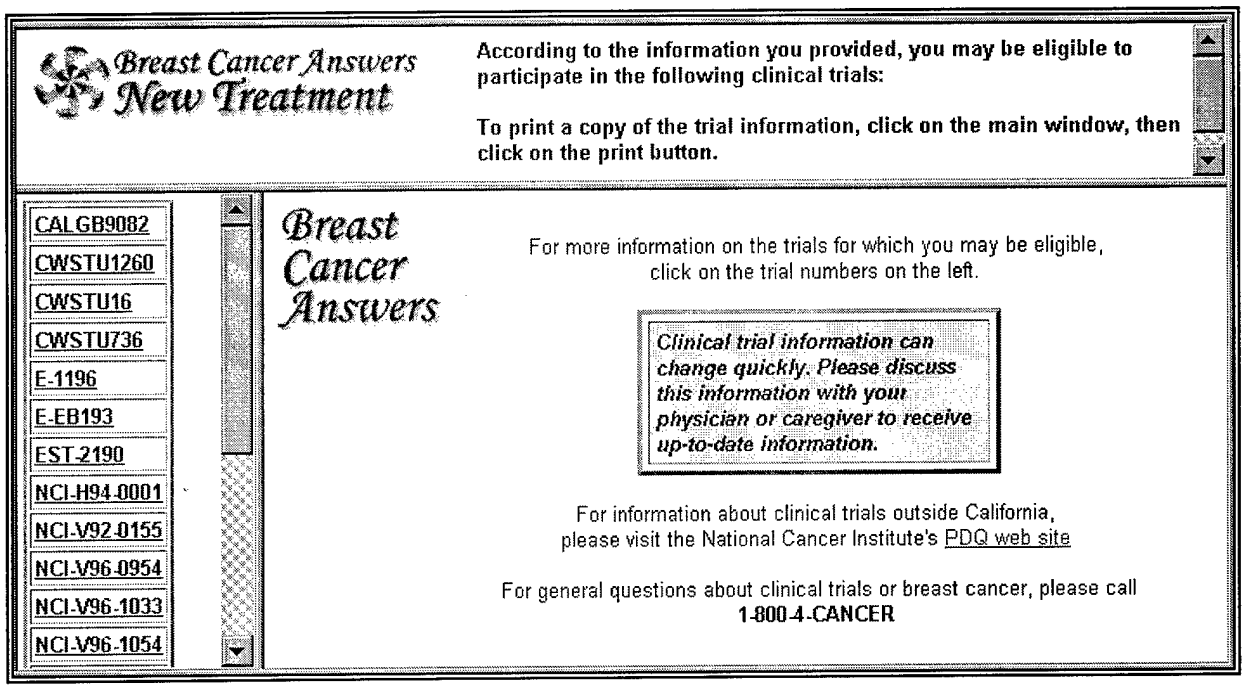
Are you pregnant?
- Don't Know
- Yes
- No

Do you have cardiac (heart) problems?
- Don't Know
- Yes
- No

Match Me | Clear

Previous | BCA Home

Appendix J-2
Example of Trial List Returned to User



Breast Cancer Answers
New Treatment

APPENDIX K

Example of User-Oriented
Clinical Trial Summary

COMPARE THE EFFICACY AND SAFETY OF ANASTROZOLE (Arimidex) AND TAMOXIFEN IN WOMEN WITH LOCALLY ADVANCED OR METASTATIC BREAST CANCER

ID Number: 957512: 10331L/0030:0025

Enrollment Period: two years

**** Trial financed by Zeneca Pharmaceuticals.***

Stage III : Locally advanced (Large tumor (>. 5cm) with positive lymph nodes or any size tumor with large lymph nodes)

Stage IV: Metastatic(Disease has spread to vital organs and or bone)

PURPOSE OF STUDY

Find out if the drug anastrozole (Arimidex) is more effective and safer than tamoxifen in treating women with Stage III and Stage IV breast cancer, who are candidates to receive hormone therapy for the advanced disease.

WHY IS THE STUDY IMPORTANT?

Women with locally advanced and metastatic breast cancer are usually treated with hormonal therapy if they are estrogen/progesterone positive. Tamoxifen is the drug most often used to suppress estrogen in trand it helps eating the cancer. However, there is some risk of developing endometrial cancer with the use of tamoxifen. Anastrozole (Arimidex) is believed to be better in suppressing estrogen and therefore may be more effective in treating breast cancer. It also does not carry the risk of endometrial cancer, therefore it may be a better treatment choice for women.

ABOUT THE STUDY

The enrollment will consist of a minimum of 426 patients (213 patients per group) in 100 different centers across North America. Participants must be candidates to receive hormone therapy as first line therapy for advanced breast cancer. Participants will be randomized to receive one of two oral regimens: 1) anastrozole1mg daily and tamoxifen citrate placebo daily or 2) tamoxifen citrate 20 mg daily and anastrozole placebo daily. Participants will not be told which dose they are receiving. Participants will be monitored for response to the therapy and for any side effects. Participants will be followed every 4 weeks for 3 months and every 12 weeks thereafter until progress is evident. Participants who withdraw from the study for any reason will be followed every 6 months.

WHO IS ELIGIBLE TO PARTICIPATE IN THIS STUDY

- Must be at least 18 years old
- Diagnosed with advanced breast cancer (Stage III or Stage IV)
- Women who are postmenopausal
- Is estrogen/progesterone positive
- Received adjuvant hormonal therapy but has an interval of at least 12 months between stopping and entering the study
- Received adjuvant chemotherapy but has an interval of 12 months between the start of chemotherapy and entering the study
- Must be willing to complete the study
- Must sign a consent form

WHO IS NOT ABLE TO PARTICIPATE

- Received previous chemotherapy for advanced breast cancer
- Is currently receiving gonadotropin-releasing hormone (GnRH) analogues
- Has life-threatening organ disease such as extensive liver, lung or brain disease
- Has less than 3 months to live
- Significantly abnormal laboratory tests as determined by the investigator
- Is currently being treated or was treated within four weeks before entering the study with another investigational drug
- People not likely to comply with study requirements

RISK FACTORS

Arimidex

- Weakness/lack of energy
- Back pain, headache, hot flushes, and nausea
- loss of appetite, constipation, diarrhea, vomiting, water retention, depression

Tamoxifen

- Hot flushes, nausea, vomiting
- Vaginal bleeding, menstrual irregularities, skin rashes
- Increased bone and tumor pain
- Endometrial cancer

STUDY PAYS FOR:*

- Investigational drugs
- Analysis of blood samples for research purposes

**** Trial financed by Zeneca Pharmaceuticals.***

WHO TO CALL FOR MORE INFORMATION

City/Area	Trial Location	Contact person	Phone
Northern CA	UCSF-Mount Zion Cancer Center	Dr. Debasish Tripathy	(415) 476-2907

See also UCSF 957512.

Date of this information: 3/15/97

This trial summary was prepared by the Breast Cancer Answers staff.
For the latest information about this trial, please contact the person listed above.

NATIONAL CANCER INSTITUTE

PDQ Clinical Trial Summary

Medroxyprogesterone Acetate for Breast Cancer Patients Taking Tamoxifen

The purpose of this randomized phase III trial is to study the effects of medroxyprogesterone acetate in the prevention of endometrial disorder in breast cancer patients taking tamoxifen. Patients will be randomized to one of two groups: one group will take tamoxifen and will receive medroxyprogesterone acetate for 14 days every 3 months for 5 years. The other group will take only tamoxifen for 5 years. To be eligible, patients must have had stage I or stage II breast cancer, be postmenopausal, and must not have endometrial disorder. Patients must not be receiving chemotherapy or estrogen replacement therapy.

Protocol IDs: SWOG-S9630, SWOG-9630

For more information call:

Ronald Keith Potkul at 708-327-3314

The PDQ summary contains a detailed, more technical trial description and list of the physicians participating in this trial.

APPENDIX M

Collaboration with CTIP

Memo of Understanding

Our meeting on 3/27/96 proved to be mutually beneficial. We decided to create separate Websites, however we agreed to collaborate in the following areas: 1) You will provide C/NET Solutions with a database of PDQ and IRB approved California clinical trials translated for consumer understanding, 2) We will provide the physical location for the CTIP Website, where you can put up whatever content you wish remotely, 3) Our Website will cite CTIP as the clinical trial data provider for our matching system, and 4) Both of our Websites will link to eachother where appropriate.

Other points of agreement include the following:

- We would like monthly updates of the CTIP clinical trial database. If no relevant trials need to be added to the database on certain months, then you will inform us of this either on the phone or in writing. Every month, contact will be made regarding database updates.
- If you want the CTIP Web site to have its own unique web domain name, such as CTIP.ORG, we need you to pay the unique name setup fee of $195.00. If you would like to share a web domain name, such as ASKCNET.ORG/CTIP, there would be no fee.
- Your contact person at C/NET Solutions regarding technical issues will be Matt Gainsborough. Matt is our programmer and will make all technical decisions regarding your Website.
- We would like to pilot this collaboration for a 6-month trial period. After six months, we will discuss future collaboration.
- Our six-month collaboration will formally begin June 1, 1996, and continue through November 30, 1996. In the event that we decide not to collaborate after 6 months, CTIP and C/NET will independently retain all rights to and control of the content, programs, data, and other property they have developed, and relinquish any interest in such property of the other party. In addition, CTIP agrees to move the CTIP Website to another location by February 1, 1997, if C/NET does not agree to continue to provide that service.

I understand the points of collaboration and agreement stated above and will abide by them.

Barry Gordon, Ph.D.
Principal Investigator
C/NET Solutions. Breast Cancer Answers Project

Deborah Collyar
Director
CTIP

What is CTIP?

CTIP stands for Clinical Trials Information Project. Our mission is to develop and implement a new standard of clinical trial information that is comprehensive, dynamic, and understandable to participants, support organizations, and healthcare professionals.

The Problem...

There is currently no single place to go for the latest information on breast cancer. We believe the last thing someone facing a cancer diagnosis should have to do is become a treatment detective. Unfortunately, people are forced to contact a variety of sources to find out what treatments are available. Then they have to decipher medical jargon into information they can use.

It is critical to improve enrollment into studies so research questions can be answered quickly and accurately. By providing the unique viewpoint of participants, we believe we can positively impact research results.

Collecting and Distributing Information

Getting information to people in a usable format is the first step to making real progress. CTIP's initial pilot will present all breast cancer clinical trials and research studies in the nine greater San Francisco bay area counties in 1997 through the following methods:

- Internet access
- Printed guide
- Fax retrieval system

Information will also be available by phone through the organizations that have established lines.

What research is included?

Trials and research studies from NCI, DoD, pharmaceutical companies, institutions, private foundations, and individual investigators will be accepted as long as they have gone through Institutional Review Board (IRB) approval or an equivalent process. All trials that interest a person who may be or is diagnosed with cancer are included:

- Alternative therapy
- Biological therapy
- Cancer Control
- Chemotherapy
- Complementary therapy
- Diagnostic
- Environmental
- Epidemiology/Survey
- Hormonal therapy
- Immunology
- Nutrition
- Plastic Surgery
- Prevention
- Prognostic
- Psycho-Social
- Quality of Life
- Radiation
- Registries
- Risk Assessment
- Supportive Care
- Surgical
- Transplants

What are CTIP's Goals?

- Humanize the entire clinical trial and research study process.
- Provide a comprehensive listing of bay area breast cancer clinical trials and research studies.
- Help researchers gain access to more physicians and participants for increased accrual.
- Develop educational programs for women and community physicians.
- Eliminate clinical trial barriers from a participant perspective.
- Expand CTIP geographically and into other types of cancer.

A Collaborative Effort

Our basic tenet is to remain neutral in the complex world of medical research and services, and to include everyone who wants to help us reach our goals. The following organizations are a part of the network that we are continuously developing:

- Advocacy Core
- Alta-Bates Medical Center
- American Cancer Society
- Bay Area Tumor Institute
- Better Health Foundation
- Biotech Companies
- Breast Cancer Action
- Breast Cancer Fund
- Sutter California Healthcare System
- California Pacific Medical Center
- Community Breast Health Project
- David Grant Medical Center
- Department of Defense
- Food & Drug Administration
- Good Samaritan Hospital
- Kaiser-Permanente
- The Susan G. Komen Breast Cancer Foundation
- Marin Oncology Associates, Inc.
- Mills-Peninsula Hospitals
- Mount Zion Cancer Center
- Mount Zion Health Systems
- John Muir Medical Center
- National Breast Cancer Research Foundation
- National Cancer Institute
- North Bay Cancer Services
- Northern California Cancer Center
- Office of Alternative Medicine
- Office for Protection from Research Risks (OPRR)
- Oncology Nursing Society
- Pharmaceutical & Biotech companies
- Public Health Institute
- Redwood Regional Oncology Center
- Santa Rosa Hematology / Oncology Group
- Soroptomists International
- Stanford Medical Center
- Steve Dunn's Cancer Guide
- Sutter Cancer Center
- UC Davis
- UCSF Cancer Center
- Veteran's Administration Centers
- Women's Cancer Resource Center
- Y-Me Bay Area Breast Cancer Network

Who is Involved in CTIP?

CTIP is a community-based venture that includes individual volunteers from patient groups, grassroots advocacy groups, women's organizations, healthcare professionals, and cancer support, service and resource organizations throughout the San Francisco bay area.

We originated from a group called the Advocacy Core. It consists of advocates and individuals who actively participate with researchers in the San Francisco SPORE program. Their goals include accelerating and enhancing research efforts for people experiencing breast cancer, and a main focus is the clinical trial process. CTIP is also affiliated with Patient Advocates In Research (PAIR), whose goal is to streamline the entire research process - from patients to Ph.D.s.

CTIP was established in March 1994, and has 501(c)(3) status through its fiscal agent, Mount Zion Health Systems. Deborah Collyar serves as Director of CTIP, with Dr. Laura Esserman as Medical Director. Jacquelyn Zimmerman is the Project Manager, and Bob Collyar is the Systems Manager.

Why We Will Succeed

CTIP, PAIR, and the Advocacy Core want to influence and enhance the quality of clinical trials and research studies. Simply put, we want to streamline the entire clinical trial process.

We realize the need to make changes at all levels. That is why we are developing relationships at national, regional, state, and local levels. Since we do not have a vested interest in the systems or institutions that exist today, we are in a unique position to offer truly objective alternatives to improve the clinical trial process for everyone involved. Our goals are ambitious, but not unattainable. They can be reached through a partnership approach that addresses all aspects of the clinical trial and research study process.

EXAMPLE OF CTIP TRIAL SUMMARY

High Dose Chemotherapy and Bone Marrow Transplant vs. Intensive Dose Chemotherapy in Stage II - IIIA Breast Cancer with ≥ 10 Nodes

CTIP RANDOMIZED

STAGE II-IIIA (regional disease)
Phase III
Financed by NCI

WHO IS IT FOR: Women 18 or older in all menopausal stages
*** This study requires hospitalization**

Purpose of this Study

Identify whether bone marrow transplant is more effective than high dose chemotherapy by comparing the side effects, as well as disease-free and overall survival of women that have Stage 2 or 3 breast cancer with 10 or more positive lymph nodes.

Official Title

Phase III Randomized Comparison of High-Dose Cyclophosphamide/Cisplatin/Carmustine (CTX/DCCP/BCNU) with Autologous Marrow and Peripheral Stem Cell Support vs. Standard-Dose CTX/CDDP/BCNU Following Adjuvant Cyclophosphamide/Doxirubicin/ Fluorouracil (CAF) in Women with Stage II/IIIA Breast Cancer with at Least 10 Positive Axillary Nodes (CALGB 9082, SWOG 9114)

About the Study

All patients receive CAF chemotherapy before they are placed in treatment □Arm□ I or II. If the woman is assigned to Arm I, she will receive High Dose chemotherapy (CTX/DCCP/BCNU), a Bone Marrow and Stem Cell transplant with G-CSF (to help stimulate her blood cells for recovery), Radiation, and Tamoxifen if her hormone receptors are ER+. If the woman is assigned to Arm II, she will receive an Intensive Dose chemotherapy (CTX, CDDP, BCNU), G-CSF (if needed), radiation, and Tamoxifen if ER+. Results will be studied by institution, disease stage, and type of ER and PR. Patients will be followed closely for 2-1/2 years, and annually after that.

☐ *Required*	♋ *Permitted*	☒ *Not Allowed*
☐ Documented insurance coverage for this trial	☐ All menopausal stages ok (before, after and during)	☐ Other cancers (cervical or non-melanoma skin cancer ok)
☐ Stage II or III breast cancer	☐ All types of ER and PR receptors	☐ Breast cancer in both breasts
☐ 10 or more positive lymph nodes		☐ Heart disease
☐ Mastectomy or lumpectomy within 8 weeks of starting CAF		☐ Consistent numbness or hearing loss
☐ Tissue around tumor free of disease		☐ Prior chemotherapy

Please see □Drugs and their Effects□ and □Glossary□ sections for more information and definitions.
Clinical trial information can change quickly. Please discuss this with medical professionals to receive up to date information.

- ☐ Normal liver, kidney, heart and lungs
- ☐ No blood viruses (HIV, Hepatitis C)
- ☐ Normal blood counts
- ☐ No identified metastasis
- ☐ Must be over 18 years old
- ☐ Radiotherapy before this treatment
- ☐ Medical or mental illnesses
- ☐ Pregnancy or breastfeeding

Who to Call for More Information

City/Area	Trial Location	Contact Person	Phone
Concord	Mount Diablo Medical Center	Michael Messer	XXXXXXXXXXXX
Daly City	Seton Medical Center	John Siebel, M.D.	XXXXXXXXXXXX
Oakland		Karen Egan	XXXXXXXXXXXX
Santa Rosa	Northern CA Cancer Center	Sue Silkworth	XXXXXXXXXXXX
Sacramento	UC Davis	Frederick Meyer, M.D.	XXXXXXXXXXXX
San Francisco	UCSF	Nick Jorgenson	XXXXXXXXXXXX

Known Side Effects

Due to the high doses of chemotherapy in both arms of this study, there can be serious side effects involving the heart, lungs, skin, stomach, liver, kidney, bladder, blood, nervous system, and immune system. Rarely, there are additional illnesses and cancers that could also occur. Approximately 2-15% of patients die as a result of this kind of treatment. Chemotherapy also causes menopause in most younger women.

Breast Cancer Answers
Art Gallery

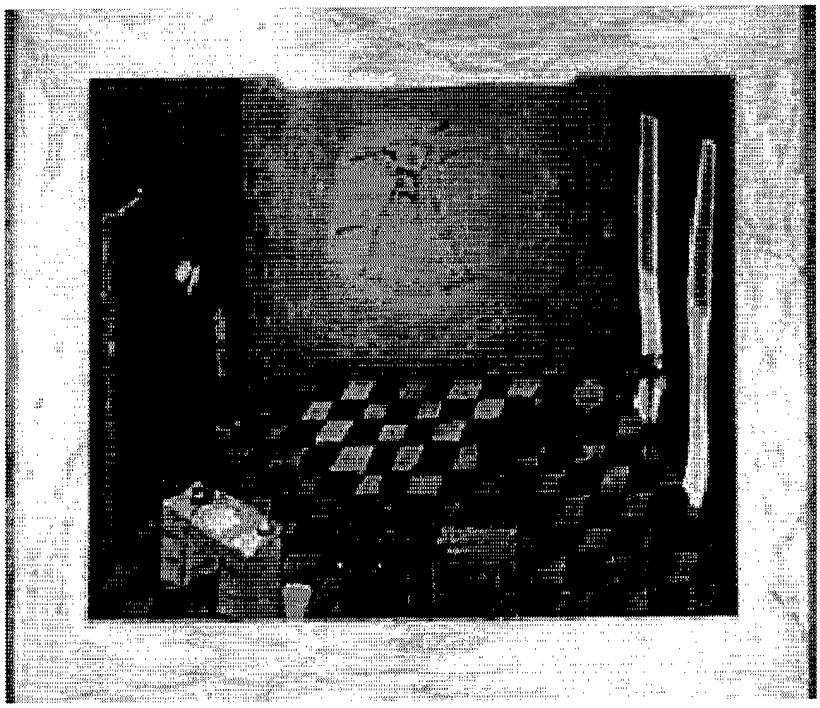
APPENDIX O

Example from Breast Cancer Answers Art Gallery

WHAT DOES THE LADY DO WITH HER RAGE?

As far back as 537 BC, the ancient and respected physician Galen noted that women who were depressed and melancholy were more apt to get breast cancer than cheerful ones. *A Psychological Study of Cancer*, it was found that grief (due to a loss) of a significant relationship was the most predisposing cause in cancer

And where does the anger go? What am I supposed to do with my anger? My emotions fluctuate between feeling sorry for myself and rage. And then there is the thought that this is all a bad dream that will go away.



© 1992, Hollis Sigler

Oil pastel on paper, 34" x 29# with painted frame

Hollis Sigler, 1992

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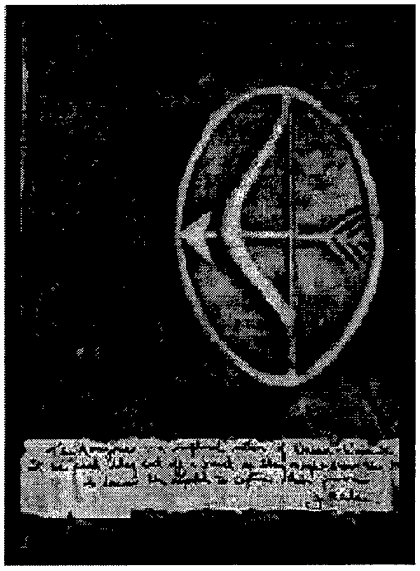
According to Greek Mythology, the Amazons were female warriors and it is said they removed their right breasts in order to draw the bow more easily. This tale gave me a sense of empowerment when I lost a breast to cancer. I wish to pass on this symbol of power to women across the nation. Welcome to the Sisterhood of Amazons!



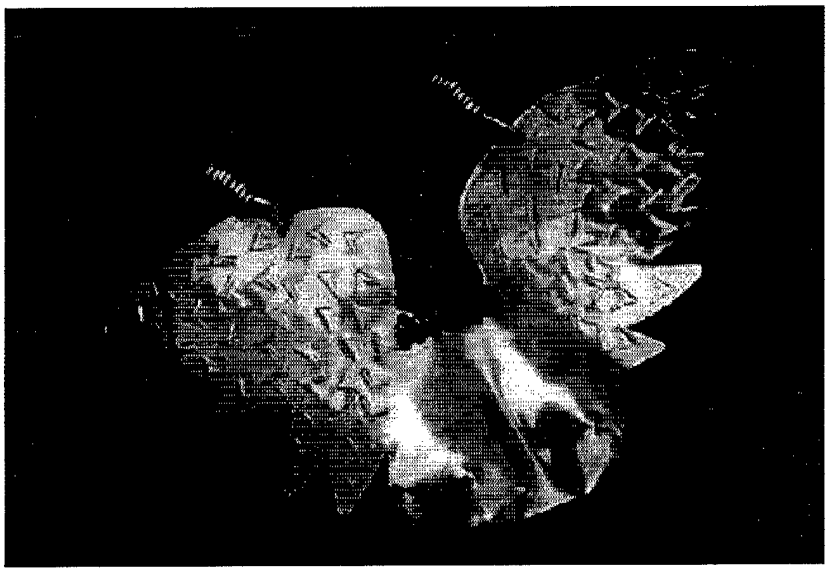
© 1993, Jo Raksin

Breast Cancer Answers
Art Gallery

Woman with Wings

The Woman With Wings Necklace is making her way into the lives of women affected by breast cancer. Many wear her to honor their womanhood or keep her as an altar piece in memory of a love lost. To me, Woman With Wings symbolizes beauty, freedom and the flight of letting go.

Woman With Wings is made in memory of my Aunt Josephine Morris, and my girlfriends Camilla Hunt and Mary Tanis.



© 1994, Jeannie Mooney

Copper and garnets, necklace, 3" x 4"

Jeannie Mooney, 1994

Artist

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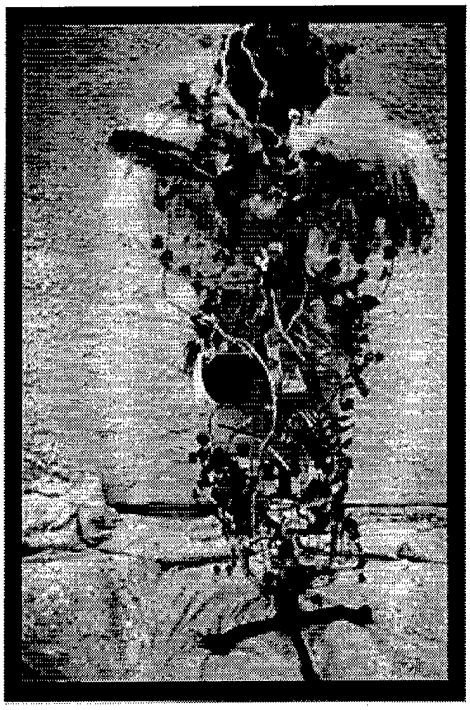
WINGS WITHIN

The entanglement of breast cancer binds me in its wire and vines. My strength lies not in the struggle simply for myself, but for my family, whose scars run as deep as mine. Their photos hide the hurt and the continual pain.

The cast of players who enter on to this stage bring breast cancer full circle. There are the doctors who stabbed me in the back with their lack of sensitivity, leaving me uninformed, denying me of my own inner healing. It is the insurance companies with their greed who have control over the situation. Through glasses, I look for many things: a cross for hope, the American society for understanding, and of course for a cure. I look for a guardian angel, except within myself, in the hopes that I can take flight above this earthly pain. My initial shame led me to veil myself as others would have me stay. It is for those others who need to lift their veil that I continue to fight for advancement in research, an increase in support groups, public awareness, and extended care programs.

© 1996, Linda Hostetter



© 1996, Linda Hostetter

These things pierce me like needles, tearing me apart at the seams. I feel we are beads strung together by a common thread, that our bodies are fragile and long to shine in the light of hope. So, with body disfigured but with heart regained, I ask for strength to look in the mirror. With renewed pride that I might be like the spring flower to those who knew me, the forget-me-nots, the words I heed. For no person can find her inner peace until they find their wings within.

This is dedicated to my Grandmother who survived breast cancer for forty years and helped me to stand like the dress model. Also: to Dr. Paul Wood (deceased) who still lives in me, to Dr. May B. Maxann for believing in me, my family and two sons, friends and all cancer patients, to my two new women doctors for listening to me, and finally, to the new hope I look forward to in Belle~Amie.

Artist

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Breast Cancer Answers
Art Gallery

Sarah Hutt

My Mother's Legacy consists of 1,000 wooden salad bowls collected from second hand stores and donated by friends. Burned into the underside of each bowl is a sentence that describes a memory I attribute to my mother. The bowls are displayed on long, narrow tables so that they can be easily handled and turned over like a page of a book to find the secret place where a memory has been left. In this way it is both a document and a process- a way to collect fragmented, disconnected and one-dimensional memories and stories and compile them together to create a more whole image of a person through the use of multiple, yet similar, objects and the repetition of turning over each bowl.

My Mother's Legacy was done in part while a resident at the MacDowell Colony and with financial support from the New England Foundation for the Arts and Massachusetts Cultural Council.

© 1995-96, Sarah Hutt

© 1995-96, Sarah Hutt

My Mother's Legacy
1,000 Wood Salad Bowls, 1995-96
Detail

Click on the thumbnails to view the works, or follow the arrow below

Sarah Hutt studied sculpture and drawing at the Boston School of the Museum of Fine Arts. She has had several one-person exhibitions in Boston including Gallery 28/New England School of Art and Design, Akin Gallery and Gallery 52. Her works have been part of many group exhibitions throughout the United States. She has received numerous awards and research grants. In 1994, Sarah received a residency fellowship to the Vermont Studio Center in Johnson, Vermont. Her work is in the collection of major museums and corporations including Boston College, Boston Museum of Fine Arts, DuPont Collection and the Fogg Museum Collection at Harvard University. Currently, Sarah works for the Mayor's Office of Cultural Affairs in Boston.

Begin →

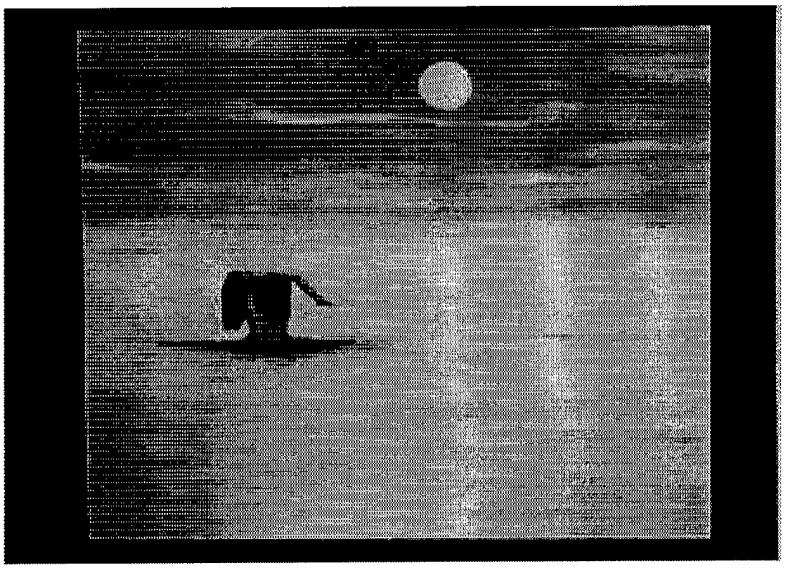
Sarah Hutt

© 1995-96, Sarah Hutt

My Mother's Legacy
1,000 Wood Salad Bowls, 1995-96

Art Gallery

The Healing



© 1989, Ethel Herst

The Healing

As I walked among the trees with the ocean nearby
a vision appeared before me.

A hand held my body from out of the earth
as the sun healed my wounded breast.

Artist

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Whatever Country

(for Talma Zoiberman of Petach Tikvah, Israel 1941-1994)

You won't share the pleasure of impatience at the post office
waiting to exchange air letters or watch the dark and light faces
of postal clerks and wonder what secrets they harbor
while hoping for what's possible in your country--any country;

no more Feldenkreis, picnics in the Galilee
to which you carry linen cloths, forks, roasts, felafel,
cooked corn, to spread elegance admist terrorism

You won't write eager to know the best seller or phone
at two a.m. to say we'll meet in Spain where we'll shop
for two Sephardic Stars of David. The last time I saw you,

I arrived from California with a crystal
which you wouldn't accept unless
I too brought back your locket to my country
You hung it around my neck

Your strong frame set against your dark hair
and full lips red with lipstick from the States
pouring forth perfect English
flavored with Hebrew gutturals

In your small flat you cooked that enormous dinner
though your arm was huge and swollen from that disease
you would not name. We laughed
with Saturday night pleasure after the Sabbath
had allowed you to rest

Today it is time to tear the roof from the post office,
and trill my tongue the way I learned
how to wail of loss in your land
this time not for holy wars

but from that disease every woman dreads in any country where she may live.

© 1994, Elaine Starkman

Artist

THREE REFLECTIONS

May

I look in the mirror. Who am I now?
In the reflection I see
a curly headed blond.

Out into the world I go
feeling the wig
around my head
wondering who notices;
feigning confidence,
trying to forget.

I look in the mirror. Who am I now?
In the reflection I see
a thin-haired old woman.

Into my world of pain I hide
aware of the hair loss,
telling others it's like
a baby's fine hair;
trying to deny the real thoughts,
the old woman thoughts.

I look in the mirror. Who am I now?
In the reflection I see
a cover-up.

Feeling my head getting cold
in the comfort of my home
I add a scarf
which offers warmth,
which hides reality.
A scarf. And yet,
another symbol.

From *Journey Unknown* (Journey Press, 1994)
© 1994, Margaret Phalor Barnhart

Sister V.

THE CURSE OF THE MOTHER.

That's how I jokingly refer to my breast cancer. I had so often been told that I was at risk. But I stood my ground. Not even the threat of cancer could push me to begetting children and being tied to family life. I was a free spirit following a unique path. It caught up with me in 1993 at age 51.

MAMMOGRAMS: THE PARTIAL TRUTH.

My mammograms had always been 'negative' so I was not terribly concerned to find a small lump and did not act on it immediately. I later came to know that it is a rather common occurance to have cancers undetected by this technology.

OFF WITH THEM!

The journey officially began with the biopsy. Minutes after the procedure the news came that it was cancer. My immediate response was not what the surgeon expected. I said that if it came to a mastectomy, both breasts would have to go. I had no intention of going through life literally out of balance. Fortunately, the surgeon was able to convince the insurance company of the prophylactic efficiency of doing two for one. A new lightness and freedom was about to come into my life. The loss....two useless sacks of fat.

While I generally have a distrust of and contempt for conventional medicine, I had no problems with the idea of a mastectomy. The procedure is superficial and non-invasive. I was also fortunate enough to find a surgeon with an open mind who let me be very involved with decisions and who supported my choices.

NEWS OF THE DAY.

The lab reports said that I had a slow growing estrogen receptive cancer. That was the good news. The not so good news is that several lymph nodes were involved.

SURVIVING THE HOSPITAL.

Hospitals are very toxic environments run by people who with the best of intentions offer drugs and food that deplete the body's resources. I consulted with almost everyone involved before the surgery. I demanded glucose free saline and refused anti-nausea drugs. (I even checked the bags in the OR!) I also passed on post-op anti-biotics. I brought most of my own food which was supplemented with specific foods prepared according to my directions. Amazingly, everyone was quite cooperative and fortunately my stay was short.

JUST DO IT.

I had to stay in the hospital for two days as there was no one home to help me. Obviously I was not 100% with the limitations of movement and tubes decorating my chest. But I had prepared the house to make things workable. I was able to cook and even managed to keep the garden watered, a must in the hot Texas summer. One week later I drove 30 some miles to the doctor. Three weeks later I was mowing

the lawn. It's a BIG lawn. Someone had to do it.

TO CHEMO OR NOT TO CHEMO.

Just as all was going so well, the prospect of chemotherapy came up. Just the word oncology makes me shudder. This is the inner sanctum of modern medical insanity and it felt like I was being thrown to the lions. I consulted not one but three high priests before finding one with whom I felt marginally comfortable to preside at the initiation. Once was enough. More than enough. Fool me once, shame on you. Fool me twice, shame on me. This treatment had nothing to do with healing. It was pure insanity. I took the fastest exit, firing the high priest and severing the cord which would have kept me bound for life to the health care industry and pharmaceutical corporations. The high priest predicted doom and gloom. But I choose to live and die on my own terms without regrets. I felt like I had dropped a thousand pound weight.

In retrospect, this seems more and more a logical decision. The statistics predict a 50% five year survival rate without chemical intervention. Chemotherapy only raises the percentage slightly. Yet 100% of women were being subjected to this near lethal treatment. It became obvious that the biggest benefit was not to the patients but to those offering it. (The procedures and tests are fiendishly expensive!)

OTHER OPTIONS.

Divorcing myself from the medical establishment did not mean there were no alternatives. Most of my life I had been collecting healing tools and this was the time to put them to the test.

I had been a vegetarian since the early 70's (though I still included dairy and other questionable foods). But by the early 80's I had become familiar with macrobiotics and concluded that it was the most balanced approach. Unfortunately, I did not stay on the diet but through reasons not under my control went back to a more refined grain diet that included dairy, sugar etc. I decided the day of my diagnosis that there was no option but to return to a strict macrobiotic regime.

I also had a background in various body therapies including acupressure and at one point practiced massage therapy. This knowledge has been very helpful in releasing adhesions and reconnecting meridians that were severed and imbalanced from the stress of surgery and chemicals. Within just a few months of the surgery, I had regained full movement of my arms. The numbness has taken longer but now has returned to about 95%. The only sensation I cannot register in that area is temperature. In time I feel that everything will return to 100%.

When I can't fix myself, I rely on others to do the work. I have an excellent chiropractor who speaks my language. I have had some acupuncture too but have not yet connected with just the right person for in depth work.

But the most important tool in my treasure chest deals not with the body but with the mind. Since 1980 I have been practicing Vipassana mediation, a Buddhist practice based in moment to moment awareness. It became such an important part of my life that I spent nearly four years in monasteries in Sri Lanka leading to ordination in 1987. This deep spirtual rooting allowed an ease in dealing with the cancer and life under the new circumstances. There were no tears, no emotional upheavals. Just an observing of changing circumstances as the mind has been trained to do.

SO FAR SO GOOD.

It is now over three years since the surgery and I'm not dead yet. In fact I seem to be in good health. The surgery seems like a distant blip in the tapestry of life. But I don't deny I'll feel some relief when I can report that five years have passed.

There is no way to know how long I will live. Or if I will die from cancer or other causes. But I stand by

the decisions I have made and accept the consequences whatever they might be. To date those choices have brought a high quality of life (actually better than before the surgery) and peace of mind. What more can be asked of life?

FROM ME TO YOU.

I hope that my story encourages other women to embark on their individual paths with self-reliance and conviction. If you feel that personal contact would be helpful to you on your journey, I can be contacted at:

Sister V.
P.O. Box 382
Cedar Creek
Texas 78612

Gayla Lacatena

In February, 1991, I was diagnosed with lobular invasive carcinoma. At the time, I was 38 years old with no family history of breast cancer and no reason to believe my life was about to change dramatically. I discovered a hard lump about the size of a small bean, just above my right breast, and I worried about it for almost three weeks before I realized it wasn't going away and I should consult a doctor. I was very apprehensive. I knew this lump might mean something was terribly wrong.

The first doctor I saw diagnosed it as a subcutaneous cycst and declared it was nothing to worry about. I was flooded with relief. She gave me a choice---leave it alone or have it surgically removed, if I was uncomfortable with it. Fortunately for me, I didn't want to have a lump on my chest, so I opted to have it removed. The biopsy report showed that it was a malignant tumor. The surgeon who removed it told me he recommended a radical mastectomy and a partial mastectomy of the unaffected breast, as a preventive measure because lobular invasive carcinoma has a higher risk of being bilateral and/or recurrent. I was shocked and numb. I left the doctor's office with very little information about the disease and no idea what I was gong to do about it. I felt like I had just been given a death sentence.

It's hard to imagine, until it happens to you, what if feels like to be told you have a malignant tumor growing inside you. I imagined the worst. I immediately pictured a black, spongy substance like mold creeping around inside me where healthy pink tissue should be instead. It was particularly hard for me to hear this diagnosis and the recommended treatment because my father and borther-in-law were having chemotherapy treatments at the time for aggressive lung and brain cancers. Their prognosis was not good and I felt mine would be just as bleak.

My husband was a blessing and the Rock of Gibralter. Without his love and support, I know I would have been an emotional wreck. He immediately sought second opinions about treatment options and helped me get through those first few weeks of anxious decision-making. We decided to learn as much as we could about the nature of my particular kind of breast cancer. We went to the library, did some research and talked it over thoroughly before deciding what was the best course of action.

It was difficult for me because the treatment options were so disfiguring. I felt my femininity was being threatened, as much as my life. My husband reassured me that he would love me with or without breasts, but I was suspicious of such an invasive procedure and the lack of guarantee that a surgeon would even be able to remove all the breast tissue. Everything I read about survival rates and treatment options for my particular situation led me to the decision to have a modified lumpectomy and radiation. I scheduled the re-excision and removal of lymph nodes in order to "stage" the cancer since the original biopsy did not have clear margins. We wanted to be sure that the tumor had been entirely removed and see if the cancer had migrated. I began radiation treatments about a month later, after the scar tissue had healed. Chemotherapy was not recommended, but the oncologist left that choice up to me. All he could do was describe my options, explain the benefits and risk involved and leave the choice up to me. Since my tumor was not larger than 1 centimeter, I chose to decline chemotherapy. The negative side-effects of chemotherapy did not hold much appeal for me and the benefit seemed slim, just a marginal 10% boost in my statistical chance or preventing recurrence.

At the time of my treatment, our daughter was a junior in high school. I tried to keep a lot of the stress of the situation away from her because I knew she had a lot going on in her young life without having to worry that her mother might be getting seriously ill. She was told about it, or course, but I tried to keep my attitude light and breezy with her so she wouldn't be

unnecessarily alarmed about it. I think it helped me to feel more positive just trying to give her the impression I was not falling apart at the seams.

Looking back, I was very fortunate, although it didn't feel like it at the time. My tumor was small, just 1 centimeter, and I had no lymph node involvement. In my case, even though it was early detection, it was "accidental detection." I had mammograms beginning at age 35 at two year intervals, but the tumor was above the area which can be filmed so it would not have been detected if it didn't present itself so close to the surface. They said lobular invasive carcinoma is usually found deep inside the breast tissue where it is more difficult to notice or feel it.

I have gradually begun to believe that I will survive this. For at least two years after my treatment, I still had doubts about cancer and read almost obsessively about recurrent cancer. My father and brother-in-law both died within two years of their cancer diagnosis and of course I read about women who die with breast cancer, but I have changed my attitude about a lot of things; about death and about health in general. I became vegetarian. I give myself a break and don't worry so much anymore about things that used to seem so important. I have a more positive outlook on life, and I don't visualize a black, insidious cancer inside me anymore. I still pay attention to my regular check-ups, but I don't obsess about them anymore.

I think I was lucky, but I was also assertive about my treatment. I didn't just let doctors tell me what to do and suffer the consequences. I was proactive and I got involved. It was the most difficult thing I've had to do, but I had a lot of support, from my husband, my daughter, my extended family and friends, even my co-workers and my boss helped to make my treatment a positive force for getting healthy again.

Realistically, I'm probably healthier today than I was ten years ago! I would encourage anyone facing the difficulty of breast cancer to reach out for the support that is available. There are a number of women's cancer resource centers and even though I didn't participate in a post-operative cancer support group, there are support groups that are right for any individual, no matter what your situation. And there are women who survive breast cancer and go on with their lives.

Gayla Lacatena

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Breast Cancer Answers
Personal Stories

Jeanne Borden

I am a divorced mother of two teenage daughters. After 20 years of marriage, one year of legal separation, and almost two years divorced, while still trying to reorient my life, I was diagnosed on March 1, 1994.

It has been a very hard year of aggressive chemotherapy and radiation treatment, which I will complete this March 10. During these last few years, I had been doing a lot of writing about my life since my divorce, and more recently I have written about my illness.

My writing is an attempt to convey how these circumstances have affected my life, but ultimately my writing hopes to reach and touch others, with or without a similar experience, with some significant parallel in their lives or at least to bring to us all some better understanding of these particular processes.

The Animal Trap

Running Scared

Personal Statement, Lauren Borden
(Jeanne's 16-year-old daughter)

Jeanne Borden

THE ANIMAL TRAP

And now I am trapped like an animal in the wild--once free to roam as if life would last forever! Unexpectedly, I have fallen into the trap, down down deep I fell, the ground resounding with my impact, my foot now caught and bloody from the heavy saw-toothed iron now clamped around it, while a boa constrictor slithers around my neck loosely now, threatening to constrict and stop my life forever whenever he chooses. Can I ever escape the trap? Will this experience ever be only a miserable memory of the past?

For now I must be content to live within the trap--I must make friends with the snake and be grateful that my life has been spared so far. For now I am indeed trapped in this prison within myself-alone to experience the horrow and despair, yet not alone to think of how I am loved, of that I am sure. I have given much, I remember now, and my heart is proud and full with the knowledge that I will not endure this experience alone because of who I am, how I have loved others, and how I am loved in return. Still I can never forget that, even when I leave the trap for good, the snake comes with me and can threaten me with his long teeth, or bite me, or squeeze the life out of me slowly any time he decides to. How can I make friends with such a monster-- but I must--we are now and will always be together.

About my giving, again I remind myself, it is returned to me, as I recall hearing the quiet gasps in my friends' voices to learn the news, as if to say: "Oh no, not you!" Now I see you all standing at the edge of the trap unable to assist my exit. I feel your warm wet teardrops fall on me from above and I too am warmed and heartened by the salted splash of tears which confirm the years and times we've shared. Yet I am sorry to bring you sadness, so sorry this truth comes from my lips, and sorrier still, that your pain is for me, but knowing you are here now induces comfort. Content with this feeling, I sink to the ground, quietly and deliberately curling around the bloody saw-toothed iron that is now my foot. So weary and dazed from the disbelief of my circumstances, I begin to depart and drift off into sweet sleep to avoid the stinging pain of reality. I smile now to know these friends all stand guard at the trap's edge waiting and hoping to help me. I feel the pull of their arms reaching out to me but I must make my own way, and for now there is nothing they can do. My eyes are closed and I give thanks for their presence in my heart and my presence in their hearts. My tears overflowing, I too cry, a soft daunting wounded animal cry, into the silence of my sleep.

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RUNNING SCARED

Submitting myself for treatment must be how a mother feels sending her son off to war-- not knowing if he will return safely to her just the way he is now, well and happy--but what will the war take out of him, from him, that cannot be replaced--will he die along the way, never to return home again to the safety of her love and care? I am not sick today, I feel mostly fine except for the ache in my heart about my illness--the emotional roller coaster of what treatment to take, where to get the treatment, and how sick it will make me feel, and of course insurance problems abound. But still I am well, I think, and I think again and realize I am very sick with a life threatening disease and I must make myself sicker with toxic medicines and I.V. drips of burning chemicals in order to really be well again. Like the soldier, what will this all take out of me that I can't replace--will I die along the way? People do die from this, but today I promise myself that I won't and that I can be cured--I must believe that for now!

Today I am told I will not have to lose my breast and for that I am grateful. Thankful, unless the treatment doesn't work and then what, and so on and so on the dominoes fall creating new patterns of existence or nonexistence and what good is a breast without a life; and on and on this goes until I could scream. I touch my skin and wonder how could I live without a part of myself. I can't make this all OK, not today anyway, but I'm told people do come to terms with this part too; but they are stronger, they are more, they always were. I have always been the cute one, soft, gentle, kind, and loving, the one people thought it easy to take advantage of and they have sometimes, because I loved them and let them and yes, I have even mistaken wolves in sheep's clothing. I don't think I have been much more than this not yet, that is until now. I still feel that one has to be much more than what I am to make it through all the varying scenarios of this illness. No, those who make it through must be more than I am. They have to be!

But whom am I fooling? We are all just people, women trapped and trying our hardest to make it OK somehow no matter how insurmountable it all seems. Oh God, today I pray I may be spared the agony of the loss of part of my physical self; that will never be OK with me, and today I am spared. Thank you, God, and THANK YOU to those who have gone before and endured the experience of all I have described and fear most! YOU have touched me with your aliveness, your wellness, your love and hope. YOU are an inspiration to me to move forward, take the medicine, move on and live and give hope to those who will follow and join our increasing ranks of diverse treatment protocols. You are all the living proof our mission can be accomplished, and today I join forces with you and we now march side by side.

So to begin my journey with you, today I accept the challenge of submitting myself for treatment to save my own life. I must submit to treatment like the soldier sacrifices his life for life. I must sacrifice my life as I know if for the ability to continue my life. I must also remember that sometimes soldiers come back from war having learned from their experiences and therefore become deeper, more compassionate, more open and caring people; always they are different people than they were before the war. The are forever changed and so are we in this process of getting well.

I hope this will be my experience--for now, I am the soldier saying goodbye to those who cannot join me in the battle, and for now I pray I can return and live on trying to make sense of this time in my life as something that not only made me better but made me a better person too. I am heartened knowing those who went before me take me by the hand into this unknown war. The passageway is lit now, we have only to follow those in the lead.

Lauren Borden
(Jeanne's 16-year-old daughter)

PERSONAL STATEMENT, LAUREN BORDEN

On the evening of March 30, 1994, during my sophomore year of high school, I came home to an uncertainty. I remember it being a cold and crisp night, I was wet and shivering because I had just finished swim practice. As I walked in the door I had a feeling of emptiness, like something was wrong. I was right, my mother was in her room sobbing. She was outraged, confused and unable to explain to my sister and me what was wrong. Dreadful and appalling thoughts were shooting through her head, as if she was about to reach the end of her life any second. She wondered what she had done wrong. Finally she was able to calmly tell us that she had been diagnosed with breast cancer.

I felt a knife jab me in the chest and my jaw fell to the floor in shock. I was terrified and convinced that my mother was about to keel over and die within the next minute. When that did not happen, I realized that the process she had to go through was almost as bad. For instance, the chemotherapy she took altered her blood chemistry in order to kill the cancer cells, it also made her hair fall out; and she felt nauseated and sick frequently from the radiation and chemotherapy treatments. Our family hoped the medicine would kill the cancer before it killed my mom. Her personality changed because of all of this and we fought constantly, it seemed impossible for me to be near her without having an argument with her. The reality that she may die made me realize I needed to be compassionate towards her. No one can imagine what it is like to be constantly afraid of losing a parent. It feels like something is slipping through your fingers and you can't get a tight grip.

Eventually I learned to understand that everyone has problems; although, it was difficult since my parents are divorced and I live with my mother and sister. For example, money has always been a challenge for our family and it became worse with this dilemma. But no matter what, it seems like we always pulled through together.

From this hardship came many good additions to my life. I had to mature almost overnight. During the stage of my life between the ages of thirteen and sixteen, I lived my life carelessly and did not realize that if I wanted to accomplish something, I would have to work for it. After the diagnosis I became more independent and interested in new things. My time was much more well spent and I became a responsible and reliable person. I spent more quality time with my family and good friends. In addition, I found out who my real friends are, the ones that were there for me during those hard times. Even though my mother had a deadly disease and we fought all the time, I still feel this was a unique experience and I would not trade it for anything.

It has been a year and a half since that cold shivering night and now that all the trauma is over, I feel relieved. My mother is healthy and moving on with her life. Harmony has returned to our household and I am just happy that my mom is alive and well.

Sandra Teeters and Deanna Leveque

A Journey

Just shortly after my 56th birthday in 1994, I discovered a lump in my left breast. During the 1980's I was an oncology nurse specialist, so upon my discovery I was well aware of what I was facing. Knowledge may empower you but for me it brought only fear.

After the biopsy it was confirmed that I had breast cancer. Life changed.

I wanted both breasts removed and no lymph dissection, unfortunately our insurance companies would not cover that kind of treatment without proper staging. We were lucky to have both private and HMO coverage so I had a second opinion. Then decided to continue treatment with the HMO, one reason being my confidence in the doctor, one of the oncology professionals I had practiced with in the 80's. Together we began the journey down the lane of survival.

We proceeded with a lumpectomy, but never succeeded in obtaining a clear margin. We also discovered one positive lymph node. The pathology report indicated three types of cancer. One being rare and progressive variety. Only 6% of patients get this type of cancer, and the prognosis was poor, stage two. Also during the staging I had a Breast Saintigraphy which is new method being done to possibly elimate staging lymph nodes. It showed a 4-5 cm mass.

We then agreed on a Chemotherapy plan of quadruple dosages of drugs for four treatments in three week increments. The high dosages were in response to the type of aggressive tumor. I cut my long shoulder length hair short in preparation of beginning chemo. However, no amount of knowledge of the disease or preparation can truly make you ready for this stage of treatment. My treatment plan was very hard. I was very ill in response to the drugs, along with the emotional trauma of losing all body hair, and the bloating due to steroids. It was an emotional roller coaster of hope and despair not only for me but my entire family. I barely survived the first two quadruple dosages, my white count plummeting dangerously low. In response we backed off and used normal dosages for the third and fourth rounds.

After a month of rest we began radiation and treatments for six weeks. Now, I started to feel more alive and yet was extremely tired. Sleep was my friend. Slowly, I regained my strength, prospective on life and my hair!

I joined a cancer survivor support group, started alternative treatment and went to see a psychologist. Cancer changes your life. The dance with death changes your priorities. Family, friends and enjoyment of life have never been so important. The race for possessions is gone. Every ache and pain send you into a panic and the fear of its return. The desire to fulfill your dreams keeps you motivated to use your time wisely. Because you know too well the time will come.

APPENDIX Q

Breast Cancer Answers

Breast Cancer Links

General Information

National Cancer Institute's CancerNet	http://cancernet.nci.nih.gov/
National Cancer Institute's PDQ Clinical Trials Search	http://cancertrials.nci.nih.gov/
Oncolink	http://www.oncolink.upenn.edu/disease/breast/
National Alliance of Breast Cancer Organizations (NABCO)	http://www.nabco.org/
American Cancer Society's Breast Cancer Network	http://www.cancer.org/bcn.html
Beth Israel Health Care System's Guide to Breast Cancer	http://www.bimc.edu:80/netscape2/breastcancer/intro.html
Breast Cancer Information Clearinghouse	http://www.nysernet.org/bcic/
The Breast Cancer Fund	http://www.breastcancerfund.org/
National Action Plan on Breast Cancer	http://www.napbc.org/
Women's Cancer Center	http://womenscancercenter.com/

Psychosocial Support

Y-ME National Breast Cancer Organization	http://www.y-me.org/
Community Breast Health Project	http://www-med.stanford.edu/CBHP/
Nancy Delaney's *One Woman's Reconstruction* (discussion group)	http://www1.mhv.net/~delaney/owr.htm
Celebrating Life (African Americans with Breast Cancer)	http://www.celebratinglife.org/
Breast Cancer in Men	http://interact.withus.com/interact/mbc/
Mothers Supporting Daughters with Breast Cancer	http://www.kentcounty.com/msdbc/htm/
Transformations (self help, support, and recovery)	http://www.transformations.com/contents.html

Personal Stories/Artwork

Breast Cancer Answers	http://www.canceranswers.org/
Art.Rage.Us	http://www.breastcancerfund.org/artrageus.html
Patricia Murray	http://web.mit.edu/afs/athena.mit.edu/user/p/a/pamurray/www/artbc.html
Breast Cancer, A Family's Story	http://www.breastcanceronline.com/
Stephanie Byram's *Cancer Destroys, Cancer Builds*	http://english-www.hss.cmu.edu/cultronix/stephanie/

Internet Guides To Breast Cancer Information

CancerGuide: Steve Dunn's Cancer Information Page	http://cancerguide.org/
Cansearch: National Coalition for Cancer Survivorship Guide to Cancer Resources	http://www.access.digex.net/~mkragen/cansearch.html#Breast Cancer
Best Web Sites on Breast Cancer	http://darkwing.uoregon.edu/~jbonine/bc_sources.html

On-line Brochures on Breast Cancer

National Cancer Institute's *WhatYou Need to Know About Breast Cancer*	http://nysernet.org/bcic/nci/general/what.need.93-1556/what.need.html
National Cancer Institute's *Breast Cancer-Understanding Treatment Options*	http://nysernet.org/bcic/nci/bcpubs/treatment/breast.html
National Cancer Institute's *Questions to Ask Your Doctor About Breast Cancer*	http://nysernet.org/bcic/nci/bcpubs/questions.html
National Cancer Institute's *After Breast Cancer: A Guide to Followup Care*	http://nysernet.org/bcic/nci/bcpubs/after-bc-90-2400/
National Cancer Institute's *What Are Clinical Trials All About?*	http://www.oncolink.upenn.edu/pdq_html/4/engl/400109.html

Hotline Numbers

National Cancer Institute's Cancer Information Service	**1-800-4-CANCER**
American Cancer Society	**1-800-ACS-2345**

E-Mail Survey E-Mail BCA Home

Appendix R
Breast Cancer Answers On-line Baseline Evaluation Survey

Thank you for visiting the Breast Cancer Answers web site. In order to evaluate our web site, we would like to know more about you and how you feel about our web site. Below is a short survey that asks you questions about (1) your opinion of the Breast Cancer Answers web site, (2) basic demographic information: your age, race, and education, and (3) your health status and behavior.

This survey is strictly confidential and voluntary. All of your responses to this survey will only be reported as a summary in combination with the responses from other web site users. Your name, address, and email address will be separated from survey responses and will not be identified in project files or reports. None of the information will be used or released in any way that would identify you. If there are any questions which you do not wish to answer, please feel free to skip them.

Completing this survey will benefit both the Breast Cancer Answers Project in evaluating this web site and the many breast cancer survivors who rely on the Internet for health information. Breast Cancer Answers staff will use the survey results to continually improve the quality of the treatment and support information provided on the web site. The primary risk to completing this survey is the slight possibility of a breach of confidentiality. Several precautions (stated in the paragraph above), however, will be taken to reduce this risk.

For additional information about the survey, you may call Susie Wertheimer, MPH, at 510-549-8915 at the Breast Cancer Answers Project, Public Health Institute. You may also contact the Public Health Institute Institutional Review Board if you have questions. They can be reached at 510-644-8200 between the hours of 9:00 am and 5:00 pm (Pacific time).

Breast Cancer Answers

1. How did you access the Breast Cancer Answers web site?

    a. At home
    b. A friend or family member's computer
    c. The library
    d. A consumer organization
    e. A hospital
    f. Other (please specify) _____

2. How did you hear about the Breast Cancer Answers web site?

    a. A health care professional
    b. A friend of family member
    c. A consumer organization

d. Another web site or web site directory
e. The library
f. The media
g. Other (please specify) _____

3. On a scale of 1 - 10, where 1 is not at all effective and 10 is very effective, please rate the overall effectiveness of the following areas of the Breast Cancer Answers web site:

   a. The California Clinical Trials Matching System

   Not at all Very

   1 2 3 4 5 6 7 8 9 10 N/A

   b. The Personal Stories

   1 2 3 4 5 6 7 8 9 10 N/A

   c. The Art Gallery

   1 2 3 4 5 6 7 8 9 10 N/A

4. On a scale to 1 - 10, where 1 is not at all likely and 10 is very likely, how likely is it that you will refer other women to the Breast Cancer Answers web site?

   Not at all Very

   1 2 3 4 5 6 7 8 9 10 N/A

5. Do you have any comments or suggestions on how we can improve the Breast Cancer Answers web site?

   _____

   _____

Demographics/Health Behavior

6. Please check any of the following items that best describe(s) you:

7. Have you ever brought up the topic of breast cancer clinical trials with a health care professional?

   a. Yes
   b. No
   c. Don't know

8. Has a health care professional ever brought up the topic of breast cancer clinical trials with you?

   a. Yes
   b. No
   c. Don't know

9. What is your sex?

   a. Male
   b. Female

10. What is your age

    _____

11. Where do you live?

    _____ City _____ State _____ Country

12. Which of the following best describe(s) you?

    a. Aleutian Eskimo
    b. American Indian
    c. Asian or Pacific Islander
    d. Black, African American
    e. White, Caucasian
    f. Hispanic
    g. Other (Please specify) _____

13. What is the highest grade or year of school you completed?

    a. Grade 1 through 8
    b. Grade 9 through 11
    c. Grade 12 or GED
    d. Junior or vocational college
    e. College 1 year to 3 years, or no degree
    f. College 4 years or more, or received degree
    g. Graduate of professional school
    h. Don't know

Appendix S
User Reactions to Breast Cancer Answers Site

Reactions to Personal Stories

[In response to Jeanne's personal story] "I'm from New York and was diagnosed with breast cancer almost a year ago. I have three children, have lost a breast, and have been through eight months of hell and back. I sure can relate to the writings. It's interesting how Jeanne's daughter was dealing with breast cancer. My older sons for the most part acted like nothing was going on. I would love to hear from you. My heart is with every woman who has gone through this. No one understands like we do."

[In response to Gayla's personal story] "Gayla, if this note reaches you, I just want you to know, I DO UNDERSTAND. Your story is my life also, just the names are changed. I have experienced three and one-half years of horror, frustration, sadness, hope, and all the other emotions which go along with being told 'you have breast cancer.'"

[In response to Gayla's personal story] "I have been diagnosed with non-invasive lobular carcinoma in situ, and my surgeon is recommending a bilateral mastectomy as a preventive measure. My chances of developing breast cancer over the next five years has increased from 20% to 50%. Your horror is familiar. I have a choice of mastectomy or continued biopsies about every six months. Monday is the day my surgeon wants a definitive decision from me. You know I'm ready for this! Thanks for sharing your story. It does help."

[In response to Gayla's personal story] "Gayla, I just finished reading your story and it is so encouraging. My tumor, like your's, was small, only .8 cm. I am just now finishing up radiation therapy, four more sessions to go and then I will have follow-up every three months. While I feel my chances are the best they could be given the circumstances, the fear of recurrence is always there. They are so many women dying of this disease. I am young, 41 with 2 children 6 and 10, and I am divorced. The fear of who will take care of my children without me around is horrifying. I would love to hear from you to see how you are doing as a five year survivor. It will give me so much encouragement."

[From Gayla] "Thanks for forwarding the messages (see above). It is comforting to know that your web site is reaching so many people! I appreciate the opportunity to respond to them. Thanks again."

"I enjoyed your web site. I am a 35 year old woman, mother of four, and was diagnosed with breast cancer almost two years ago when I was 33. I am also a registered nurse. Reading the stories on your web site was helpful. Even though this happened to me almost two years ago, I am constantly reminded of it every time I get dressed (I had a double mastectomy with reconstruction). I hope that you continue to add more personal stories to your site because it would be helpful to read about many other women dealing with this ugly disease. Thank you."

"I enjoyed reading the personal stories. I am a breast cancer survivor. I was diagnosed with

breast cancer approximately two years ago. I had a mastectomy and the TRAM procedure. I then went through six treatments of chemo. So far so good. I will say you need to have a positive attitude with this disease. It was the scariest day of my life when I found out I had cancer. But with all the support of friends and family, I made it through it. The most important thing that got me through it was prayer."

"I just wanted to let you know that I think this is a wonderful site. I'm glad you are here, and I hope my friend Susie can write a story for you."

"Thanks for being there. A close friend, who happens to be a breast pathologist at the Mayo Clinic told me about this site, actually about the art gallery. Not sure she's even aware of the rest. But she and I both loved the art gallery - very relevant and moving. I'll try to go to Michigan State this fall for the Distinct Grace exhibit. By the way, I'm a 52 year old survivor - diagnosed at 44, recurred with extensive bone mets five years later. Following 15 fractures, I started chemo. After six months treatment, I had a stem cell rescue in October 1996. Lost my left shoulder/upper arm to the cancer and have had myriad problems. Am now awaiting test results for possible recurrence - lumps on my skull. So it continues. I try to make each day count and have a good time. There are not enough hours in a day for me. Because of my meds, I sleep alot, so my days are short. Hopefully tomorrow I'll be able to look at your personal stories and maybe add mine. Thanks again."

Reactions to the Art Gallery

"When I heard about this site I dropped everything and explored. I of course had tears of joy in my eyes. It is wonderful!! You have done a terrific job. The art and poems touched me, much thanks."

"Thank you for the art gallery, it is incredible"

"Your site is most wonderful. I have been touched by the artwork in the gallery. The poems are so absolutely 'on the money' as far as feelings go. I just wanted to thank you for this site."

Reactions to the Clinical Trials Matching System

"Excellent job. This is exactly what women are looking for. This is a great service for the women in California."

"Your site is wonderful! I'd love to link to it. I ran myself through the patient profile and I was surprised at some of the selections it offered like metastatic disease. The lack of publicity about clinical trials is a source of concern for me and other women with breast cancer, so I'm glad to see your efforts to get the word out. Especially since I live in California."

"I just wanted to say how much I have enjoyed your site and obtaining data via your query system. I have a site on the web for my cancer registry contracting service and have linked your page to it hoping that other registrars will find and use your page. Thanks again for a great site."

Reaction to the Graphics

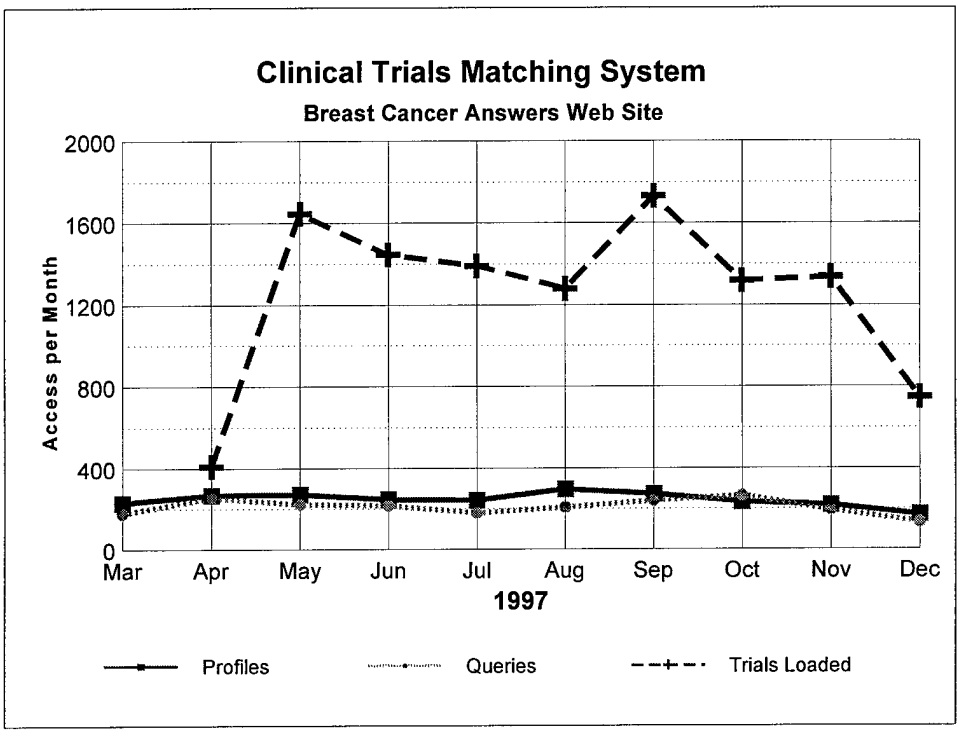
"Thanks for the informative and beautiful web site. As I was setting my site up I gained a lot of respect for designers!"

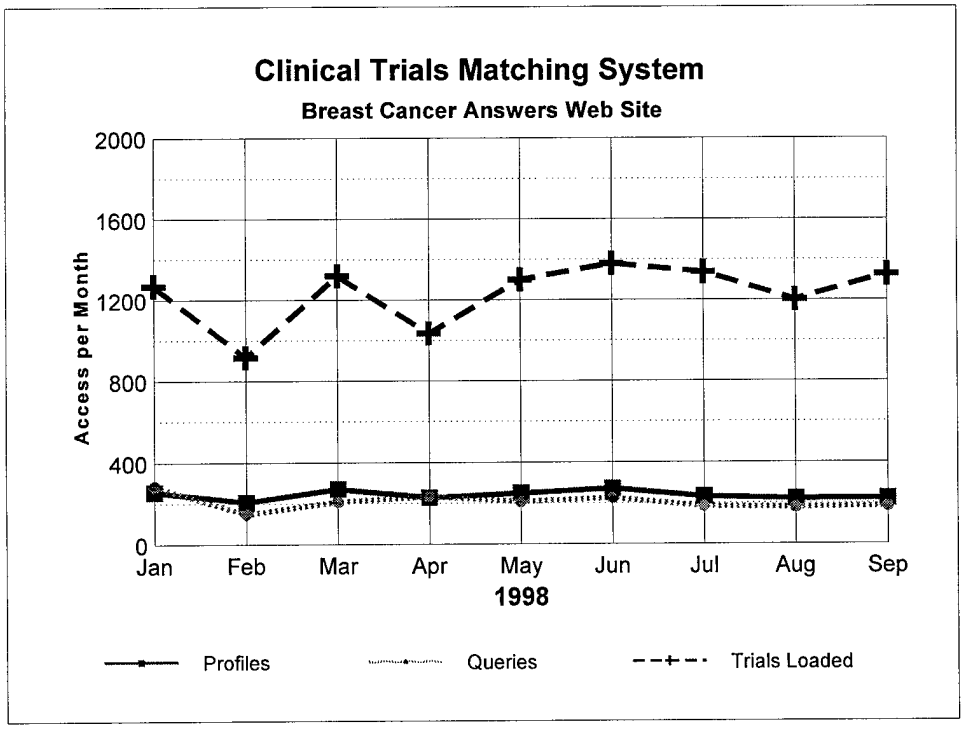
User Suggestions

"You should include information about lymphedema, especially for those women who have no idea that axillary lymph node dissection and or radiation can cause them to develop lymphedema, a condition they will have for the rest of their lives. Overall, a very nice web site."

"You need a chat room. As a survivor, I would love to talk to other women. It can be a very lonely place."

Appendix T-1
Users and Queries by Month, Clinical Trials Matching System





BCA Web Access Report

	Totals	1996 Nov-Dec	1997 Jan-Dec	1998 Jan-Sep	1998 Jan	1998 Feb	1998 Mar	1998 Apr	1998 May	1998 Jun	1998 Jul	1998 Aug	1998 Sep
Total Pages Accessed	**200,342**	**834**	**87,994**	**111,514**	10,732	10,853	13,683	13,225	13,032	12,891	12,144	12,730	12,224
Home Page	**29,777**	**155**	**12,897**	**16,725**	1,363	1,440	1,944	2,094	2,319	2,098	1,831	1,773	1,863
Gallery Home Page	**5,145**	**89**	**2,098**	**2,958**	259	287	344	368	400	369	330	313	288
All Gallery Pages	**66,561**	**500**	**24,740**	**41,321**	3,588	4,789	4,567	5,056	4,411	4,398	4,568	5,305	4,639
Stories Home Page	**8,675**	**36**	**4,167**	**4,472**	433	389	524	478	514	557	544	539	494
All Story Pages	**29,514**	**64**	**13,777**	**15,673**	1,515	1,368	1,974	1,828	1,897	1,960	1,690	1,822	1,619
Treatment Home Page	**16,194**	**40**	**9,317**	**6,837**	833	743	806	710	803	804	699	708	731
Profiles	**4,604**	**0**	**2,445**	**2,159**	256	206	271	229	249	272	232	221	223
Queries	**3,946**	**0**	**2,090**	**1,856**	284	148	208	233	208	225	185	180	185
* Trials Loaded	**22,381**	**0**	**11,301**	**11,080**	1,268	915	1,319	1,034	1,300	1,380	1,337	1,201	1,326
PI Info	**1,499**	**0**	**778**	**721**	78	77	76	64	97	104	94	69	62
List All Trials	**928**	**0**	**582**	**346**	56	37	32	22	45	37	48	27	42
CT Summaries	**2,893**	**0**	**1,731**	**1,162**	160	88	152	145	194	167	98	60	98
Links Page	**9,061**	**0**	**3,300**	**5,761**	433	392	1,429	687	636	572	570	527	515
Survey	**732**	**0**	**150**	**582**	60	51	73	73	54	60	53	69	89
Other Pages	**15,063**	**75**	**4,886**	**10,102**	1,192	852	1,165	1,354	1,209	1,182	1,032	993	1,123

* Until 4/97, we were unable to track the number of off-site clinical trial pages loaded.

Appendix U
Characteristics of Persons Using the Clinical Trials Matching System

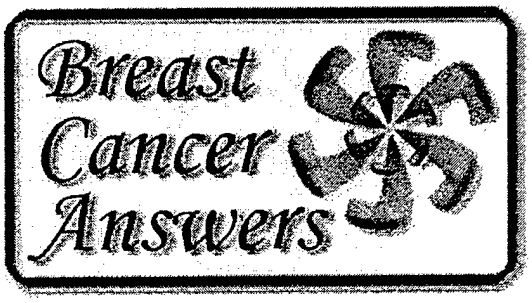
Age	
Under 20	0.5%
20-29	2.4%
30-39	17.2%
40-49	31.7%
50-59	24.8%
60-69	10.7%
70-79	3.4%
80 & up	0.7%
Not stated	8.7%

Stage	
0	4.8%
1	9.4%
2	19.1%
3	8.5%
4	8.6%
Inflammatory	2.6%
Recurrent	20.8%
Not stated	26.2%

Other characteristics	Yes	No	Not stated/Don't know
Nodes involved	46.6%	25.5%	27.8%
Bone metastases	18.6%	52.8%	28.5%
Brain metastases	3.4%	65.3%	31.3%
Surgery	71.7%	7.9%	20.4%
Radiation	50.4%	20.2%	29.4%
Chemotherapy	58.2%	14.6%	27.2%
Hormone therapy	31.3%	27.4%	42.3%
Pregnant	1.0%	86.1%	12.9%
Cardiac history	5.2%	78.0%	16.8%

The Public Health Institute is pleased to announce:

APPENDIX V



http://www.canceranswers.org/

Mission Statement

Our mission is to improve access to and awareness of breast cancer clinical trial information, support patients receiving treatment, and improve the quality of life of patients with breast cancer.

New Treatment

A Clinical Trials Matching System that matches breast cancer patients to clinical trial information in California based on stage of disease, prior treatment, and other specific disease criteria. All clinical trials are IRB-approved.

Art Gallery

A unique artwork collection from those touched by breast cancer.

Personal Stories

Stories from breast cancer survivors describing their experiences with breast cancer treatment.

Links

Other online resources for breast cancer information.

This site is hosted by C/NET Solutions

Appendix W
Bibliography

Barry A. Gordon, Ph.D., and Alan R. Houser, M.P.H. "Web-based Breast Cancer Data Query and Clinical Trial-matching Systems," poster presentation at "Era of Hope," The Department of Defense Breast Cancer Research Program Meeting, October 31-November 4, 1997, Washington, D.C.

Appendix X
Personnel

The following staff members received compensation from this contract:

Barry Gordon, Director, C/NET Solutions, Public Health Institute
Susie Wertheimer, Director, Breast Cancer Answers Project
Alan Houser, Research Scientist
Harry McCart, Administrative Assistant
Julia Posylkin, Programmer Analyst I
Linda Cline, Programmer Analyst I
Matt Gainsborough, Programmer C