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Case Series Investigation of Amyotrophic Lateral Sclerosis (ALS) Among Former Kelly Air Force Base Workers

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Concerns over a possible cluster of amyotrophic lateral sclerosis (ALS) among former workers at Kelly Air Force Base (Kelly AFB) prompted a series of scientific investigations. In an attempt to gain insight into the occupational, environmental and lifestyle exposure histories of persons with ALS (PALS), the ALS Association-South Texas Chapter and the Air Force Institute for Operational Health (AFIOH, formerly the Air Force Institute for Environment, Safety, and Occupational Health Risk Analysis, or AFIERA) collaborated on a case series investigation of persons linked to Kelly AFB who reported having ALS. In all, ninety-three PALS returned questionnaires that were included in the final analysis. Using reported prevalence figures as a comparison, PALS appeared similar to other ALS cases and U.S. adults for ALS disease course, recreational, immunization, infection/trauma, tobacco use, alcohol use, and family medical histories. Historically, these cases may have been more physically active than other ALS case series and U.S. adults, perhaps due to a "healthy worker" or "healthy soldier effect." The limitations of the study, including the highly heterogeneous population, amount of proxy report, absence of a control group, length of the questionnaire, and use of generalized comparison figures, must be considered when discussing and interpreting the results.

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Science Applications International Corporation (SAIC) was contracted to complete portions of the case series investigation. These portions included designing the Microsoft Access questionnaire database; completing and validating telephone questionnaires; validating electronic and hardcopy interviews; and questionnaire data entry.

EXECUTIVE SUMMARY

Concerns over a possible cluster of amyotrophic lateral sclerosis (ALS) among former workers at Kelly Air Force Base (Kelly AFB) prompted a series of scientific investigations. In an attempt to gain insight into the occupational, environmental and lifestyle exposure histories of persons with ALS (PALS), the ALS Association-South Texas Chapter (ALSA-STC) and the Air Force Institute for Operational Health (AFIOH) collaborated on a case series investigation of persons linked to Kelly AFB who reported having ALS.

Study questions

- In what ways are the Kelly AFB PALS similar to or different from the ALS cases described in the scientific/medical literature?
- In what ways are the Kelly AFB PALS similar to or different from the U.S. adult population in general?

Methods

- Individuals were primarily identified through self-referral to the ALSA-STC and were accepted as potential cases if they self-reported both ALS and a Kelly AFB connection.
- Data collection began in February 2002 and was completed in March 2003.
- The data collection tool covered demographic, lifestyle, medical, residential, and occupational history factors.
- Proxy reports were accepted if patients were deceased or unable to complete the questionnaire.
- Descriptive analyses were run for all sections; frequency and percent distributions were reported.

Results

- Out of 142 potential cases initially identified, 93 returned questionnaires that were ultimately included in the analysis. The results below apply to those 93 cases.
    - Cases were mainly white (82%) and male (91%).
    - Four participants (4%) reported having a blood relative with ALS, signifying a familial case of ALS.
    - Among deceased PALS, median time from symptom onset to death was 27.6 months, while median time from diagnosis to death was 14.4 months.
    - The most frequently mentioned concurrent or prior medical conditions were high blood pressure (n=22, 24%), heart disease (n=18, 19%), cancer (n=12, 13%), and arthritis (n=10, 11%).
    - 7 (8%) cases sustained an injury requiring a doctor or emergency room visit in the year prior to diagnosis.
    - 18 (19%) cases underwent surgery for reasons other than injury in the year prior to diagnosis.
    - The top five recreational activities regularly participated in by PALS included gardening (n=46, 50%), auto repair (n=31, 33%),

woodworking/carpentry (n=21, 23%), hiking/camping (n=20, 22%), and hunting (n=19, 20%).

- Six (6%) PALS had been professional or semi-professional athletes.
- Two-thirds (n=62, 67%) of PALS had smoked at least 100 cigarettes in their lifetime.
  - A quarter (n=22, 24%) of all PALS were current smokers at diagnosis.
- 80% (n=74) of cases had served in the military.
  - Over half of all cases had served in the Air Force (n=54, 58%).
  - Over half (n=53, 57%) had also served during campaigns.
  - 39% of cases were WWII veterans.
- Kelly AFB was not as principal a work location as initially expected for the 20-year work history preceding cases' diagnoses.
  - Only 40 PALS (43%) held a Kelly AFB job during this time frame.
  - The remainder either worked at (or was somehow linked with) Kelly AFB outside that time frame or did not provide enough date information to identify Kelly AFB jobs.
  - Among jobs occurring at Kelly AFB, half (n=30) were white collar, and half (n=30) were blue collar.
- Of the 79 last jobs held prior to diagnosis, including Kelly and non-Kelly employment, 53% were white collar, and 47% were blue collar.
- Professional, technical, and managerial jobs were most prevalent overall and also among job subsets—on Kelly AFB, outside Kelly AFB, and last job held.

Discussion

- Upon loose comparison to publicly available prevalence figures, PALS appeared similar to other ALS cases and the U.S. population for:
  - ALS disease courses
  - Recreational activities
  - Family medical histories
  - Immunization histories
  - Infection/trauma histories
  - Tobacco and alcohol usage histories
- Historically, these cases may have been more physically active, in general, than other ALS series and the general population.
  - Cases reported a low prevalence of obesity-related diseases.
  - Cases were also athletic; 6 of the 93 PALS had been professional or semi-professional athletes.
- The preponderance of males was a major difference between this ALS case series and those described in the literature.
  - Possible explanations for this difference include that many of the WW-II respondents were at Kelly AFB learning to fly or training for other war-time jobs, opportunities that were not available to women at the time.
- A "healthy worker" or "healthy soldier effect" might be present, as our cases reported extensive military histories.

- It is very important to keep in mind that this study was necessarily limited in several respects:
    - All information was self-reported.
    - Since no comparison group was selected for this highly heterogeneous case series, no risk assessments or causal inferences could be made.
    - At 77 pages, the survey was lengthy and time-consuming to complete.
    - Proxies, not patients, completed a majority of the questionnaires.
        - Proxy recall of exposures is generally less reliable.
        - Proxies tend to underreport more often than patients do.
    - General U.S. population prevalence figures were used for comparisons to many sections of the questionnaire.
        - U.S. figures specific to the age, gender, and ethnic background of this series were not always available.
        - The validity of these comparisons should not be overestimated.

Conclusions

- Using reported prevalence figures as a comparison, PALS appeared similar to other ALS cases and the U.S. adult population for ALS disease course, recreational, immunization, infection/trauma, tobacco use, alcohol use, and family medical histories.
- Historically, these cases may have been more physically active than other ALS case series and U.S. adults overall, perhaps due to a "healthy worker" or "healthy soldier effect."
- The limitations of the study, including the highly heterogeneous population, amount of proxy report, absence of a control group, length of the questionnaire, and use of generalized comparison figures, must be considered when discussing and interpreting the results.

CASE SERIES INVESTIGATION OF AMYOTROPHIC LATERAL SCLEROSIS (ALS) AMONG FORMER KELLY AIR FORCE BASE WORKERS

INTRODUCTION

Concerns over a possible cluster of amyotrophic lateral sclerosis (ALS) among former workers at Kelly Air Force Base (Kelly AFB) prompted a series of scientific investigations. In an attempt to gain insight into the occupational, environmental and lifestyle exposure histories of persons with ALS (PALS), the ALS Association-South Texas Chapter (ALSA-STC) and the Air Force Institute for Operational Health (AFIOH, formerly the Air Force Institute for Environment, Safety, and Occupational Health Risk Analysis, or AFIERA) collaborated on a case series investigation of persons linked to Kelly AFB who reported having ALS. The results of the case series investigation will supplement the results of a cause-specific mortality study,[1] a comprehensive literature review of potential Kelly AFB environmental contaminants,[2] and an analysis of Bexar County, TX ALS death rates,[2] all previously released. None of these studies found more ALS cases than expected among former Kelly AFB workers, or linked Kelly AFB environmental exposures with ALS cases.

History Behind Case Series Investigation

Beginning in the fall of 1995, attendees of a San Antonio-area ALS support group noticed what seemed to be a disproportionate number of former Kelly AFB workers among their ranks and wondered about a possible linkage between having worked at Kelly AFB and later developing ALS. In the spring of 1999, the ALSA-STC sent a Kelly AFB civilian official a list of PALS who had worked at Kelly AFB.

Earlier, in 1998, the AFIOH Epidemiology Services Branch reviewed the conclusions of a Phase I Agency for Toxic Substances and Disease Registry (ATSDR) report regarding Kelly AFB and subsequently recommended a general mortality study to investigate and clarify the ATSDR conclusions. In July 2000, AFIOH received the list of PALS and immediately contacted the San Antonio Metropolitan Health District (SAMHD) to initiate a collaborative evaluation.

Kelly AFB formally requested epidemiological support from AFIOH in August 2000. The following month, AFIOH began issuing frequent status reports to key officials and agencies about ongoing investigative efforts. These efforts were a precursor to the Kelly Health Issues Working Group (KHIWG), an oversight body formed to direct the epidemiologic investigation of Kelly AFB community health concerns, consisting of SAMHD, the Texas Department of Health (TDH), and AFIOH, and including participation from the ALSA-STC, the National ALS Association office (who convened a panel of independent ALS experts to support KHIWG efforts), and others. This group emphasized transparency, open communication, and data sharing; all aimed at ensuring the best possible science. In early October 2000, amidst a series of high-profile media stories covering

perceived health issues among Kelly AFB neighborhood residents and former workers, AFIOH and SAMHD completed their initial analyses of local ALS cases. Neither found evidence for a community-based cluster of ALS. However, concerns about an occupational, rather than a community-based ALS cluster prompted AFIOH and others to again advocate for a general mortality study of the Kelly AFB worker population.

AFIOH contacted the ALSA-STC in late October 2000, to initiate direct communication and collaboration between the two groups. Both parties agreed to work together on a case series investigation of the identified ALS cases. Through extensive media coverage, PALS and their families, self identified themselves to ALSA-STC bringing the final count of PALS with ties to Kelly AFB to 142. AFIOH received approval for a case series study from the Brooks AFB Institutional Review Board in November 2001 and began collecting information from the Kelly AFB PALS in March 2002.

Clinical Features of ALS

ALS is a progressive wasting disease of the central nervous system for which no cure or cause is currently known. First described clinically in the late nineteenth century and well described in the literature since, the ALS disease process involves the gradual death of both upper and lower motor neurons and results in partial to complete immobility, followed by death, of the affected person. While patients most commonly present to a practitioner with asymmetrical muscular weakness,[3, 4] initial symptoms may appear to involve upper or lower motor neurons (or both) and tend to occur in the two systems with equal frequency.[3] Symptoms indicating upper motor neuron (UMN) loss include manual dexterity problems, such as trouble with buttoning shirts, turning keys, and picking up small items, among others. More troubling UMN problems, such as hyperactive gag reflex, muscle stiffness, and emotional lability,[3, 4] usually follow. Problems in one's gait and the resulting trips and falls are symptomatic of lower motor neuron (LMN) cell death and are followed by progressive muscle wasting, twitching, and cramps.[3, 4] Notably, several functions remain undamaged by ALS, including the extraocular and bladder/bowel functions. The protective factors for these systems remain unknown.[3, 4]

The World Federation of Neurology approved the El Escorial criteria in 1990 as international standard criteria for the diagnosis of ALS.[5] Under these criteria, patients exhibiting ALS symptoms are placed into one of five categories of increasing certainty of diagnosis. Until recent years, perhaps partly due to the fatal prognosis and the lack of effective treatments for ALS, the diagnosis of ALS was usually given only after all other neuronal diseases could be ruled out.[4] However, recent strides in ALS treatment, including additional palliative therapies, have created arguments both for and against early diagnosis[6, 7] as well as discussion and debate of the effectiveness of such treatments on increasing survival times and quality of life.[8-10] Some of the symptoms that can be treated palliatively include fatigue, dysphagia (i.e., difficulty swallowing), muscle spasticity, emotional lability, sleeping problems, pain, depression, and sialorrhea (i.e., drooling).[3, 4] Death is usually the result of respiratory failure,[3, 4] and patient survival averages 1.5 to 2 years following diagnosis[10-12] and 2.5 to 3 years[4, 10-14] following the appearance of the initial symptom.

Epidemiology of ALS

The worldwide incidence of ALS is generally found to range from 1.0 to 2.5 cases per 100,000 persons,[3, 4, 10, 13-17] while the prevalence ranges from 2.5 to 5.0 cases per 100,000 persons.[13-15, 17] Historically, males are slightly more affected, with male to female ratios reported at 1.5:1 to 2.0:1.[3, 4, 17-19] However, in recent years, the gender gap in ALS incidence rates has appeared to narrow for unknown reasons.[8, 10, 13, 14] A robust association is seen between ALS and increasing age, with peak onset in the 55 to 75 age group.[3, 10, 15, 16] As for race, evidence for higher ALS incidence rates in whites compared to non-whites is inconsistent.[15, 16] Geographic differences, perhaps related to latitude, may correlate with any noted race/ethnicity differences.[15] In addition, population genetics may somehow contribute to geographic variations and also to unexplained spatial clusters of ALS cases.[8, 20] About 5-10% of ALS cases are familial, and some have been linked to an autosomal dominant gene mutation.[4, 21]

Causes of ALS

Although ALS has been observed clinically for over a century, no specific, overwhelming environmental or biochemical triggers for the disease have been identified. Numerous environmental factors have been hypothesized and investigated as possible disease triggers, but these studies have found only weak associations, if any, between these exposures and ALS.[18] In May 2001, the ATSDR responded to a request from 28th District Congressman Ciro Rodriguez of Texas to investigate the medical literature pertaining to Kelly AFB contaminants and their possible links with ALS. The ATSDR report, released in May 2002, included a focused literature review, a description of the epidemiology and clinical features of ALS, and an analysis of ALS death rates in Bexar County, TX from 1989-1998.[2] Only those papers considering associations between ALS and environmental pollutants that might be present on or around the former Kelly AFB, such as heavy metals, dietary trace elements, agricultural/non-agricultural solvents and chemicals, specific types of occupational exposures, and radiation (both ionizing and non-ionizing), were included in the ATSDR review. The report concluded that there is currently no clear, overwhelming evidence for an association between any of these environmental factors and the future development of ALS.[2]

Studies of exposures thought to be related to ALS but not included in the ATSDR report, including smoking, alcohol, and physical activity, are conflicting as well and have indicated only mild associations, if any.[22-25] Care must be taken when interpreting the results of many ALS risk factor studies, as most employ a case-control design and depend largely upon subject recall to measure past exposures. Indeed, a couple of studies based on independent, third-party characterizations of past exposures, particularly those related to occupation, found no significant associations between the studied exposures and ALS.[26, 27]

Goals of the Case Series Investigation

Unique features of this study population, compared to other ALS populations, include its scope (with participants potentially spanning over 80 years of Kelly AFB operations) and

its occupational focus. The key purpose for the case series study was to delve into the life histories of persons self-reporting both ALS and a link with Kelly AFB in an attempt to identify any potential commonalities among the participants that might warrant further study. Given the vast heterogeneity in the life histories and exposures of our study population, along with the difficulties of identifying an appropriate control population with which to compare the PALS to, our research questions were necessarily reduced to these:

- In what ways are the self-reported Kelly AFB PALS similar to or different from the ALS cases that have been described in the scientific/medical literature?
- In what ways are they similar to or different from the U.S. adult population in general?

The sections that follow include the methods and materials employed by AFIOH and ALSA-STC to answer this study question along with a descriptive summary and interpretation of the information gathered through the questionnaire.

METHODS

Study Design

A case series design was used to gather selected demographic, lifestyle, medical history, residential history, and occupational history information from participants.

Population

Individuals with ALS and any Kelly AFB history were accepted as potential cases and identified primarily through self-referral to the ALSA-STC. If the patient was unable to communicate or deceased, a surrogate for the patient was offered an opportunity to participate in the study. Additional potential cases contacted the ALSA-STC after learning of the investigation through local or national media coverage or by referral from acquaintances or physicians. Potential cases identified by the National ALS Association (ALSA-N) or by investigators working on other ALS studies were also referred to either AFIOH or ALSA-STC. Ultimately, persons with ALS who had spent any amount of time at Kelly, regardless of their status while on base, were accepted as potential cases.

Final inclusion in the case series was dependent upon receipt of a completed questionnaire and a valid informed consent document, along with a self-reported diagnosis of ALS by case or proxy. Validation of both ALS diagnosis and Kelly AFB employment history was initially planned in order to limit the analysis to only those respondents meeting the standard El Escorial criteria for ALS and having a Kelly AFB work history of at least one year. However, given the probability for incomplete case ascertainment and the resulting inability to calculate valid incidence and/or prevalence rates, the emphasis was shifted from determining rates to simply describing a unique series of ALS cases. Of note, 18 (19%) of

the 93 final participants were also included in the Kelly mortality cohort. Appendix A outlines these overlapping cases and describes further the differences between the Kelly mortality and case series study populations.

Procedures

Data collection began in February 2002 and was completed in March 2003. More time was allowed for the data collection phase than originally planned due to the length and complexity of the data collection tool, a 77-page questionnaire specifically designed for the investigation (Appendix B). The questionnaire, along with an informed consent document and a medical records release form, was sent to each patient or surrogate via postal or electronic mail, according to their preference. Participants were also given the option of completing the questionnaire over the phone. Professionally trained phone interviewers were hired through a contract vehicle (Science Applications International Corporation (SAIC)) and validated the written or electronic surveys, in addition to conducting the phone interviews, when necessary.

All questionnaire data were hand-typed into a contractor-developed (SAIC) Microsoft Access 9.0 (Microsoft Corporation) database. AFIOH staff then exported the data from MS Access files into Stata 8.0 (StataCorp LP, College Station, TX) files for analysis.

Analytical Methods

Basic descriptive analyses were run for all sections of the questionnaire. Frequency and percent distributions were created for the questionnaire responses, and for selected questions, percent distributions were adjusted for the number of non-missing responses. Time variables were reported with means, medians, and standard deviations and were usually categorized for ease of data interpretation and presentation. All age and time calculations were based on participant response, and if the participant failed to provide calendar date and/or number of years information, that particular case was excluded from the calculation in question. Whenever calendar dates were requested by month and year, day 15 of the month was used to calculate time intervals. When only year was provided, July 1st was used.

Particular attention was paid to the work history section, given the reasons for the investigation. Participant occupations were coded, post-data collection, according to the United States Department of Labor's *Dictionary of Occupational Titles* (DOT).[28] The DOT is a three-tiered coding scheme, with three-digit codes providing the most descriptive information about occupations and one-digit codes providing the least descriptive information. Based on the free-text answers provided by participants for job titles, primary duties, and company purposes in the work history section of the questionnaire, each job was assigned a three-digit DOT code. The three-digit codes were then collapsed into their corresponding one-digit and two-digit codes for ease of analysis and interpretation. The one-digit codes were further collapsed into a binary, "white collar/blue collar" coding scheme, with codes 0-2 (0/1-"Professional, Technical, Managerial;" 2-"Clerical and Sales") classified as "white collar" and codes 3-9 (3-"Service;" 4-"Agricultural, Fishery, Forestry, and Related"; 5-"Processing," 6-"Machine Trades," 7-"Benchwork," 8-"Structural Work," 9-

"Miscellaneous Occupations") classified as "blue collar," according to U.S. Census Bureau standards.[29]

Other sections requiring a considerable amount of recoding due to a large number of free-text fields included the medical history, family medical history, and recreational activities sections. Whenever possible, similar activities were grouped together in the recreational activities section. Efforts were made throughout the report to demarcate those free-text items that required a significant amount of recoding.

RESULTS

A total of 142 persons were ultimately referred to AFIOH. Of these, 120 (84%) initially agreed to participate in the case series investigation. Reasons given for non-participation included diagnosis with a motor neuron disease (MND) other than ALS and the emotional distress or fatigue that might result from completing the survey, among other reasons. Of the 120 participants who initially agreed to participate, two later requested withdrawal from the study, and 23 more were withdrawn for either non-response following multiple attempts at contact (n=22) or diagnosis with another MND (n=1). Ninety-five completed questionnaires arrived at AFIOH; 93 (65% of the original 142) of these were ultimately included in the descriptive analysis (a valid informed consent document could not be obtained for one of the participants who returned a questionnaire, and the other was diagnosed with progressive lateral sclerosis) (Figure 1). Of the 93 full surveys included in this study, 6 PALS completed their own surveys while another 14 PALS completed their surveys with the assistance of a proxy (usually a wife (9/14)). The remaining 73 surveys were completed by proxies (all were relatives, mostly wives (44/73), daughters (15/73), and sons (7/73)) on behalf of deceased PALS. Fortunately, 139 (98%) of the 142 potential cases also completed a brief, preliminary questionnaire administered by the ALSA-STC that contained several demographic, military history, and work history questions and ultimately provided a useful source of comparison data for participants vs. non-participants.

Demographics

Basic demographics of the participants are listed in Table 1. The overwhelming majority identified themselves (or were proxy-identified) as White, married, and male (n=68, 73%). The 93 participants were similar to the 49 non-participants in terms of gender, the only demographic variable available from the preliminary survey. Of those who participated in the study, 83% identified themselves as White/Caucasian, and only 13% self-identified as Hispanic/Latino. This finding is different from the prevailing demographic pattern in Bexar County, where Hispanics constituted 56% of the Bexar County population in 2003 (SAMHD Health Profiles 2003),[30]. The percentage of Hispanics in Bexar County has exceeded 50% in the past decade and has been steadily increasing throughout South Texas for several decades. This shift in demography makes it difficult to evaluate any potential ethnic influences on ALS given the extensive time period encompassed by these PALS.

Most were married (n=83, 90%) or had previously been married (n=6, 7%). The education levels attained were fairly evenly spread, with 30% (n=28) attaining a high school degree and 30% (n=28) attaining some college/vocational training or an Associate's degree. Another 28% (n=26) completed a Bachelor's degree or beyond. One-quarter (n=23) of the PALS self-reported a family income level of ≥$60,000 for the year prior to their ALS diagnosis, with the median family income level calculated at $40,000 to $49,000. However, 23% (n=21) of participants marked "Don't Know" or declined to answer the income question and were not included in this calculation.

ALS Disease Course

Characteristics of the patients' ALS disease courses are located in Table 2. Participants did not differ significantly from non-participants in ALS disease course characteristics (Table 2). The median age of participants at the time of their ALS diagnosis was 62.4 years and ranged from 28.5 to 82.8 years. Among the 72 deceased participants (as identified at the time the survey was received), the median age at death was 64.5 years and ranged from 36.3 to 85.0 years. The time span from first symptom to ALS diagnosis ranged from 0 to 10.0 years, with a median value of 0.7 years (8.4 months). The time from first symptom to death ranged from 0.4 to 12.4 years, with a median of 2.3 years (27.6 months), and the time from ALS diagnosis to death ranged from 0 to 7.8 years, with a median of 1.2 years (14.4 months). Figures 2 and 3 show survival times, in years, by age group at symptom onset. Figure 2 includes only those deceased at the time of the survey, while Figure 3 includes all participants, deceased or not, with the date of survey administration as the endpoint among those living. Generally, survival time appeared to decrease with age only through the 55-64 year age group, after which it appeared to level off. Many of the PALS' first symptoms were muscle changes, with 23% (n=21) of first symptoms occurring in the muscles of the upper extremities and 20% (n=19) of first symptoms involving the muscles of the lower extremities. All but one respondent reported that a doctor diagnosed their case. Three participants (3%) reported familial, rather than sporadic, ALS in the ALS diagnosis section of the questionnaire, although one-half of participants reported not knowing which type of ALS they (or the patients) were diagnosed with. The number of PALS reporting familial ALS was similar in the family history section of the questionnaire, where 4 (4%) PALS reported having a blood relative with ALS.

Medical History

Of the fifteen health issues of PALS specifically addressed in the questionnaire, high blood pressure was most frequently mentioned (n=22, 24%), followed by heart disease (n=18, 19%); cancer (n=12, 13%); arthritis (n=10, 11%); and asthma and reactive airway disease, stroke, and other motor neuron diseases (n=7, 8% each) (Table 3).

History of Infection or Trauma

Eight participants (9%) answered "yes" to having taken antibiotics for an illness or infection in the year prior to diagnosis, while 40% (n=37) did not know if they/the patient

had taken antibiotics during this period (Table 4). Seven (8%) PALS sustained an injury requiring a doctor or emergency room visit in the year prior to their diagnosis; four of these visits were for head injuries exclusively. In addition, eighteen participants (19%) had surgery for reasons other than injury in the year prior to diagnosis; the highest percentage of surgeries (n=5, 28%) was for musculoskeletal problems. Most of the PALS who underwent surgery (n=14, 88%) required hospital stays of >1 day.

Immunization History

Over half (n=52, 56%) of the participants had received the influenza vaccine in the year prior to diagnosis (Table 5). This is certainly expected as influenza vaccine has been recommended for older individuals for some time. Four (10%) of those who received the influenza vaccine mentioned having flu-like symptoms as a side effect. Other vaccinations reported in the year prior to diagnosis included tetanus/diphtheria (n=14, 15%), polio (n=11, 12%), diphtheria/pertussis/tetanus (n=8, 9%), MMR, (n=7, 8%), chicken pox (n=6, 7%), hepatitis A (n=2, 2%), hepatitis B (n=1, 1%), and tetanus toxoid (n=1, 1%) vaccinations. The likelihood that so many childhood vaccinations (MMR, chicken pox, and polio) were actually administered in the year prior to diagnosis in this adult population is quite low. More likely, these responses reflect a misunderstanding of the question or simple errors. Sixteen respondents marked "Yes" to PALS having received one or more of the predominantly childhood vaccinations (polio, measles/ mumps/rubella, DPT, or chicken pox) in the year prior to ALS diagnosis. Most of the "Yes" responses (n=12, 75%) were from proxy report; one report was proxy-assisted, while three were from living cases. Eight cases reportedly received more than one of the aforementioned childhood vaccinations in the year prior to diagnosis; all these were proxy or proxy-assisted accounts. In general, cases reporting these vaccinations were among the more recently diagnosed, with only 3 (19%) having expired prior to 1997. Without the medical record, however, it is difficult to determine whether these reports are accurate. It is likely they are not, as these vaccines are not generally indicated for adults.

Recreational Activities

The top five recreational activities that participants regularly participated in, either at any time in their lives or only as adults, were gardening (n=46, 50%), auto repair (n=31, 33%), woodworking/carpentry (n=21, 23%), hiking/camping (n=20, 22%), and hunting (n=19, 20%) (Table 6). Model building (n=10, 11% of "anytime" activities) replaced woodworking/carpentry as one of the top five activities participated in as both a child and an adult. Other activities not specifically inquired about in the questionnaire but written in by participants included "intense" sports (e.g. football, racquetball; n=13, 14%), fishing (n=10, 11%), golfing (n=7, 8%), and mental/thinking-type games (e.g. card games, n=7, 8%).

History of Physical Activity

Half of the PALS participated in high school athletics (n=46, 50%), with almost a third (n=27, 29%) of all PALS lettering or making the varsity team (Table 7). The top three sports lettered in during high school were baseball and football (n=11 each, 12% each among

all PALS), along with basketball (n=10, 11%). Three PALS lettered or made the varsity team at the intercollegiate level; they lettered in baseball (n=2, 2% of PALS) and tennis (n=1, 1%). Six PALS were professional or semi-professional athletes; sports were baseball (n=2, 2 % of PALS), boxing (n=2, 2%), football (n=1, 1%), and basketball (n=1, 1%). Twenty-one PALS (23%), at some time as an adult, regularly participated in a socially-sponsored sport; the top five sports mentioned by participants were bowling (n=7, 8%), basketball (n=6, 7%), softball (n=6, 7%), golf (n=5, 5%), and baseball (n=4, 4%).

History of Tobacco and Alcohol Use

PALS' cigarette smoking histories are summarized in Table 8. Two-thirds (n=62, 67%) of PALS had smoked at least 100 cigarettes in their lifetime. Almost one-quarter (n=22, 24%) of all PALS and one-third (n=22, 36%) of "ever" smokers (100+ cigarettes) were current smokers upon their ALS diagnosis; 10% (n=7) of the 72 deceased PALS were smokers at the time of their death. Among "ever" smokers, the median category for number of years smoked was 20 to 39 years (n=28, 45%). Over one-quarter of "ever" smokers (n=17, 27%) quit smoking more than 20 years prior to their diagnosis. Another 21% (n=13) of smokers quit 10 to 20 years prior to diagnosis, while an equal percentage (n=13, 21%) quit in the 10 years prior to diagnosis. However, due to incomplete data, the percentage of smokers (n=22, 36%) found to be smoking upon their diagnosis from the "Yes/No" question conflicted with the percentage of smokers (n=15, 24%) who appeared to be smoking at diagnosis based on "ever" smoker status and smoking start/end dates. Adding the four smokers who did not provide enough date information for years smoking to be calculated to the 15 PALS who were actually calculated to be smokers upon diagnosis totaled 19 smokers (31% of smokers). Because of this, we estimated that between 30% and 35% (n=19-22) of "ever" smokers were still smoking at their diagnosis. Pack-years smoking (the equivalent of one 20-cigarette pack per day for 1 year) were also calculated for the subset of smokers (n=35, 56% of "ever" smokers) not missing smoking start/end dates. Among "ever" smokers, 12 (19%) had smoked less than 15 pack-years. Another 15 (24%) smoked 15 to 29 pack-years, and 16 (26%) smoked 30 to 59 pack years. Ten (16%) smokers, or 11% of our PALS, smoked more than 60 pack-years. It is unknown how many pack-years the remaining 27 "ever" smokers actually smoked. Also, 57 (61%) PALS had lived with a smoker. Three-quarters (n=47, 76%) of smokers had lived with another smoker, while only a third (n=10, 32%) of non-smokers had ever lived with a smoker.

The alcohol usage summary of case series participants is found in Table 9. Eighty (86%) PALS had "ever" drunk an alcoholic beverage, while 13 (14%) had not. Almost one-fifth of the 72 deceased PALS (n=14, 19%) were current drinkers at the time of their death. Among drinkers not missing age and/or date of drinking information (n=52), more (n=16, 31%) fell into the 40 to 49 years of drinking category than fell into the categories of 30 to 39 years (n=14, 27%) and 20 to 29 years (n=11, 21%) of drinking. The median category for drinkers was also 40 to 49 years of drinking. Almost one-half of those who "ever" drank alcohol drank less than 1 beverage per week (n=38, 48%). Another 20% (n=16) of "ever" drinkers drank 1-4 drinks per week, while the next highest percentage (n=10, 13%) drank 8 to 14 drinks per week. The median category, among "ever" drinkers, was <1 beverage per week. Only two PALS reported drinking more than 15 drinks per week (3% of "ever"

drinkers). Overall, participants drank beer more frequently than liquor and liquor more frequently than wine.

Military Service History

Eighty percent of the cases had served in the military (n=74) (Table 10). More participants served in the Air Force (n=54, 73% of those who served) than in any other branch. Over two-thirds of the 74 PALS with military service histories (n=53, 72%) and over half of all PALS (57%) had served during campaigns. In addition, almost half of those with a service history (n=36, 49%), totaling 39% of all PALS, had served during WWII. Among those serving during WWII, 36% (n=13) served in Europe, and 28% (n=10) served in the Pacific. Seventeen percent (n=6) did not serve in either Europe or the Pacific, while 6% (n=2) served in both locations. Eight percent (n=3) did not know where the PALS had served during WWII, and 2 (6%) did not answer the question. Another 21% (n=15) of those with military histories served during the campaign in Vietnam, while 15% (n=11) served during the Korean War. Only 2 participants (3% of those with military histories) had served during the first Gulf War. Questions regarding the locations of PALS during conflicts post-WWII were not included in the questionnaire, so further location information is unavailable. In retrospect, the wording of the military service history questions could have been better, e.g., "Did you serve in the Gulf War?". The intent was to identify whether people had deployed to the conflict rather than just having been serving in the military at the time of the conflict, i.e., never left the U.S. Of those with military service histories, 19% (n=14) claimed an exposure to biological or chemical agents; the agents mentioned are located in Table 10 as well. Three participants (4% of those with a military history) claimed an exposure to ionizing or non-ionizing radiation.

Work History

The work history analysis summarized the self-reported employment of 82% (n=76) of the PALS for the 20 years leading up to their ALS diagnosis. The rest of the PALS' work histories were missing either the date of ALS diagnosis or the starting/ending dates for employment. Among all jobs held in the 20 years prior to the PALS' diagnoses, 54% (n=124) were categorized as white collar, and 46% (n=104) were categorized as blue collar (Table 11). Among those jobs reported as occurring at Kelly AFB, exactly half (n=30) were white collar, and half (n=30) were blue collar. Among non-Kelly AFB jobs, 56% (n=94) were white collar, and 44% (n=74) were blue collar. A separate analysis of only the last jobs held prior to ALS diagnosis, which totaled 79 jobs from 76 PALS (three PALS held two jobs simultaneously), indicated that 53% (n=42) of last jobs were white collar, and 47% of last jobs were blue collar. Among last jobs located at Kelly AFB, 46% (n=11) were white collar, and 54% (n=13) were blue collar. Last jobs not related to Kelly AFB were 56% (n=31) white collar and 44% (n=24) blue collar. Among all white collar last jobs, the 1-digit DOT codes for "Professional, Technical, and Managerial" applied to more jobs (n=30, 38%) than the other white collar code for "Clerical and Sales" (n=12, 15%). Among all blue-collar last jobs, the 1-digit DOT code for "Machine Trades" characterized the highest percentage (n=11, 14%), followed by "Structural Work" (n=8, 10%), "Service," (n=7, 9%) and others. The top three 2-digit DOT codes for all last jobs, regardless of collar status, were "Managers and

Officers, n.e.c." (n=11, 14%), "Mechanics and Machinery Repairers" (n=10, 13%), and "Administrative Specializations" (n=7, 9%) (Table 12). Similarly, the top three 2-digit DOT codes for overall Kelly AFB employment (n=60 jobs) were "Managers and Officers, n.e.c." (n=12, 20%), "Building and Related Service" (n=9, 15%) and "Mechanics and Machinery Repairers" (n=9, 15%).

A listing of substances (chemical, metal, and others) those workers could have come in contact with while working at any of the jobs held in the 20 years prior to their diagnosis was also included in the questionnaire; Table C1 (see Appendix C) contains a summary of these. Cleaning solvents and degreasers were the substances that PALS reported coming into contact with at the most number of jobs; they totaled 7% of all substance mentions and were found among 21% of all jobs. When examining for the total number of participants reporting a particular exposure at any time during their 20-year work history, leaded gasoline fumes were the substances most frequently reported (n=17, 22% of the 76 PALS included in the work history analysis). The most frequently reported substances among participants (vs. among total number of jobs) were similar for overall history and for Kelly-specific work history. Among those workers who reported working at Kelly in the 20 years prior to diagnosis (n=40), the most frequently contacted substance was jet fuel fumes (n=12, 30%), followed by cleaning solvents/degreaser (n=11, 28%) and aluminum (n=10, 25%). (see Appendix C)

Miscellaneous work history characteristics are located in Table 13. Seven percent (n=6) of participants saw a doctor following a chemical exposure on the job. Another 11% received an electrical shock at some time prior to their ALS diagnosis, either on or off the job. Two of the shocked patients also suffered burns; a third was knocked unconscious. As noted above, only 40 participants (43%) actually reported holding a Kelly AFB job in the 20 years prior to their diagnosis; the rest of the participants either worked at Kelly more than 20 years before their diagnosis or did not provide information indicating which years (if any) were spent working at Kelly AFB. A majority of these 40 workers were civil service employees (n=24, 63% of Kelly AFB subset). Another five (13%) were active duty military while at Kelly, and two were contractors (5%). Seven (19%) participants worked in more than one of the aforementioned capacities or in some other capacity while at Kelly AFB. The greatest percentage of these workers spent more than 20 years at Kelly AFB (n=14, 38% of subset), with a median category of 11 to 15 years working at Kelly AFB (Table 13).

Partial workplace information was available for 92 of 142 potential PALS, either from the ALS Association questionnaire or the case series questionnaire. Table C3 summarizes the 164 locations provided. One third (n=29, 32%) of the 92 potential PALS with building information cited more than one workplace during their careers at Kelly AFB. The most common responses were Bldg 171 (n=21, 23%), Bldg 375 (n=13, 14%), HQ USAF Security Service (n=10, 11%), Bldg 324 (n=7, 8%), and Bldg 43 (n=6, 7%). Statistical analysis was not possible due to the significant amount of missing and incomplete data. In many cases no building number or precise location was available and there were no building-specific population documents to verify who worked there, the duration of employment, or the type of work done at each site. The populations of these more commonly cited buildings were quite large. The administrative Bldg 171 accommodated several thousand people

workers and well over a thousand employees were housed in the large hangers, such as Bldg 375. Additionally, many individuals started their career as blue collar workers and later moved into administrative or managerial roles, which were centralized in Bldg 171. The listed workplaces cover a broad range of activities from flight line industrial shops to electronic communication areas to purely administrative offices.

Family Medical History

The medical histories of participants' blood relatives are summarized in Table 14. More participants reported having blood relatives with cancer (n=48 PALS, 52%) than having blood relatives with heart disease (n=39, 42%), high blood pressure (n=32, 34%), diabetes (n=28, 30%), arthritis (n=25, 27%), asthma (n=23, 25%), or stroke (n=22, 24%), among other diseases. As previously mentioned, four participants (4%) reported having a blood relative with ALS; two PALS had first-degree blood relatives with ALS, while two had second-degree (or more distant) relatives with ALS. Six had blood relatives with Parkinson's (7%), while 11 had blood relatives with Alzheimer's (12%). Three PALS (3%) mentioned having blood relatives with multiple sclerosis.

DISCUSSION

We compared the information provided by case series participants to characteristics of ALS cases as reported in the medical literature and also to published U.S. prevalence data, looking for similarities and differences. While comparison data for patient demographics, ALS disease course, and selected environmental factors were available from other ALS studies, we were obliged to rely on U.S. population prevalence data, such as those published in National Health Interview Survey and U.S. Census Bureau reports, when comparing characteristics such as military service histories and recreational activities. We elected to pursue a descriptive case series because there was no reasonable way to identify an appropriate control group spanning some 80 years and including the diverse backgrounds of the PALS. A case series study is used to describe a group or series of patients with a common trait or illness. As a result, no hypotheses were tested; they can only be generated as a result of our findings.

Demographics

Our ALS case series was similar in educational attainment to series from Washington State[22, 24, 27] and New England.[23, 31] While 58% of case series participants received training beyond high school, 52% of those in the Washington series and 65% of those in the New England series were educated beyond high school. As for income, our series' median self-reported family income stratum of $40,000 to $49,000 in the year prior to diagnosis was similar to the median stratum of $30,000 to $55,000 per year at 5 years prior to diagnosis for the New England series, the only other series we could find that reported income information. Given the time frame for New England incomes (roughly 1986 through 1991)

and the fact that a quarter of our PALS were diagnosed prior to July 1989, our cases might have been wealthier than the New England cases when factoring in increases in U.S. average incomes over time.

Over 90% of the 93 case series participants were male, which constituted a major difference between our cases and those described in the literature. Possible explanations for this difference include that many of the WW-II respondents were at Kelly AFB learning to fly or training for other war-time jobs, opportunities that were not available to women at the time. To account for this, U.S. population prevalence figures for males were used for most comparisons, when available. A full 90% of our cases were married, while 80% or less of the New England and Washington State cases were married. As for ethnicity, 82% of PALS described themselves as White/Caucasian, while 13% were self-described Hispanic/Latinos. Almost 95% of the Washington State and New England cases were white, and ALS incidence rates were higher for whites in Washington State. In contrast, an incidence study in Harris County, Texas, surrounding Houston, by Annegers et al.[15] found similar ALS incidence rates among White, Hispanic, and Black males. Given the heavily Hispanic ethnicity of San Antonio and prominent representation in the Kelly AFB worker population, it is possible that the proportion of Hispanics in our case series was underreported. However, our cases were predominantly white and appeared similar to other series in regards to ethnicity.

ALS Disease Course

In terms of ALS disease course characteristics, our cases were similar to those in several other series in age at symptom onset and age at diagnosis, both for measures of central tendency and in age strata. Our cases' median ages at symptom onset and diagnosis were 61.7 and 62.4, respectively. Italian studies by Chio et al.[11](mean of 62.8 years), Bettoni et al.[13](mean of 59.6 years), and Mandrioli et al.[14](mean of 63.1 years) reported similar ages at onset, while an Irish study by Traynor et al.[17](median of 64.2) reported a similar age at diagnosis. By age strata, Washington State[22, 24, 27] and New England[23, 31] recently diagnosed cases were nearly identical to ours, with median age strata of 55-64 years and 56-65 years, respectively, compared to our median age stratum at diagnosis of 55-64 years. Symptom onset also peaked and then leveled off at the 55- to 64-year age category in the Harris County, TX study.[15]

In contrast, a slightly older population with a median age at diagnosis of 66 years was reported in a study of incident cases in Rochester, MN for years 1925 through 1977.[19] The Rochester researchers commented that perhaps the age discrepancy was due to differing study methodologies, as their series was population-based and not gathered from referral centers. Patients referred to specialty centers were theorized to be younger; however, this would not necessarily explain the agreement between our case series and others reporting younger cases, as our cases were not drawn exclusively from specialty centers. Also, although Rochester incidence rates appeared to increase after 65 years of age, they were not statistically different from the 55- to 64-year age stratum. Interestingly, a follow-up paper for this series by Sorenson et al.[10] for cases diagnosed through 1998 found ALS incidence

between 1990 and 1999 peaking at a perhaps slightly younger, 60-69 year age strata, with a mean age at symptom onset of 63 years.

Survival time for our series was also similar to that reported in the literature. Fifty percent of our cases survived to 2.3 years, and 20% survived to 4.7 years after symptom onset. Likewise, Jackson[4] reported 50% survival at 3 years and 20% survival at 5 years post-symptom onset in her clinical review of ALS. Our series' mean and median survival time from symptom onset to death, at 2.3 and 3.1 years, respectively, were similar to Sorenson et al.'s[10] Rochester follow-up study (mean 3 years), Chio et al.[11](median 2.5 years), and Bettoni et al.[13](mean 2.5 years). As for survival from diagnosis, only 7% of the Washington State series survived to 5 years, according to del Aguila et al.,[12] whereas 10% of our cases survived 5 or more years after diagnosis. Sorenson et al.'s[10] series' mean survival time of 2 years after diagnosis was identical to ours; no changes in survival time after diagnosis or onset were seen among Rochester cases diagnosed after 1990 when compared to Rochester cases from previous years.[10, 19]

Medical History

Concurrent or prior medical conditions reported by our cases are interesting as well. U.S. comparison figures were based on the prevalence of selected chronic conditions by age and sex, as reported by the National Center for Health Statistics for years 1983-85,[32] 1997-98,[33] and 2001.[34] We created a companion table that lists the cases' prevalence of selected diseases, along with U.S. comparison figures for those diseases, to assist in the interpretation of the medical history results (see Table 15). For consistency, only figures specific to all U.S. adults aged 45+ and to U.S. males of similar ages were used.

Participants reported very similar percentages of kidney disease, asthma, and thyroid disease compared to self-reported disease rates by U.S. adults of similar ages in the National Health Interview Survey. Cases were also similar to, and perhaps somewhat less affected than, U.S. adults in the prevalence of heart disease and cancer. Cases were lower in the prevalence of hypertension, arthritis, and diabetes when compared to U.S. adults. In contrast, cases fell closer to the high end of U.S. figures for stroke and were notably higher than U.S. adults in the prevalence of liver disease. The higher prevalence of liver disease is interesting, as Mundt et al.[1] found elevations in mortality from liver cancer (when compared to U.S. figures) for the civilian cohort in the Kelly AFB civilian mortality study. However, mortality from liver cancer was not in excess in the Kelly mortality cohort when compared to Texas figures; this may partially explain the elevation we saw in liver disease as well.

None of our case series participants reported having epilepsy, and only one had polio (1%). Cruz et al.[22] calculated the prevalence of polio in their Washington State series at 3.4%. It is difficult to compare our figure with Cruz et al.'s, though, as their cases were diagnosed over a four-year period in the early 1990s, while our cases were diagnosed over a 30+-year time frame beginning in the 1960s. The prevalence of polio among the U.S. population at large would have changed markedly over that time period, as polio vaccination in the United States with the Salk vaccine began in the 1950s.

History of Infection or Trauma

When compared to U.S. estimates from the 1993 National Hospital Discharge Summary, injuries among case series participants were not more common. Between 8% and 12% of all U.S. adults aged 45 to 84 made an injury-related visit to a hospital emergency department in 1992-93.[35] Similarly, 8% of the case series participants suffered an injury requiring a visit to a doctor and/or an emergency department in the year prior to their diagnosis. Also, we compared 1993 overall discharge rates for surgical procedures at short-term hospitals in the U.S. to the percentage of case series participants requiring hospitalization following surgery in the year prior to their diagnosis. Overall, 9% of the U.S. population was discharged from a short-stay hospital following a surgical procedure in 1993.[36] When looking at only persons aged 65+, the percentage increased to 22%. In comparison, 15% of the case series stayed more than one night in the hospital following a surgery at some time in the year prior to their diagnosis. Overall, hospitalizations among the case series participants did not appear more prevalent than hospitalizations among the general population.

Immunization History

The immunization histories of the case series participants were also difficult to interpret, as U.S. comparison figures were scarce. Only influenza and pneumococcal vaccination figures are widely reported for U.S. adults, and only then for those who are at high risk. In 1999, 66% of all persons aged 65+ received the influenza vaccine.[37] In comparison, about 56% of the case series reported receiving the flu vaccine in the year prior to diagnosis. Between 10% and 64% of adults report side effects, such as muscle soreness, at the vaccination site,[38] which was also typical of our cases. As for other immunizations, 15% of our cases reported receiving a tetanus/diphtheria (Td) shot in the year prior to diagnosis. As boosters are recommended every 10 years, the prevalence of Td shots among the case series did not appear excessive. However, percentages of participants reporting polio (12%), diphtheria/pertussis/tetanus (9%), measles/mumps/rubella (8%), and chicken pox (7%) vaccinations in the year prior to diagnosis were unusually high, as most are childhood immunizations. We speculate that persons did not limit their responses to only vaccinations received in the year prior to diagnosis, thus inflating the percentages of cases reporting these vaccinations. There may have been other errors as well since some of the immunizations, such as chicken pox and measles/mumps/rubella, either did not exist and/or were not recommended for use in the age groups represented in this study.

Recreational Activities

Recreational activities of the case series participants also appeared remarkably similar to those of the general U.S. adult population as reported by the U.S. Census Bureau.[39] In 1992, 55% of the U.S. adult population reported participating in gardening at least once in the past 12 months. Another 34% participated in camping, hiking, and canoeing. Similarly, in 1991, 19% of the U.S. population over age 16 fished, while 7% hunted. In 1992, 12% of U.S. adults participated in photography at least once in the prior 12 months, while 8% engaged in pottery work (including ceramics, jewelry, leatherwork, and metalwork). Ten

percent of adults had painted (including drawing, sculpture, and printmaking). Also in 1992, 39% of the U.S. adult population had played sports or exercised in the past 12 months. Although the regularity with which these activities were performed by U.S. adults is not available, the percentage of U.S. adults reporting participation in these activities either equaled or surpassed the percentage of our cases reporting participation in the same activities (Table 6).

History of Physical Activity

The athletic history of the case series was similar to that reported by Longstreth et al.[24] in regards to high school sports participation; 50% of our cases participated in high school athletics, while 46% of Longstreth et al.'s cases did. Their cases were only slightly more likely to participate in high school sports than controls. As for high-level/varsity sports participation, our cases were similar to, and perhaps less active than, the cases in Scarmeas et al.[25] Thirty-eight percent of Scarmeas et al.'s cases were varsity athletes, while about 30% of our cases were. However, 26% of patients in Scarmeas et al.'s control group were also varsity athletes, which might reflect a geographic and/or subject difference in their New York City-based sample of patients with neurologic diseases compared with our cases. Our cases' adult participation in socially-sponsored sports also appeared similar to, or perhaps slightly less than, physical activity participation among U.S. adults, as 23% of our cases reporting regular participation in a socially sponsored sport. About 25% of adults aged 18+ regularly participated in a medium-high level of physical activity in 2000, while 19% participated in regular, high-level activities.[40] Most striking, though, among the physical activity histories of our cases was the percentage that had participated in professional or semi-professional athletics. Scarmeas et al.[25] actually found associations between ALS, being slim, and performing in athletics at a high level. Six (7%) of our case series participants had participated in professional or semi-professional sports, while only 0.6% of Longstreth et al.'s ALS cases were ever employed as professional athletes. Our cases participated in baseball (n=2), boxing (n=2), football (n=1), and basketball (n=1) as professionals or semi-professionals; any commonalities among these cases or these sports are unclear. Still, it seems reasonable that people who compete as paid athletes experience more physical trauma (albeit at differing levels of severity depending on the sport, number of injuries, number of years played, and other factors) for longer periods of their lives compared to recreational athletes or the average American who rarely participates in strenuous exercise.

History of Tobacco and Alcohol Use

Tobacco usage histories among our cases were somewhat similar to those described for Kamel et al.'s[23] New England-based series. Though Kamel et al. associated smoking with an increased risk of ALS, they found no dose-response relationships between ALS and number of years or number of cigarettes smoked. Forty-six percent of our cases had smoked 20+ years, compared to 44% of their cases. Twenty-seven percent of Kamel et al.'s cases smoked 31+ pack-years, while only 17% of our cases had (though 15% of our smokers were missing the information necessary for the pack-year calculation). Additionally, the percent of "ever" smokers in our case series (67%) was similar to, if not lower than, theirs (71%), especially considering the criteria used by Kamel et al. to define one as an "ever" smoker—

which was smoking "at least one cigarette per day for a year or more." Ours needed only to have smoked 100+ cigarettes in their lifetime to be considered an "ever" smoker. Though more of our cases were self-reported smokers at their diagnoses (24%) than cases in Kamel et al. (15%), it appears that Kamel and colleagues reported smoking status at the actual time of interview, not at diagnosis.[23] Many of their cases may have already stopped smoking by the time of the interview, as interviews were carried out sometime within the two years following diagnosis with ALS.

Equal proportions of our cases and the Washington State cases (33%)[12, 22, 24, 27] were "never smokers." Similarly, in 1997-1998, 35% of U.S. men aged 45-64 were "never smokers."[41] The prevalence of current smoking (24%) among our cases was also similar to figures reported for U.S. males of roughly the same age; between 25% and 33% of all men aged 45-64 were current smokers in 1990-1991, while an even greater percentage (32% to 36%) of U.S. men of these ages were current smokers in 1983 and 1985.[42] Current smoking among our cases was also similar to the Washington State series, as 29% of their cases were current smokers at interviews held an average of 5 months after diagnosis.[12, 22] From our descriptive analyses, then, smoking patterns among our PALS did not seem to differ markedly from the U.S. adult male population or from Kamel et al.'s ALS series.[23] However, smoking cannot be eliminated as a risk factor for ALS; more research into this area is required before a definitive answer can be reached.

For alcohol, a larger percentage of our cases were "never drinkers" (14%) than those in Kamel et al. (5%).[23] Among U.S. men in 2001, 22% of 45-64 year olds and 23% of 65+ year olds were current or former "infrequent drinkers" (<12 drinks per *year*).[34] Among case series participants, 41% might be considered "infrequent" drinkers (<1 or no drinks per *week*). Also, while approximately 40% of case series participants could probably be considered "regular" drinkers (>=1 drink per *week*), between 59% and 67% of U.S. men aged 45+ in 2001 were current or former "regular" drinkers (>12 drinks per *year*).[34] It is difficult to compare these figures, though, as weekly drinking totals were requested from the case series, while only yearly totals were available from the NHIS report.[34] Though case series participants might initially appear to be somewhat lighter drinkers than U.S. males at large, the risk for misclassification among the case series participants into the "regular" and "infrequent" drinker categories was high.

Military Service History

It is difficult to compare the military service history of our case series to that of U.S. males in general, as our case series includes PALS diagnosed over almost four decades, beginning in 1965. U.S. veteran demographics have shifted dramatically over that period of time. Even so, the military history of the case series does not seem atypical when compared to that of the overall U.S. population of aging males. A large percentage (80%) of PALS reported having a military service history. This high percentage is not unusual given that people with military experience are/were more likely to apply for positions at military bases after separating or retiring from military service. There are also government civil service hiring rules that provide additional weight to such applications, making them more likely to get hired. Additionally, San Antonio is a city where there is a high percentage of military

retirees because of the favorable cost of living, climate, and ready access to military regional medical centers. Fifty-seven percent of our PALS had served during campaigns; in 1990, 55% of the U.S. males aged 65+ and 28% of U.S. males aged 75+ had served in campaigns.[43] More recent figures projected that 63% of men aged 65+ would be veterans in 2000; however, in line with the dramatic shifts that occur as veteran cohorts age, this figure was expected to fall to 49% by 2010 and to 33% by 2020.[43] By 2000, Vietnam vets were most prevalent (32%), followed by WWII (22%) and Korean War (15%) vets.[44] In contrast, a full 68% of our case series veterans were WWII vets, followed by Vietnam (28%) and Korean (21%) vets. So while the percentage of overall PALS who were veterans (57%) appeared to be in line with U.S. estimates in 1990, it appears that a proportionately higher percentage of our vets were WWII veterans. Given the demographics of our series and the time frame over which our cases were diagnosed, though, the large percentage of WWII vets is not particularly alarming. Of note, only two case series vets (4%) had served during the first Gulf War. These patients served at different times and in different job capacities; no positive radiation exposures, chemical exposures, injuries, surgeries or electrical shocks were mentioned for either case.

Indeed, a debate concerning former military service and ALS continues as two papers published in 2003 found increased ALS incidence among Gulf War veterans.[45,46] Haley[45] reported increases in ALS among Gulf War veterans under age 45 between 1991 and 1998, but the study was not limited to veterans who actually deployed to the Gulf region. A companion study by Horner et al.[46] reported greater risks of ALS among Gulf War veterans who deployed to the Gulf Region over those who did not. However, Rose[47] and Armon[48] pointed out potential methodologic flaws in these studies, including problems in underreporting, both among non-deployed members and in national mortality statistics, and also a lack of convincing follow-up data concerning mortality and age-specific incidence rates. Interestingly, a recent report by Weisskopf et al.[49] found that U.S. males with any military service history (prior to the Gulf War) are 60 percent more likely to develop ALS than U.S. males without a military service history. The apparent preponderance of veterans in our series might somehow be associated with this phenomenon; however, there is no way to tell from our study. In any case, more years of data will be required to determine if there is indeed increased incidence of ALS among U.S. vets, and if so, what might have triggered these increases.

Work History

The remarkable similarities in the distribution of white- and blue-collar employment, both for Kelly and non-Kelly AFB overall and last jobs held, on the surface would suggest that no specific job types were directly related to future development of ALS in this series of cases. When limiting the analysis to only blue-collar last jobs, mechanics and machinery repairers (all "Machine Trades") held 27% and electrical or electrical equipment assemblers, repairers, and installers (all "Structural Work") held 16% of these last jobs. For blue-collar jobs overall, 23% were considered mechanic and machinery repair jobs, while 16% were electrical or equipment assembly, repair, and installation jobs. Given Kelly's historical mission as an aircraft maintenance depot, though, the percentages of our cases holding mechanical and electrical jobs are not surprising.

In the medical literature, no specific occupations or occupational hazards have been conclusively linked to ALS. However, a few associations have been reported; Strickland et al.[50] found that welding and soldering occupations were significantly related to ALS in a 25-case, 50-control study. Savitz et al.[51] found increasing ALS risk with increasing duration of employment among electrical utility workers. Cruz et al.[22] found that 2.3% of their cases had suffered a shock resulting in unconsciousness, while 7.5% of their cases were burned. Their cases were similar to controls. Similarly, we found small percentages of cases reporting a history of electrical shock that resulted in a burn (2%) or unconsciousness (1%). In addition, only a small percentage of our cases experienced an occupationally-related chemical exposure requiring medical attention (7%).

McGuire et al.[27] saw associations, but no dose-response trends, between ALS and the occupational use of cleaning solvents/degreasers as well as alcohols and ketones; however, they found no association between ALS and solvent usage overall. They did, however, find an unexpected association between ALS and insecticides/agricultural chemicals. The percent distributions for substances contacted at Kelly AFB jobs closely resembled the percent distributions for substances contacted among overall jobs (Appendix C). For substances contacted during the overall 20-year employment history of our case series, general cleaning solvents and degreasers were most frequently mentioned, totaling 7% of all agents mentioned among 21% of all jobs. Metals, as a group, were fairly common (~30% of agents mentioned). When combined, though, agricultural chemicals (pesticides, herbicides, fertilizers, insecticides, fungicides) counted for only 14% of overall agent mentions. Similarly, only 15% of Kelly AFB-contacted substances were agricultural. Exposures to agricultural chemicals did not appear excessive for our cases.

As mentioned in Results, only 76 of the 93 PALS provided information that could be included in the 20-year work history analysis, based on times provided in their employment history. Also, less than half of the respondents (n=40, 43%) reported working at Kelly AFB in the 20 years prior to diagnosis; a majority of these workers were civil service employees (n=24, 63% of Kelly AFB subset). The jobs held by the 17 PALS not included in the 20-year work history analysis (because either no jobs were given for the requested 20-year time frame or start and dates for jobs provided were completely missing, all proxy report) as well as the extra jobs provided by the rest of the PALS are listed in Table C2. These jobs were not noticeably dissimilar from jobs included in the work history analysis; the jobs listed as occurring at Kelly AFB, including jobs for 10 of the 17 PALS not included in the work history analysis, are denoted.

Family Medical History

Information is lacking in the medical literature concerning the disease histories of family members of ALS cases. However, in their study of physical trauma and family history of neurological disease, Cruz et al.[22] found that 4.6% and 2.3% of their cases' first-degree relatives had Alzheimer's and Parkinson's disease, respectively; their cases were no different from controls. The percentages of our cases reporting family members with these neurological diseases were somewhat higher, with 8.6% reporting a first-degree relative with

Alzheimer's disease and 4.3% reporting a first-degree relative with Parkinson's disease. Given that 1 in 10 persons over age 65 and almost half of persons over age 85 have Alzheimer's disease,[52] the prevalence among our cases' family members did not appear excessive. Similarly, 1 in 100 of the U.S. population over 65 is diagnosed with Parkinson's disease;[53] whether or not our cases were disproportionately affected by a family history of Parkinson's is unclear. Of interest, though, is the percentage of case series participants reporting a family history of ALS. It is generally accepted that between 5-10% of ALS cases are familial (and not sporadic) in origin;[18, 21] in line with this, 4.3% of our case series had a blood relative with ALS. Similarly, in Cruz et al.,[22] 5.2% of patients had a blood relative with ALS; their cases were significantly more likely to have blood relatives with ALS than were controls.

CONCLUSIONS

As mentioned in the demographics summary, the preponderance of males in the case series constituted a major difference between our case series and those described in the literature. At 10.6 males per female, the gender ratio was roughly 5 to 6 times greater than what is normally reported.[3, 4, 8, 11, 13, 14, 17, 18] The predominantly male case series also differed from the U.S. adult male population in the prevalence of several medical conditions mainly associated with obesity and/or metabolic syndrome. Another noteworthy and rather unexpected finding was that 6.5% of the cases had been professional or semi-professional athletes. This reported athleticism of the series, coupled with a low prevalence of obesity-related diseases, suggests that our cases were generally more active than U.S. males of similar ages. In addition, though not all cases were conclusively linked with Kelly employment, a "healthy worker effect" or a "healthy soldier effect" might be present, as described in the literature.[54, 55]

No information provided by the case series participants concerning their ALS disease courses, recreational activities, family medical histories, immunization, infection/trauma, or tobacco and alcohol histories appeared to differentiate them from the ALS cases that have been reported on in the medical literature. However, conclusions regarding the military and 20-year work histories of our cases were difficult to draw, as appropriate comparison figures for other ALS case series and the U.S. population at large were difficult to obtain. Even so, nothing in particular seemed to stand out within our cases' military or work histories, aside from the fact that a large percentage (80%) had a military service history. It is also important to keep in mind that U.S. comparison figures specific to the age, gender, and ethnic background of our series were not always available, so very general measures from the U.S. population were used to make many of these comparisons.

Our case series study had other limitations that should be taken into account when interpreting the results. The very broad case definition combined with self-referral of cases via social networking and media coverage, while good for maximizing the opportunity for concerned individuals to participate, precluded any opportunity for rigorous analysis. The

resulting heterogeneity made it impossible to detect differences among the group. One key limitation was the dependence upon proxy report for much of the information gathered. Proxy accounts are more likely to suffer from information bias than personal accounts. In addition, many of the patients had been deceased for a number of years, introducing the possibility of additional recall bias by their proxies.

The questionnaire itself had limitations; at 77 pages, it was lengthy and time-consuming to complete. It is also possible that there was something common to the patients (other than a reported Kelly AFB link, for instance, some aspect of nutrition) that we were not able to capture with our survey instrument. Indeed, our case definition was very broad and produced a highly heterogeneous group of cases from which it was difficult to identify unique characteristics or differences. Any person with ALS and a reported link to Kelly AFB was invited to participate in the study. Unfortunately our questionnaire did not always capture the information regarding the case's link with Kelly AFB. This made it even more difficult to look for any Kelly AFB-specific commonalities. As previously noted, less than half of the cases reported working at Kelly AFB in the 20 years prior to their ALS diagnosis based on responses to the questionnaire. Another limitation might be that the 20-year window of work history preceding diagnosis was not broad enough to capture any potential work-related exposures.

Given that this Kelly AFB ALS Case Series was undertaken in parallel with the Kelly AFB Mortality Study, it is inevitable that people will seek to make comparisons between the two studies. However, these studies focused on different Kelly AFB worker populations and given the dissimilarities between the groups and study designs, meaningful comparisons are not possible. Appendix A contains more details about the differences between these studies.

In all, the lack of salient predictors for ALS, combined with the varied Kelly ties among the participants and the observational nature of our study (i.e. no comparison group), makes it difficult to hypothesize what kinds of detrimental exposures, if any, might have been common to the cases. However, we hope the investigation of the personal life histories of these PALS offers a unique glimpse into a series of ALS cases possibly linked together geographically and/or occupationally.

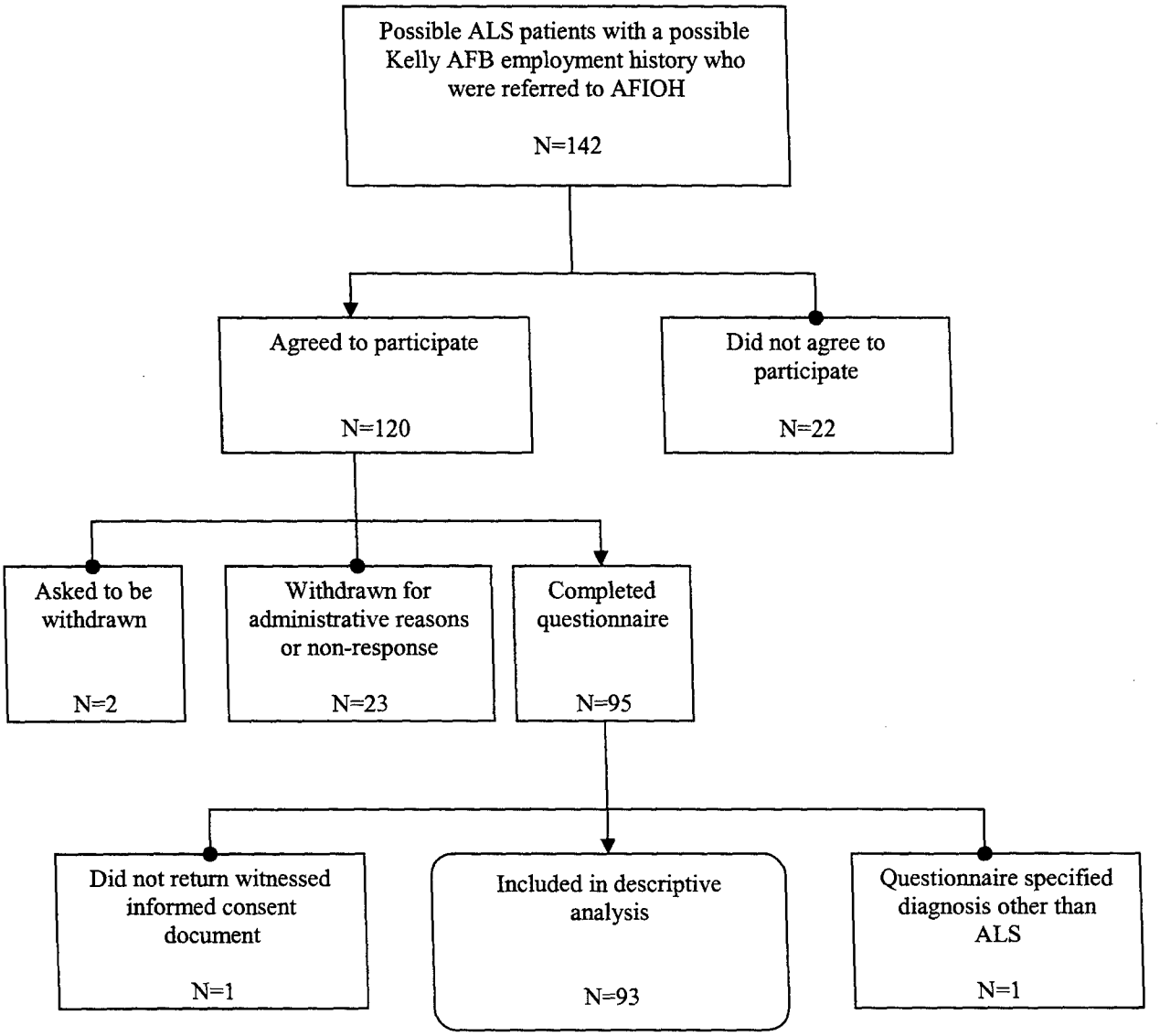

Figure 1. Recruitment flow chart for Case Series Investigation of Amyotrophic Lateral Sclerosis (ALS) Among Former Kelly Air Force Base Workers

TABLE 1. Self-Reported Demographics of ALS Case Series

	Participants (N=93)		Non-Participants/Non-Respondents (N=49)	
	No.	(%)	No.	(%)
Gender				
Male	85	91.4	44	89.8
Female	8	8.6	5	10.2
Ethnicity				
White/Caucasian	76	83.5	*N/A*	
Hispanic/Latino	12	13.2	*N/A*	
Black/African-American	2	2.2	*N/A*	
Other	1	1.1	*N/A*	
Missing=2				
Marital Status				
Married	83	90.2	*N/A*	
Divorced	4	4.3	*N/A*	
Single/Never Married	2	2.2	*N/A*	
Widowed	2	2.2	*N/A*	
Refused	1	1.1	*N/A*	
Missing=1				
Highest Education Level Attained				
<12th Grade	9	9.7	*N/A*	
High School/GED	28	30.1	*N/A*	
*Vocational training/Some college/Associate degree	28	30.1	*N/A*	
College graduate	13	14	*N/A*	
Graduate degree/schooling	13	14	*N/A*	
Don't know	2	2.1	*N/A*	
Income Level in Year Prior to ALS Diagnosis				
<$15,000	6	6.5	*N/A*	
$15,000 to $29,999	14	15.1	*N/A*	
$30,000 to $39,999	13	14	*N/A*	
*$40,000 to $49,999	7	7.5	*N/A*	
$50,000 to $59,999	9	9.7	*N/A*	
≥$60,000	23	24.7	*N/A*	
Don't Know/Refused	21	22.5	*N/A*	

*Median category

TABLE 2. Self-Reported ALS Disease Characteristics Among Case Series Participants and Non-Participants

	Participants (N=93)					P-value*	Non-Respondents/Non-Participants** (N=49)				
	No. (%)	Range	Mean	S.D.	Median		No. (%)	Range	Mean	S.D.	Median
Age at Diagnosis		28.5 to 82.8	62	11.8	62.4			26.5 to 83.6	63.8	13.9	64.7
<45 years	7 (8.1)					*Ref.*	5 (11.9)				
45-54 years	17 (19.8)					0.999	6 (14.3)				
55-64 years	24 (27.9)					0.997	10 (23.8)				
65-74 years	25 (29.1)					1.000	11 (26.2)				
75+ years	13 (15.1)					1.000	10 (23.8)				
	(Missing: n=7)						*(Missing: n=7)*				
Age at Death		36.3 to 85.0	66.2	10.6	64.5			31.1 to 92.2	68.9	13.4	70.9
Still living at time of survey	21 (22.6)					--***	14 (28.6)				
<45 years	2 (2.2)					*Ref.*	3 (6.1)				
45-54 years	6 (6.5)					0.998	2 (4.1)				
55-64 years	29 (31.2)					0.997	6 (12.2)				
65-74 years	16 (17.2)					1.000	10 (20.4)				
75+ years	19 (20.4)					1.000	14 (28.6)				
Time from first symptom to ALS diagnosis, in years *(n=77, missing 16)*		0 to 10.0	1.2	1.6	0.7	--***		-0.12 to 15.0	2.1	3.2	1.0
Time from first symptom to death, in years *(n=62, missing 10)*		0.4 to 12.4	3.1	2.6	2.3	0.057		0.50 to 39.5	6.1	7.9	3.7
Time from diagnosis to death, in years *(n=65, missing 7)*		0 to 7.8	2.0	1.8	1.2	0.105		-0.30 to 38.4	3.9	7.3	1.7
Did a doctor diagnose the ALS case?											
Yes	92 (98.9)										
No	1 (1.1)										
Diagnosis Type											
Familial	3 (3.2)						1 (2.2)				
Sporadic	41 (44.1)						41 (89.1)				
Other	2 (2.2)†						2 (4.3)‡				
Don't Know	47 (50.5)						2 (4.3)				

†*Written in as "Bulbar"*

‡*PLS (n=2) (Missing: n=3)*

TABLE 2. Self-Reported ALS Disease Characteristics Among Case Series Participants and Non-Participants (Cont.)

	Participants (N=93)					P-value*	Non-Respondents/Non-Participants** (N=49)				
	No. (%)	Range	Mean	S.D.	Median		No. (%)	Range	Mean	S.D.	Median
First Symptom											
Muscle Changes—Upper Extremity	21 (22.6)					0.998	14 (28.6)				
Muscle Changes—Lower Extremity	19 (20.4)					0.998	9 (18.4)				
Multiple Sites/Other	18 (19.4)					0.998	7 (14.3)				
Cranial Nerve Symptoms	8 (8.6)					0.998	5 (10.2)				
Cerebellar Symptoms—Falls/Balance	7 (7.5)					0.998	4 (8.2)				
Systemic Symptoms	5 (5.4)					0.997	0				
Don't Know	5 (5.4)					*Ref.*	6 (12.2)				
Sensation Changes—Lower Extremity	4 (4.3)					0.997	0				
Sensation Changes—Upper Extremity	4 (4.3)					0.997	0				
Chest/Respiratory Symptoms	2 (2.2)					0.998	4 (8.2)				
Second Symptom (N=84)											
Multiple Sites/Other	16 (19.0)						N/A				
Muscle Changes—Lower Extremity	13 (15.5)						N/A				
Don't Know	12 (14.3)						N/A				
Cranial Nerve Symptoms	11 (13.1)						N/A				
Cerebellar symptoms—Falls/Balance Problems	11 (13.1)						N/A				
Muscle Changes—Upper Extremity	10 (11.9)						N/A				
Systemic Symptoms	5 (6.0)						N/A				
Chest/Respiratory Symptoms	4 (4.8)						N/A				
Sensation Changes—Upper Extremity	2 (2.4)						N/A				

*P-values were included to examine for statistically significant differences between participants and non-participants where data for both were available. A generalized linear model was run after expanding factor variables & interactions.

**Of the 142 persons identified as potential participants, 93 submitted surveys that were included in the analysis. Six PALS completed the surveys on their own, while 14 completed surveys with the assistance of a proxy. The remaining 73 were proxy-only report. Demographics for the 49 non-participants were provided from the original ALS Association survey. The 49 non-participants include two cases who completed questionnaires but were not included in the analysis; 1 was diagnosed with primary lateral sclerosis (PLS), and the other was missing the required Informed Consent Document.

***Collinear and therefore left out of model

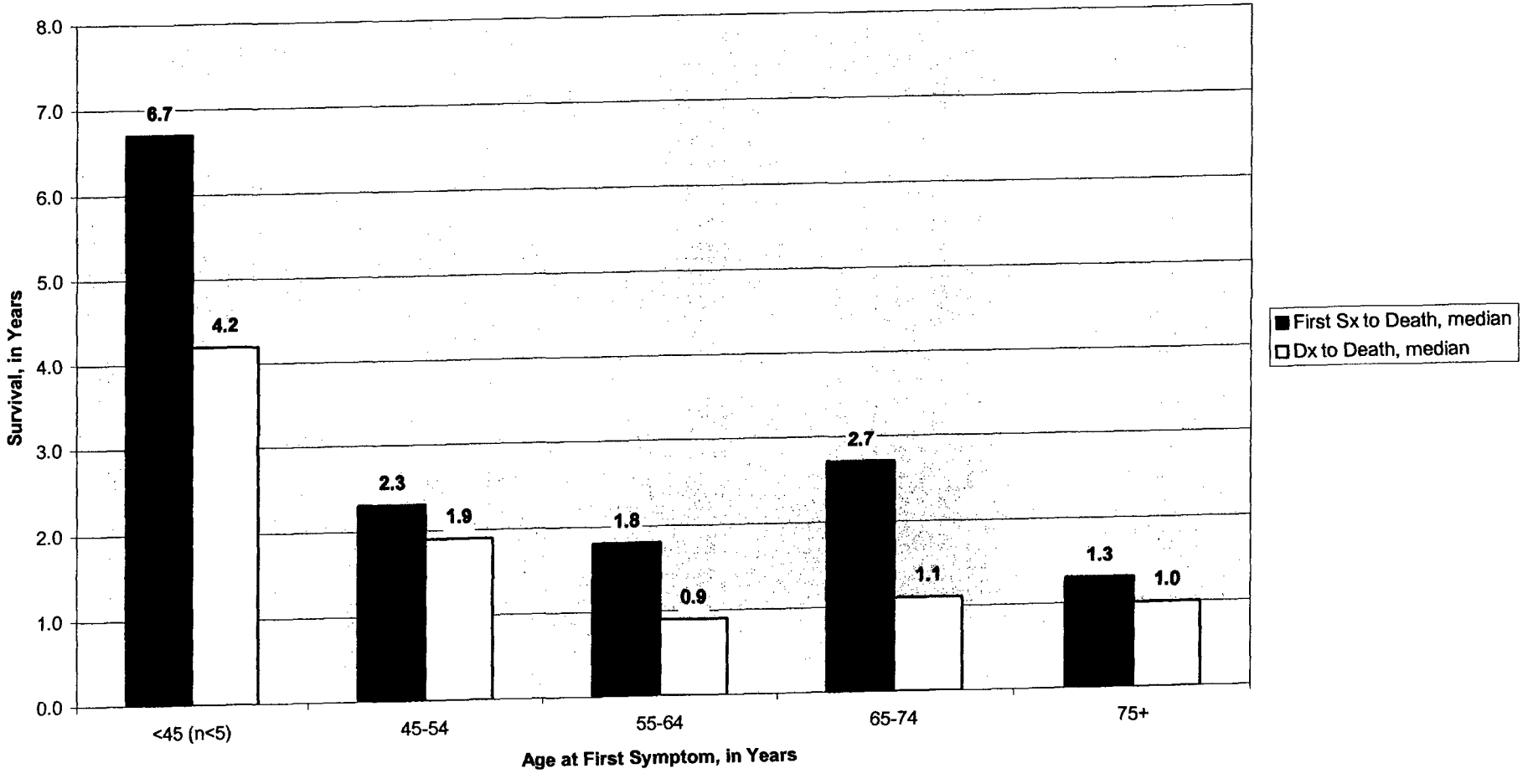

Figure 2. Median Survival, in Years, by Age at First Symptom (Deceased Only)

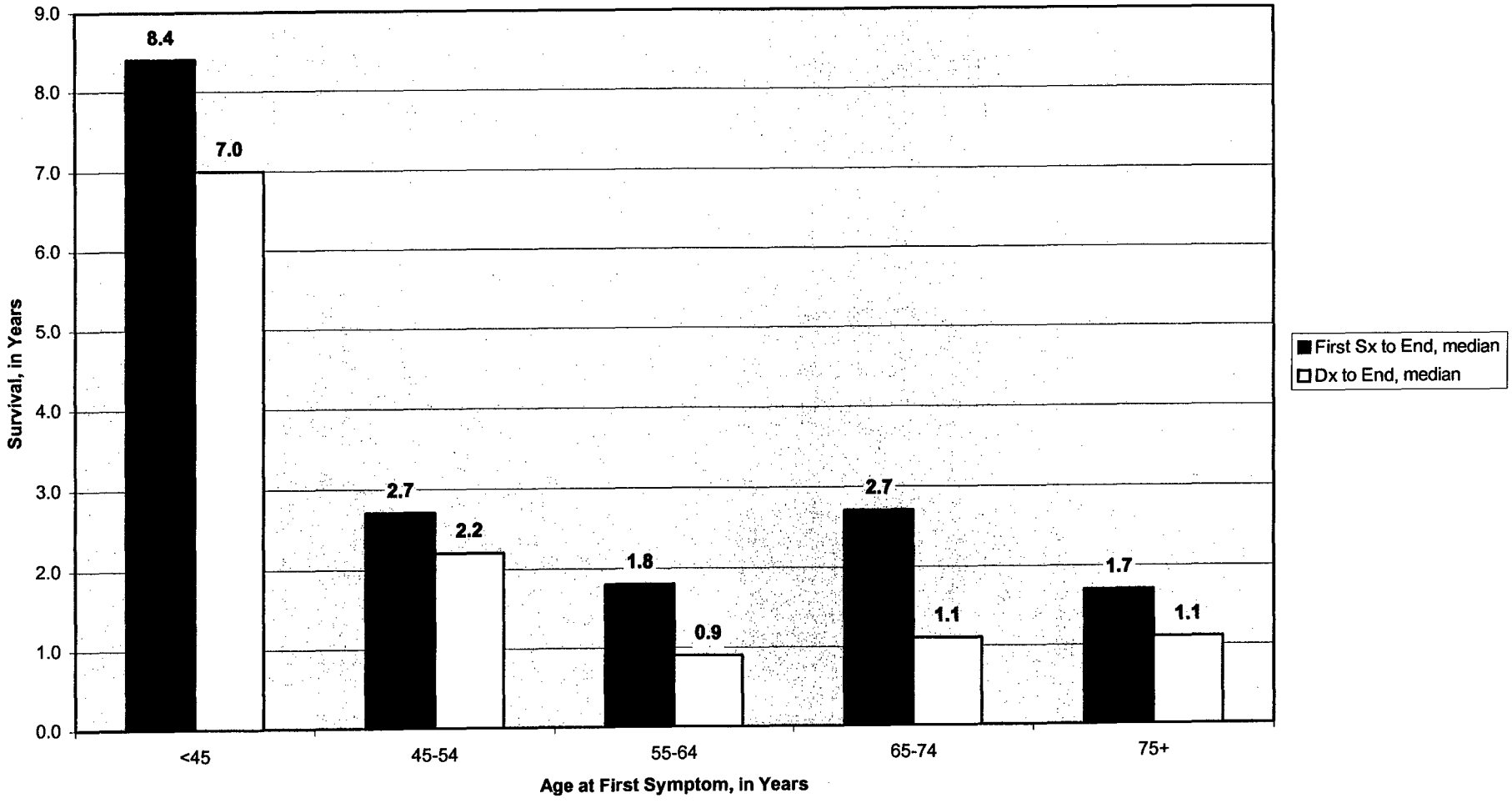

Figure 3. Median Survival, in Years, by Age at First Symptom (Deceased/Non-Deceased)

TABLE 3. Self-Reported Medical History of ALS Case Series

Question: "Did a doctor ever diagnose the patient with *Disease*?" & "With what type or types of *Disease* was the patient diagnosed?"		
	"Yes" Responses (N=93)	
Diseases diagnosed by a doctor prior to ALS diagnosis	**No.**	**(%)***
High BP	**22**	**23.7**
Heart Disease	**18**	**19.4**
Cancer	**12**	**12.9**
Prostate	*5*	*41.7*
Skin	*4*	*33.3*
Bladder	*1*	*8.3*
Colon	*1*	*8.3*
*Multiple sites***	*1*	*8.3*
Arthritis	**10**	**10.8**
Osteo	*6*	*60.0*
Rheumatoid	*2*	*20.0*
Don't know	*2*	*20.0*
Asthma or Reactive Airway Disease	**7**	**7.5**
Stroke	**7**	**7.5**
Hemorrhagic	*3*	*42.9*
Ischemic	*1*	*14.3*
Don't know	*3*	*42.9*
MND other	**7**	**7.5**
Don't know	*2*	*28.6*
Bulbar Palsy	*1*	*14.3*
Muscular Atrophy	*1*	*14.3*
Myasthenia Gravis	*1*	*14.3*
Peripheral Neuropathy	*1*	*14.3*
Primary Lateral Sclerosis	*1*	*14.3*
Diabetes	**5**	**5.4**
Type II (Adult Onset)	*4*	*80.0*
Don't know	*1*	*20.0*
Liver	**5**	**5.4**
Hepatitis	*3*	*60.0*
Cirrhosis	*1*	*20.0*
Don't know	*1*	*20.0*
Thyroid	**5**	**5.4**
Hyperthyroidism	*2*	*40.0*
Hypothyroidism	*1*	*20.0*
Goiter + Hyperthyroidism	*1*	*20.0*
Duct cyst	*1*	*20.0*
Rheumatic/Scarlet Fever	**4**	**4.3**
Kidney	**3**	**3.2**

TABLE 3. Self-Reported Medical History of ALS Case Series (Cont.)

Question: "Did a doctor ever diagnose the patient with *Disease*?" & "With what type or types of *Disease* was the patient diagnosed?"			
	Diseased kidney	*1*	*33.3*
	Infected kidney	*1*	*33.3*
	Kidney stones	*1*	*33.3*
Polio		**1**	**1.1**
Epilepsy		**0**	**0**
Autoimmune		**0**	**0**
Other diseases		**34**	**36.6**
	Other	26	76.5
	Autoimmune	5	14.7
	Neurological	3	8.8

*Italicized text represents % of disease subset
**Lung and bone cancer

TABLE 4. Self-Reported History of Infection & Trauma for ALS Case Series

	Responses (N=93)					
	"Yes"		"Don't Know"		"No"	
	No.	(%)	No.	(%)	No.	(%)
Antibiotics prescribed for illness or infection in year prior to diagnosis?	**8**	**8.6**	**37**	**39.8**	**48**	**51.6**
Reason						
Upper respiratory illness	*4*	*50.0*				
Bladder infections	*1*	*12.5*				
Multiple infections	*1*[*]	*12.5*				
Don't know/Unspecified	*2*	*25.0*				
• Hospitalization for this illness?	---	---	---	---	8	100
Injury requiring visit to doctor/ER in year prior to diagnosis?	**7**	**7.5**	**2**	**2.2**	**84**	**90.3**
Cause						
Fall	*4*	*57.1*				
Automobile crash	*2*	*28.6*				
Head collision with bed rail	*1*	*14.3*				
Body Part Injured						
Head trauma only	*4*	*57.1*				
Other body trauma	*3*[**]	*42.9*				
• Require hospital stay of > 1 night?	---	---	---	---	*7*	*100*
• Require surgery?	---	---	---	---	*7*	*100*
Surgery for reasons other than injury in year prior to diagnosis?	**18**	**19.4**	**6**	**6.5**	**68**	**73.1**
Type						
Heart	*3*	*16.7*				
Digestive	*3*	*16.7*				
Musculoskeletal	*4*	*22.2*				
Reproductive	*2*	*11.1*				
Musculoskeletal + Reproductive	*1*	*5.5*				
Excretory	*2*	*11.1*				
Other	*3*[***]	*16.7*				
• Require hospital stay of > 1 night?	14	87.5	---	---	2	12.5

[*]Antibiotics for kidney, bladder, prostate surgeries
[**]Includes injury to hand, back, neck (n=1); wrist (n=1); entire body (n=1)
[***]Eye/lung (n=1), Hernia (n=2) surgeries

TABLE 5. Self-Reported Immunization History of ALS Case Series

Immunizations in year prior to ALS diagnosis						
	Responses (N=93)*					
	"Yes"		"Don't Know"		"No"	
	No.	(%)	No.	(%)	No.	(%)
Flu	52	55.9	20	21.5	21	22.6
Tetanus/Diphtheria*	14	15.1	25	26.9	53	57
Polio*	11	11.8	21	22.6	60	64.5
Diphtheria/Pertussis/Tetanus	8	8.6	31	33.3	54	58.1
MMR*	7	7.5	20	21.5	65	69.9
Chicken Pox	6	6.5	19	20.4	68	73.1
Hepatitis A	2	2.2	34	36.6	57	61.3
Hepatitis B*	1	1.1	30	32.3	61	65.6
Other Immunizations	1**	1.1	61	65.6	31	33.3
Anthrax	0	0	24	25.8	69	74.2
Reported side effects						
	"Yes"		"Don't Know"		"No"	
	No.	(%)	No.	(%)	No.	(%)
Flu*	5***	10.2	6	12.2	38	77.6
Tetanus/Diphtheria	1	7.1	5	35.7	8	57.1
Polio*	----	----	2	20	8	80
Diphtheria/Pertussis/Tetanus*	----	----	2	28.6	5	71.4
MMR*	----	----	2	33.3	4	66.7
Chicken Pox	----	----	2	33.3	4	66.7
Hepatitis A	----	----	----	----	2	100
Hepatitis B	----	----	----	----	1	100
Other Immunizations	----	----	----	----	1**	100
Anthrax	----	----	----	----	----	----

*In several instances, responses do not total to either (1) n=93 (immunization table) or (2) the number of "Yes" answers for immunizations (side effects table). For example, only 49 of those 52 answering "Yes" to receiving the Flu vaccination answered the follow-up question regarding side-effects. The reasons for the non-responses were unknown, and percentages were adjusted to according to those who did respond to the question.

**"Tetanus Toxoid"

***Flu-like symptoms (n=4) and sore arm (n=1)

TABLE 6. Self-Reported Recreational History of ALS Case Series

Recreational Activity	"Yes" Responses (N=93)							
	Ever*		Adult Only		Child Only		Both	
	No.	(%)**	No.	(%)**	No.	(%)**	No.	(%)**
o *Activities specifically addressed by questionnaire, e.g., "Did you/the patient ever participate in Gardening on a regular basis?"*								
Gardening	46	49.5	21	22.6	1	1.1	23	24.7
Auto Repair	31	33.3	18	19.4	0	0.0	12	12.9
Woodworking/Carpentry	21	22.6	14	15.1	3	3.2	4	4.3
Hiking or Camping	20	21.5	10	10.8	3	3.2	6	6.5
Hunting	19	20.4	5	5.4	2	2.2	12	12.9
Model Building	10	10.8	1	1.1	3	3.2	6	6.5
Arts/Crafts***	7	7.5	0	0.0	0	0.0	2	2.2
Photography	7	7.5	4	4.3	1	1.1	2	2.2
Oil Painting	6	6.5	4	4.3	1	1.1	0	0.0
Furniture Refinishing	3	3.2	1	1.1	0	0.0	2	2.2
Jewelry Making	2	2.2	2	2.2	0	0.0	0	0.0
Motor Cross Spectator	2	2.2	0	0.0	0	0.0	2	2.2
Pottery Making	2	2.2	2	2.2	0	0.0	0	0.0
Motor Cross/Car Racing	1	1.1	1	1.1	0	0.0	0	0.0
Glasswork	0	0.0	0	0.0	0	0.0	0	0.0

Recreational Activity	"Yes" Responses (N=93)							
	Ever*		Adult Only		Child Only		Both	
	No.	(%)**	No.	(%)**	No.	(%)**	No.	(%)**
o *Activities provided as answers to question "Are there any other activities that you/the patient participated in on a regular basis?"*								
Intense sport	13	14.0	4	4.3	1	1.1	8	8.6
Fishing	10	10.8	4	4.3	0	0.0	6	6.5
Golfing	7	7.5	7	7.5	0	0.0	0	0.0
Mental/Thinking games	7	7.5	4	4.3	1	1.1	2	2.2
Bowling	3	3.2	3	3.2	0	0.0	0	0.0
Music	3	3.2	2	2.2	0	0.0	1	1.1
Billiards	2	2.2	2	2.2	0	0.0	0	0.0

TABLE 6. Self-Reported Recreational History of ALS Case Series (Cont.)

Recreational Activity	"Yes" Responses (N=93)							
	Ever*		Adult Only		Child Only		Both	
	No.	(%)**	No.	(%)**	No.	(%)**	No.	(%)**
Flying planes	2	2.2	2	2.2	0	0.0	0	0.0
Electronics	2	2.2	2	2.2	0	0.0	0	0.0
Volunteer/Civic work	1	1.1	1	1.1	0	0.0	0	0.0
Others/Already asked***	18	19.4	11	11.8	2	2.2	4	4.3

*Responses to the "Adult Only," "Child Only," and "Both" columns do not always total to the "Ever" column because only "Yes" answers were counted. Answers of "Don't Know" to either the child or adult questions precluded their inclusion in the "Both" category.

**All % use the entire case series as a denominator (N=93)

***Responses to the "other" and "arts/crafts" categories included repeat answers of prior questions, including hunting (n=2), gardening (n=2), model building (n=1). Other responses included yard work (n=2), home repair/maintenance activities (n=4), horseback riding (n=1), movies (n=1), travel (n=1), stamp collecting (n=1), gluing plastic dolls (n=1), skeet shooting (n=1), making fishing lures (n=1), bird watching (n=1), and upholstering furniture (n=1).

TABLE 7. Self-Reported Athletic History of ALS Case Series

		"Yes" Responses (N=93)	
		No.	(%)*
❖ **High School**	Participated in athletics?	46	49.5
	Lettered/varsity team?	27	29.0
❖ **College**	Participate in **intramural** athletics?	4	4.3
	Participate in **intercollegiate** athletics?	4	4.3
	Lettered/varsity team **intercollegiate**?	3	3.2
❖ Ever employed as **professional/semi-professional** athlete?		6	6.5
❖ Ever participate in **socially-sponsored** sport on regular basis as adult?		21	22.6

	High School Letter		College Intramural		Intercollegiate Letter		Pro/Semi-Pro		Socially-Sponsored	
Sport	**No.**	**(%)***	**No.**	**(%)***	**No.**	**(%)***	**No.**	**(%)***	**No.**	**(%)***
Baseball	11	11.8	1	1.1	2	2.2	2	2.2	4	4.3
Football	11	11.8	1	1.1	---	---	1	1.1	---	---
Basketball	10	10.8	1	1.1	---	---	1	1.1	6	6.5
Track & Field	6	6.5	---	---	---	---	---	---	---	---
Tennis	2	2.2	---	---	1	1.1	---	---	---	---
Boxing	1	1.1	---	---	---	---	2	2.2	---	---
Field Hockey	1	1.1	---	---	---	---	---	---	---	---
Soccer	1	1.1	---	---	---	---	---	---	---	---
Swimming	1	1.1	---	---	---	---	---	---	---	---
Bowling	---	---	1	1.1	---	---	---	---	7	7.5
Softball	---	---	1	1.1	---	---	---	---	6	6.5
Golf	---	---	1	1.1	---	---	---	---	5	5.4
Volleyball	---	---	---	---	---	---	---	---	2	2.2
Fishing	---	---	---	---	---	---	---	---	1	1.1
Flag Football	---	---	---	---	---	---	---	---	1	1.1
Racquetball	---	---	---	---	---	---	---	---	1	1.1
Running	---	---	---	---	---	---	---	---	1	1.1
Water-skiing	---	---	---	---	---	---	---	---	1	1.1
Crew	---	---	1	1.1	---	---	---	---	---	---

*% of all PALS (N=93)

TABLE 8. Self-Reported Tobacco Usage History of ALS Case Series

	"Yes" Responses (N=93)		
	No.	**(%) Smokers**	**(%) All PALS**
Smoked 100+ cigarettes in lifetime?	62	*N/A*	66.7
Smoking at death?	7	11.3	9.7*
Smoking at ALS diagnosis?	22	35.5**	23.7
Number of years smoked:			
Never a smoker	31	*N/A*	33.3
<20	18	29.0	19.4
20 to 39	28	45.2	30.1
40 to 59	13	21.0	14.0
60+	2	3.2	2.2
Missing=1			
Time from last cigarette to ALS diagnosis (calculated):			
Never a smoker	31	*N/A*	33.3
>20 years ago	17	27.4	18.3
10 to 20 years ago	13	21.0	14.0
<10 years ago	13	21.0	14.0
Smoking at diagnosis	15	24.2	16.1
Missing diagnosis date and/or age last smoked=4			
Pack-years (calculated):			
Never a smoker	31	*N/A*	33.3
<15	12	19.4	12.9
15 to 29	15	24.2	16.1
30 to 59	16	25.8	17.2
>60	10	16.1	10.8
One pack-year is the equivalent of smoking one 20-cigarette pack per day for one year; 27 smokers were missing pack and/or years smoking info			
Ever live with a smoker?			
Overall	57	*N/A*	61.3
❖ Among ever smokers (n=62)	47	75.8	50.5
Smoke when patient was home?	44	71.0	47.3
❖ Among never smokers (n=31)	10	32.3***	10.8
Smoke when patient was home?	8	25.8***	8.6

*% of deceased PALS (n=72)
**"Yes/No" answer; likely more accurate than the calculated smoking at diagnosis figure in "Time from last cigarette to ALS diagnosis"
***% non-smokers (n=31)

TABLE 9. Self-Reported Alcohol Usage History of ALS Case Series

		"Yes" Responses (N=93)		
		No.	**(%) Drinkers**	**(%) All PALS**
Ever drink an alcoholic beverage?		80	*N/A*	86.0
	Drinking at death?	14	17.5	19.4
Number of years drinking alcoholic beverages?				
	Never drank an alcoholic beverage	13	*N/A*	14.0
	less than 20	1	1.3	1.1
	20 to 29	11	13.8	11.8
	30 to 39	14	17.5	15.1
	40 to 49	16	20.0	17.2
	50 to 59	6	7.5	6.5
	60+	4	5.0	4.3
	"Ever drinkers" missing information for years of drinking calculations	*28*	*35.0*	*30.1*

	Overall		**5-oz glass wine**		**12-oz can beer**		**1.5-oz liquor**	
Average Drinks per week:	**No.**	**(%)***	**No.**	**(%)***	**No.**	**(%)***	**No.**	**(%)***
Never drank an alcoholic beverage	13	14.0	13	14.0	13	14.0	13	14.0
<1	38	40.9	64	68.8	46	49.5	51	54.8
1 to 4	16	17.2	4	4.3	14	15.1	11	11.8
5 to 7	9	9.7	1	1.1	6	6.5	4	4.3
8 to 14	10	10.8	1	1.1	5	5.4	4	4.3
15+	2	2.2	0	0.0	1	1.1	1	1.1
Don't know/missing (of ever drinkers)	*5*	*5.4*	*10*	*10.8*	*8*	*8.6*	*9*	*9.7*

*% of all PALS

TABLE 10. Self-Reported Military Service History of ALS Case Series

	No.	(%) Subset	(%) All PALS*
Service History?			
Yes	74		79.6
No	19		20.4
• **Branches: (includes those serving in >1 branch)**		***(%) Of those who served:***	
Air Force	54	73.0	58.1
Army	18	24.3	19.4
Marine Corps	2	2.7	2.2
Navy	6	8.1	6.5
Coast Guard	2	2.7	2.2
Other/Branch Unknown	4	5.4	4.3
Person-Years (P-Y) Spent in Branch	*Total p-y*	*Range***	*Median***
Air Force	755	2 to 32 p-y	20 p-y
Army	111		
Marine Corps	7		
Navy	71	2 to 40 p-y (for all non-AF combined)	5 p-y (for all non-AF combined)
Coast Guard	26		
Other/Branch Unknown	3		
(Missing times for 9 out of 99 service periods among 74 persons)			
Person-Years (P-Y) Spent in Status	*Total p-y*	*Range***	*Median***
Air Force			
Active Duty	650	2 to 31 p-y	13
Reserve	77	5 to 24 p-y	6.5
National Guard	28	4 to 20 p-y	4
Other Branches			
Active Duty	190	2 to 24 p-y	2.5
Reserve	27	3 to 20 p-y	4
National Guard	1	1 p-y	1
(Missing times for 9 out of 99 service periods among 74 persons)			
Served in Campaigns	***If service history is "Yes":***	***(%) Of those with service history (n=74)***	
Served in campaign	53	71.6	57.0
No campaigns listed	21	28.4	---
• **Campaigns:**		***(%) Of those with campaign history (n=53)***	
WWII	36	67.9	38.7
Korean War	11	20.8	11.8
Vietnam	15	28.3	16.1
Gulf War	2	3.8	2.2

TABLE 10. Self-Reported Military Service History of ALS Case Series (Cont.)

	No.	(%) Subset	(%) All PALS*
• **Where Served During WWII**		*(%) Of those in WWII (n=36)*	
Europe only	13	36.1	14.0
Pacific only	10	27.8	10.8
Both Europe and Pacific	2	5.6	2.2
Neither Europe nor Pacific	6	16.7	6.5
Don't know	3	8.3	3.2
Missing	2	5.6	2.2
Military Exposures:			
• **Exposed to Chemical or Biological Agents?**		*(%) Of those with service history (n=74)*	
Yes	14	18.9	15.1
No	15	20.3	16.1
Don't Know	38	51.4	40.9
(Missing=7)			
• **Agents Mentioned (could mention more than 1):**		*(%) Of those exposed (n=14)*	
Agent Orange	4	28.6	4.3
Tear Gas	1	7.1	1.1
Other	3	21.4	3.2
Don't Know	8	57.1	8.6
• **Exposed to any Radiation (ionizing or non-ionizing)?**		*(%) Of those with service history (n=74)*	
Yes	3	4.1	3.2
No	16	21.6	17.2
Don't Know	44	59.5	47.3
(Missing=11)			

*N=93 PALS
**Among subset (i.e. Air Force/Non-Air Force)

TABLE 11. Self-Reported Occupational History of ALS Case Series, by White/Blue Collar Status and 1-Digit Dictionary of Occupational Titles (DOT) Codes

- Self-reported work history, categorized by "White/Blue Collar" status, and based on the Dictionary of Occupational Titles (DOT)*
  - "White Collar" includes DOT occupational categories 0-2 (Professional, Technical, Managerial; Clerical and Sales)
  - "Blue Collar" includes DOT occupational categories 3-9 (Service; Agricultural, Fishery, Forestry, and Related; Machine Trades, Benchwork, Structural Work, Miscellaneous Occupations)

	White Collar		Blue Collar	
	No.	%	No.	%
Overall Jobs, 20 Years** (n=228)	124	54.4	104	45.6
Kelly	30	50.0	30	50.0
Non-Kelly	94	56.0	74	44.0
Last Job Held Prior to Diagnosis (n=79)	42	53.2	37	46.8
Kelly	11	45.8	13	54.2
Non-Kelly	31	56.4	24	43.6

- Self-reported work history, including both full and part-time jobs, for the 20 years leading up to ALS diagnosis and coded using the Dictionary of Occupational Titles

	Overall Employment		Non-Kelly Employment		Kelly Employment		Last Job Held	
1-Digit DOT Occupational Categories	No.	%	No.	%	No.	%	No.	%
0/1 Professional, Technical, Managerial	88	38.6	65	38.7	23	38.3	30	38.0
2 Clerical and Sales	36	15.8	29	17.3	7	11.7	12	15.2
3 Service	27	11.8	17	10.1	10	16.7	7	8.9
4 Ag, Fishery, Forestry, and Related	2	0.9	2	1.2	---	---	2	2.5
6 Machine Trades	25	11.0	16	9.5	9	15.0	11	13.9
7 Benchwork	12	5.3	7	4.2	5	8.3	5	6.3
8 Structural Work	22	9.6	18	10.7	4	6.7	8	10.1
9 Miscellaneous	16	7.0	14	8.3	2	3.3	4	5.1
Total Jobs Held in 20 Years Prior to ALS Diagnosis**	**228**	**100**	**168**	**100**	**60**	**100**	**79**	**100**

*United States Dept. of Labor. Bureau of Statistics. Dictionary of Occupational Titles. 4th ed. Washington: GPO, 1977.
**Among n=76 PALS, they held 228 different job titles in the 20 years preceding their diagnoses. The remaining 17 PALS were missing information for employment start and end dates; see Appendix C for a list of these

TABLE 12. Self-Reported Occupational History of ALS Case Series, By 2-Digit Dictionary of Occupational Titles (DOT) Codes

		Overall Employment		Non-Kelly Employment		Kelly Employment		Last Job Held	
Dig	Two-Digit Occupational Divisions*	No. (Jobs)	% (Jobs)	No.	%	No.	%	No.	%
18	Managers and Officers, n.e.c.	29	12.7	17	10.1	12	20.0	11	13.9
38	Building and Related Service	19	8.3	10	6.0	9	15.0	4	5.1
62	Mechanics and Machinery Repairers	16	7.0	9	5.4	7	11.7	7	8.9
16	Administrative Specializations	15	6.6	10	6.0	5	8.3	7	8.9
09	Education	10	4.4	10	6.0	---	---	3	3.8
82	Electrical Assembling, Installing, and Repairing	10	4.4	8	4.8	2	3.3	2	2.5
19	Misc. Professional, Technical, and Managerial	9	3.9	7	4.2	2	3.3	1	1.3
99	Unknown	9	3.9	9	5.4	---	---	2	2.5
03	Systems Analysis and Programming	8	3.5	6	3.6	2	3.3	---	---
63	Mechanics and Machinery Repairers	8	3.5	6	3.6	2	3.3	3	3.8
86	Construction, n.e.c.	8	3.5	7	4.2	1	1.7	3	3.8
29	Misc. Sales	7	3.1	5	3.0	2	3.3	3	3.8
72	Assembly and Repair of Electrical Equipment	7	3.1	3	1.8	4	6.7	4	5.1
20	Stenography, Typing, Filing and Related	6	2.6	3	1.8	3	5.0	1	1.3
24	Misc. Clerical	6	2.6	5	3.0	1	1.7	2	2.5
00	Architecture, Engineering, and Surveying	5	2.2	3	1.8	2	3.3	2	2.5
07	Medicine and Health	5	2.2	5	3.0	---	---	2	2.5
26	Sales, Consumable Commodities	5	2.2	5	3.0	---	---	1	1.3
27	Sales, Commodities, n.e.c.	5	2.2	5	3.0	---	---	2	2.5
01	Architecture, Engineering, and Surveying	4	1.8	4	2.4	---	---	2	2.5
21	Computing and Account-Recording	3	1.3	2	1.2	1	1.7	---	---
37	Protective Service	3	1.3	2	1.2	1	1.7	1	1.3
73	Fabrication and Repair of Products Made From Assorted Materials	3	1.3	2	1.2	1	1.7	1	1.3
85	Excavating, Grading, Paving, and Related	3	1.3	2	1.2	1	1.7	3	3.8
11	Law and Jurisprudence	2	0.9	2	1.2	---	---	2	2.5

TABLE 12. Self-Reported Occupational History of ALS Case Series, By 2-Digit Dictionary of Occupational Titles (DOT) Codes (Cont.)

		Overall Employment		Non-Kelly Employment		Kelly Employment		Last Job Held	
Dig	Two-Digit Occupational Divisions*	No. (Jobs)	% (Jobs)	No.	%	No.	%	No.	%
23	Information and Message Distribution	2	0.9	2	1.2	---	---	1	1.3
25	Sales, Services	2	0.9	2	1.2	---	---	2	2.5
31	Food and Beverage Preparation and Service	2	0.9	2	1.2	---	---	---	---
76	Fabrication and Repair of Wood Products	2	0.9	2	1.2	---	---	---	---
92	Packaging and Materials Handling	2	0.9	1	0.6	1	1.7	---	---
95	Production and Distribution of Utilities	2	0.9	1	0.6	1	1.7	2	2.5
14	Art	1	0.4	1	0.6	---	---	---	---
30	Domestic Service	1	0.4	1	0.6	---	---	1	1.3
32	Lodging and Related Service	1	0.4	1	0.6	---	---	1	1.3
33	Barbering, Cosmetology, and Related Service	1	0.4	1	0.6	---	---	---	---
40	Plant Farming	1	0.4	1	0.6	---	---	1	1.3
42	Misc. Agriculture and Related	1	0.4	1	0.6	---	---	1	1.3
60	Metal Machining	1	0.4	1	0.6	---	---	1	1.3
84	Painting, Plastering, Waterproofing, Cementing, and Related	1	0.4	1	0.6	---	---	---	---
90	Motor Freight	1	0.4	1	0.6	---	---	---	---
91	Transportation, n.e.c.	1	0.4	1	0.6	---	---	---	---
96	Amusement, Recreation, Motion Picture, Radio, and TV, n.e.c.	1	0.4	1	0.6	---	---	---	---
	Total Jobs Held in 20 Years Prior to ALS Diagnosis**	**228**	**100**	**168**	**100**	**60**	**100**	**79**	**100**

*United States Dept. of Labor. Bureau of Statistics. Dictionary of Occupational Titles. 4th ed. Washington: GPO, 1977.
**Among n=76 PALS, as the remaining 17 were missing information for employment start/end dates; see Appendix C for a list of these

TABLE 13. Self-Reported Miscellaneous Work History of ALS Case Series

Among Entire Case Series (N=93 PALS)			
	No.	**% Subset**	**% All PALS**
Employed at Death?			
• Among 72 deaths			
Yes	4	5.6	4.3
No	67	93.1	72.0
(Missing=1)			
• Among 21 alive at time of survey			
Employed	3	14.3	3.2
Not employed	18	85.7	19.4
		No. (%)	
See a Doctor for Chemical Exposure from Job?			
Yes		6 (6.5)	
No		68 (73.9)	
Don't know		18 (19.6)	
(Missing=1)			
Ever Received Electric Shock Prior to ALS Diagnosis (either on/off job)?			
Yes		10 (10.8)	
No		61 (65.6)	
Don't know or missing		22 (23.7)	
• Received a shock resulting in:			
No injury		9 (9.7)	
• Received a severe shock resulting in:			
Burn*		2 (2.2)	
Unconsciousness		1 (1.1)	
Among PALS Who Reported Holding Kelly AFB Jobs in 20 Years Prior to Diagnosis (n=40 PALS, 43% of series)			
		No. (%)	
Total Years Working at Kelly, Per Respondent			
Less than 5		12 (22.5)	
6 to 10		3 (7.5)	
11 to 15		5 (12.5)**	
16 to 20		6 (15.0)	
>20		14 (37.9)	
Status at Kelly			
Civil Service		24 (63.2)	
Active Duty		5 (13.2)	
Contractor		2 (5.3)	
Combination/Other		7 (18.4)	
(Missing=2)			

TABLE 13. Self-Reported Miscellaneous Work History of ALS Case Series (Cont.)

Job-Years at Kelly, Overall and By Status	No. (%)
Overall (job-years)	621
Active Duty	46 (7.4)
National Guard	25 (4.0)
Reserve	0
Civil Service	457 (73.6)
Contractor/Non-Appropriated Funds	72 (11.6)
Not specified	21 (3.4)

*The 2 persons receiving a severe shock resulting in a burn also reported receiving an additional shock resulting in no injury
** Median category

TABLE 14. Self-Reported Family Medical History of ALS Case Series

	"Yes" Responses (N=93)					
	Any Blood Relative		1° Relatives		2°(+) Relatives	
Disease	No.[1]	(%)	No.	(%)	No.	(%)
Cancer	48	51.6	44	47.3	8	8.6
Heart	39	41.9	33	35.5	10	10.8
High BP	32	34.4	30	32.3	5	5.4
Diabetes	28	30.1	24	25.8	5	5.4
Arthritis	25	26.9	23	24.7	4	4.3
Asthma	23	24.7	18	19.4	7	7.5
Stroke	22	23.7	18	19.4	8	8.6
Thyroid[2]	14	15.1	13	14.0	2	2.2
Alzheimer's	11	11.8	8	8.6	3	3.2
Liver	10	10.8	10	10.8	1	1.1
Kidney	8	8.6	8	8.6	1	1.1
Other[3]	7	7.5	7	7.5	0	0.0
Rheumatic/Scarlet fever	7	7.5	5	5.4	2	2.2
Parkinson's	6	6.5	4	4.3	2	2.2
Auto Immune[4]	5	5.4	4	4.3	2	2.2
Epilepsy	5	5.4	3	3.2	2	2.2
ALS	**4**	**4.3**	**2**	**2.2**	**2**	**2.2**
Polio	4	4.3	4	4.3	0	0.0
Motor Neuron[5]	1	1.1	1	1.1	0	0.0

[1]Goiter (n=3), Hashimoto Disease, Hyperthyroidism (n=2), Hypothyroidism (n=2), and several repeat classifications
[2]Diverticulitis, Guillain-Barre, Manic Depression, Migraine Headaches, Tuberculosis (n=2), and several repeat classifications
[3]Essential Tremors, Lupus, Multiple Sclerosis (n=2), Scleroma and two repeat classifications of diseases inquired about in other questions
[4]Multiple Sclerosis (n=1)
[5]When numbers in 1° and 2° relative columns add to a number greater than that in the "Any Blood Relative" column, then one or more PALS had both 1° and 2° relatives with illness

TABLE 15. Comparison of Case Series' Medical Conditions with U.S. Prevalence Figures

Condition	Cases (N=93) % "Yes"	Comparison	1983-85[1] Adults aged 45+ yr[4]	1997-98[2] Adults aged 45-84 yr[4]	1997-98[2] Males aged 45-84 yr[4]	2001[3] Adults aged 45+ yr[4]	2001[3] Males aged 45+ yr[4]
Hypertension	23.7	lower	26.5, 40.8	27.0, 49.0	26.5, 43.8	28.7, 52.8	29.2, 47.4
Heart Disease	19.4	lower end	13.7, 33.9	13.4, 36.0	14.0, 39.9	13.1, 37.1	14.1, 37.5
Cancer	12.9	lower end	*Not available*	7.2, 20.8	5.8, 23.6	8.3, 21.7	7.1, 23.2
Arthritis	10.8	lower	27.9, 50.8	26.1, 39.5	23.4, 34.8	27.0, 37.7	24.4, 30.7
Asthma	7.5	similar	2.6, 4.7	7.3, 9.1	6.6, 7.5	8.0, 10.4	8.1
Stroke	7.5	higher end	1.7, 8.4	2.3, 9.7	2.5, 11.0	2.3, 11.4	2.3, 9.9
Thyroid	5.4	similar	4.8, 6.5	*Not available*	*Not available*	*Not available*	*Not available*
Liver	5.4	higher	0.3, 0.7	1.0, 1.6	0.9, 1.7	1.1, 2.1	1.4, 2.3
Diabetes	5.4	lower	5.4, 9.8	7.9, 12.9	8.0, 12.9	9.4, 17.0	10.1, 17.4
Kidney disease	3.2	similar	2.3, 3.3	1.8, 3.5	1.6, 3.6	1.8, 4.1	2.1, 3.3

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[4]These are the ranges of prevalence figures for adults in these age categories (45+ years) for selected conditions over time frames listed, as reported in U.S. national surveys. Although these are not confidence intervals, the standard errors for these figures are generally very small due to the large number of respondents. Breaking down the age categories even further was not warranted, given the wide age range of our PALS (29 to 83 years, with a median of 62 years).

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APPENDIX A—CORRESPONDENCE OF CASE SERIES AND MORTALITY STUDIES

OVERVIEW

As part of the investigation into a perceived cluster of ALS among persons having a Kelly Air Force Base work history, two studies were conducted. An independent investigation team was awarded a contract for a mortality study of former and then-current Kelly workers. The second study was a case series investigation among all persons self-reporting a diagnosis with ALS and also reporting a Kelly AFB work history. The Air Force Institute for Operational Health (then AFIERA) administered the case series investigation and analyzed the data.

Mortality Study

- The study population was a 20-year cohort of 31,811 civilian workers who worked at least 1 year at Kelly AFB between the years 1981 and 2000. The study results, published in November 2002, indicated no significantly increased risk of death from motor neuron disease (MND) among the study population of former and then-current Kelly workers, when compared to United States and Texas populations. Standardized mortality ratios for MND were elevated, but not significantly, among both male and female white-collar workers when compared to blue-collar workers (SMR 59 vs.168 for blue collar vs. white collar males, 0 vs. 69 for females, respectively). Among all causes of death, significantly increased mortality risks were found only for breast cancer and only then among certain subsets of Kelly AFB male and female civilian workers. A healthy worker effort was apparent for the Kelly cohort overall.

Case Series Investigation

- Any person (or any person's proxy) self-reporting an ALS diagnosis and a Kelly AFB work history was invited to participate in the investigation. Cases were identified in several ways; the South Texas Chapter of the ALS Association referred many of the cases to AFIOH while others responded to local and national media coverage of the issue. Potential cases were given the opportunity to complete a 77-page questionnaire covering demographic, lifestyle, medical history, residential history, military history, and occupational history information. Data collection began in February 2002 and was completed in March 2003. Analysis began in August 2003. In all, 142 persons (or persons' proxies) with self-reported ALS diagnoses and Kelly AFB work histories were referred to AFIOH. Ninety-five persons (or proxies) returned questionnaires, and 93 questionnaires were included in the analysis. Questionnaire responses were used for descriptive analyses of the series and can also be used to generate hypotheses for further study of ALS and MND.

Correspondence Between the Two Studies

Of the 142 potential cases referred to AFIOH for the case series investigation, 24 (17%) were also in the mortality cohort. Eighteen (19%) of the 93 participants ultimately included in the case series analysis were also part of the mortality cohort. In addition, there were five PALS analyzed in the case series investigation (as well as an additional non-participant) who might initially have been expected to appear in the mortality study (based on information provided by the ALS Association), but did not. The most likely reason is that their personnel histories were not consistent with the time frame or civilian employee status selected for the mortality study cohort.

More than one-half of the 24 potential case series PALS that overlapped with the mortality study were not alive at the end of the mortality study period (October 31, 2001). Death in most cases was due to MND (83% of 13 potential cases and 90% of 10 analyzed cases). Table A1 provides figures for the studies' overlap and also the specific Underlying Cause of Death information for case series participants, as reported in the mortality study.

TABLE A1. Participant Overlap Between Mortality Study and Case Series Investigation, With Underlying Causes of Death

Overlap with Mortality Study	**Case Series Participants**	
	Of 142 Potential Cases:	Of 93 Analyzed Cases:
Total	24 (17%)	18 (19%)
Alive at end of mortality study period	11 (46%)	8 (44%)
Not alive at end of mortality study period	13 (54%)	10 (56%)
Underlying Cause of Death (ICD), from Mortality Study Data	*Of 13 overlapping deaths:*	*Of 10 overlapping deaths:*
Motor Neuron Disease (335.2)	11 (84%)	9 (90%)
Postinflammatory pulmonary fibrosis (515)	1 (8%)	--
Acute, but ill-defined, cerebrovascular disease (436)	1 (8%)	1 (10%)

Overall, 83% of those initially eligible for the case series investigation and 81% of those analyzed were not included in the mortality study. As the two studies were markedly different from each other, in both design and methodology, it is no surprise that the percent overlap between the two studies was under 20%. The differences between the two study populations are outlined in Table A2.

TABLE A2. Person and Time Characteristics of the Mortality and Case Series Study Populations

Mortality Study Population	Case Series Study Population
Person • Civilian workers only Time • Worked during 1981-2000 • Worked at Kelly AFB $\geq$ 1 year(s)	Person • Civilian, military, contractor, others Time • Worked any time (1930s-2000s) • Worked at Kelly AFB for any duration of time

CONCLUSIONS AND IMPLICATIONS

- ❖ Kelly AFB civilian workers from 1981 through 2000 were not found to have significantly elevated mortality risks from MND when compared to either the Texas or U.S. general population, but the MND mortality risks for non-civilian and/or pre-1981 Kelly AFB workers remain unknown.
- ❖ The case series and mortality studies examine two different Kelly AFB worker populations, with a small percent (<20%) of overlap between the populations; along these lines, dissimilarities in the studies' designs and objectives preclude many comparisons between the two studies.
- ❖ Rate and/or risk calculations cannot be made for the case series study due to incomplete case ascertainment and lack of a control group; only descriptive statistics for an ALS case series of 93 persons can be reported.
- ❖ A unique portrait of the life histories of 93 persons with ALS should provide a useful addition to the scientific and medical literature currently available on ALS.
- ❖ The analysis of specific subsets from the case series (e.g. persons who worked at Kelly more or less than 1 year, worked in a civilian or military capacity, worked in specific buildings at Kelly, war veterans, etc.) may provide insight for future hypothesis generation and further study.

APPENDIX B—ALS PATIENT AND PROXY QUESTIONNAIRES

PROXY QUESTIONNAIRE

Participant ID:_____

PALS Proxy Questionnaire
Kelly Health Issues Working Group
Version 3/18/02

Please read the Instructions sheet before beginning the questionnaire.

In the following questionnaire, please fill in any blanks that are indicated for your response, or circle the appropriate number to the right of the answer choices.

Date Completed (mm/dd/yyyy): __ __ / __ __ / __ __ __ __

Participant ID:_____

SECTION A: Patient Information

This section refers to the person who has ALS.

Please complete this form.

A.1 Patient's First Name: _____

A.2 Patient's Middle or Maiden Name: _____

A.3 Patient's Last Name: _____

A.4 Patient's Last Name when Employed at Kelly AFB (If different from A.3):_____

A.5 Patient's Social Security Number: __ __ __ -- __ __ -- __ __ __ __

A.6 Patient's Date of Death: __ __ / __ __ / __ __ __ __

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Participant ID:_____

Thank you for taking the time to complete this survey. In this questionnaire you will be asked about many different areas of the patient's life, including questions about the patient's family, medical history, and hobbies. The purpose of these questions is to help us determine if there is any one thing or several things that the patient has in common with other patients who have ALS, and the main purpose of our study is to determine if there are more people who have worked at Kelly Air Force Base that have ALS than would be expected.

Before you begin, it is important to mention a few things. All or your responses are completely confidential, and will only be seen or heard by people directly associated with the investigation. No information about any specific individual will ever be reported. Neither your name nor the patient's name will ever appear in any report about this study. You may choose not to answer any question or end the interview at any time.

This questionnaire is very lengthy, but you will not have to answer every question. This questionnaire is very lengthy, but you will not have to answer every question. Feel free to rest or take a break as you need to.

SECTION B: Proxy Information

This section is intended for you, the proxy of the patient who had ALS.

Please complete this form.

We would like to have some information about you in case we need your assistance again in the future. Your information will receive the same guarantee of confidentiality that we extend to the person you are assisting today.

B.1 What is your name?

First Name: _____

Middle or Maiden Name: _____

Last Name: _____

B.2 What is your address?

Street: _____ Apartment #: _____

City: _____ State: __ __

Zip Code: __ __ __ __ __

B.3 What is your telephone number?

(__ __ __) __ __ __ - __ __ __ __

Participant ID:_____

B.4 What is your relationship to the patient?

Husband	1	Brother	5
Wife	2	Sister	6
Son	3	Father	7
Daughter	4	Mother	8
Other Relative	_____ *(specify relationship)*		9
Other	_____ *(specify relationship)*		10

Participant ID:_____

SECTION C: Demographic Information

We are going to begin with some basic questions about the patient.

C.1 What is the patient's date of birth? (mm/dd/yyyy)

DOB: __ __ / __ __ / __ __ __ __
Don't Know 99
Declined 50

C.2 What is the patient's place of birth?

City: _____ State: __ __
Country: _____
Don't Know 99
Declined 50

C.3 What is the patient's gender?

Male 1
Female 2

C.4 What is the patient's Race or Ethnicity?

White/Caucasian	1
Black/African-American	2
Hispanic/Latino	3
Native Hawaiian/Pacific Islander	4
Native American/Alaskan Native	5
Asian/Asian-American	6
Other: _____ *(specify)*	7
Don't Know	99
Declined	50

Participant ID:_____

C.5 What is the patient's marital status?

Married	1	Single, Never Married	5
Separated	2	Don't Know	99
Divorced	3	Declined	50
Widowed	4		

C.6 What was the highest grade in school or level of education the patient completed?

0	1	GED	14
1	2	Vocational Training / Some College	15
2	3	Associate Degree	16
3	4	College Grad	17
4	5	Master's Degree	18
5	6	Doctoral Degree	19
6	7	Some Professional or Graduate School	20
7	8	Don't Know	99
8	9	Declined	50
9	10		
10	11		
11	12		
12	13		

C.7 What was the patient's family's yearly income in the year prior to your diagnosis with ALS? Please include all personal income, income from spouse and income from other members of the patient's household.

Less than $5,000	1	$30,000 - $39,999	7
$5,000 - $9,999	2	$40,000 - $49,999	8
$10,000 - $14,999	3	$50,000 - $59,999	9
$15,000 - $19,999	4	$60,000 and over	10
$20,000 - $24,999	5	Don't Know	99
$25,000 - $29,999	6	Declined	50

Participant ID:_____

SECTION D: ALS Diagnosis

I would now like to ask you a few questions about the patient's ALS.

D.1 Did a doctor diagnose the patient with ALS?

YES		1
NO	Skip to E.1	2
Don't Know	Skip to E.1	99

D.1.1 Was the patient diagnosed with sporadic or familial ALS?

Sporadic	1
Familial	2
Don't Know	99
Declined	50

D.1.2 What month and year was the patient diagnosed with ALS? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

D.1.3 What is the name of the doctor who first diagnosed the patient with ALS?

Doctor's Name: _____

Don't Know 99

Participant ID:_____

D.1.4 Where does the patient's doctor practice medicine?

City: _____ State: __ __

Country: _____

Don't Know 99

D.1.5 What was the patient's **first** ALS-related symptom? Please give one.

Symptom: _____

Don't Know 99

D.1.6 What month and year did the patient notice the first ALS-related symptom? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

*(If "**Fatigue**" is noted as the first symptom, please think of the patient's next noticeable symptom and fill in below. If another symptom or* **Don't Know** *is the reply, skip to* **question E.1***)*

D.1.6.1 What was the patient's **second** ALS-related symptom?

Second Symptom: _____

Don't Know 99

D.1.6.2 What month and year did the patient notice the second ALS-related symptom? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

Participant ID:_____

SECTION E: Work History

In this next section, we will focus on the patient's work history. Please answer the questions for all jobs the patient held, both part-time jobs and full-time jobs, beginning with the most recent job, and going back to 20 years **before** the diagnosis of ALS, which you said was [**QUESTION D.1.2:** _____/_____]. Please include all jobs, not just the jobs worked at Kelly AFB. Also include jobs performed while in the Active Duty Military, Reserves, or National Guard.

Anytime the patient's job description, job title, or the patient's assigned location changed please consider it as a "new" job. We are interested in as much information as you can recall about the patient's duties, responsibilities, and working conditions for each job, including any chemicals or equipment the patient used to fulfill those responsibilities.

(Use the JOB HISTORY WORKSHEET to make sure there are no unexplained gaps in the patient's employment history)

Current or most recent job *(Job #1 on the Job History Worksheet)*

We will begin with the patient's most recent job.

E.1 Was the patient still employed at the time of their death?

YES 1

NO 2

E.2 What was the patient's Job Title? _____

(If the answer given in **question E.2** *is* ***mother, housewife, volunteer, or unemployed****, skip to* **question E.7***)*

E.3 What is the name of the company or organization?

Company Name: _____

Participant ID:_____

E.4 What does the company do or make?

Company Purpose or Product: _____

E.5 What did the patient's division or section do or make?

Division Purpose or Product: _____

E.6 Where was the patient's assigned work location?

City: _____ State: __ __

Country: _____ Military Base: _____

E.6.1 If the patient was assigned to work at a Military Base, what was their job status?

Active Duty	1	Civil Service	4
Reserves	2	Contractor	5
National Guard	3	Non-appropriated Funds	6
		Don't Know	99

E.7 What was the month and year the patient started this job? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

E.8 What was the month and year the patient ended this job? (mm/yyyy)

Date: __ __ / __ __ __ __

Still Employed 1

Don't Know 99

Participant ID:_____

E.9 On average, how many hours per week did the patient work?

Number of hours per week: __ __ __

Don't Know 99

E.10 What were the patient's primary duties or main tasks in this job? *(Record answer in space below)*

_____

_____

_____

E.11 How did the patient accomplish these duties or tasks?
(For example: Type on a computer, drive a forklift, etc. Record answer in space below)

_____

_____

_____

E.12 Please look at the list of chemicals titled "Materials list."
Please indicate the items the patient worked with or came into contact with while doing their job.

(Circle the appropriate material numbers for your response. Also, please put the appropriate job number in the upper left hand corner of the Materials List, and fill in the blanks if you choose any of the "Other" materials.)

E.13 Prior to [QUESTION D.1.2: _____/_____], did the patient ever see a doctor for health problems related to a chemical exposure while working at this job?

YES		1
NO	Skip to **E.14**	2
Don't Know	Skip to **E.14**	99

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Participant ID:_____

E.13.1 Please list the agent or agents and describe what happened.

Agent: _____

Incident: _____

_____

_____

(Use the SUPPLEMENTAL SHEETS for all jobs prior to the most recent.)

E.14 Either on or off the job, prior to **[QUESTION D.1.2: ____/_____]**, did the patient ever received a severe electrical shock that resulted in unconsciousness?

YES 1
NO **Skip to E.15** 2
Don't Know **Skip to E.15** 99

E.14.1 At what age did the patient first receive a shock that resulted in unconsciousness?

Age: __ __
Don't Know 99

E.15 Either on or off the job, prior to **[QUESTION D.1.2: ____/_____]**, did the patient ever received a severe electrical shock that resulted in a burn?

YES 1
NO **Skip to E.16** 2
Don't Know **Skip to E.16** 99

E.15.1 At what age did the patient receive a shock that resulted in a burn?

Age: __ __
Don't Know 99

Participant ID:_____

E.16 Either on or off the job, prior to **[QUESTION D.1.2: ____/_____]**, did the patient ever received an electrical shock, but one that did not result in injury?

YES 1
NO **Skip to F.1** 2
Don't Know **Skip to F.1** 99

E.16.1 At what age did the patient receive a shock that did not result in injury?

Age: __ __
Don't Know 99

Participant ID:_____

SECTION F: Medical History

We are now interested in any health condition the patient had diagnosed by a doctor prior to the diagnosis of ALS, which you said was [QUESTION D.1.2: ____/_____].

F.1 Did a doctor ever diagnose the patient with Arthritis?

YES		1
NO	Skip to F.2	2
Don't Know	Skip to F.2	99

F.1.1 Was the patient diagnosed with Rheumatoid or Osteo-arthritis?

Rheumatoid	1
Osteo	2
Don't Know	99

F.1.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

F.2 Did a doctor ever diagnose the patient with Cancer?

YES		1
NO	Skip to F.3	2
Don't Know	Skip to F.3	99

F.2.1 With what type or types of Cancer was the patient diagnosed?

Cancer Type 1: _____

Don't Know 99

Participant ID:_____

F.2.1.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

F.2.2 Cancer Type 2: _____

Don't Know 99

F.2.2.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

F.2.3 Cancer Type 3: _____

Don't Know 99

F.2.3.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

F.3 Did a doctor ever diagnose the patient with Diabetes?

YES		1
NO	Skip to F.4	2
Don't Know	Skip to F.4	99

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F.3.1 With what type of diabetes was the patient diagnosed? Type I Diabetes, which is also known as Juvenile Onset Diabetes, or Type II diabetes, which is also known as Adult Onset diabetes?

Type I (Juvenile) 1
Type II (Adult Onset) 2
Don't Know 99

F.3.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.4 Did a doctor ever diagnose the patient with Asthma or Reactive Airway Disease?

YES 1
NO Skip to F.5 2
Don't Know Skip to F.5 99

F.4.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.5 Did a doctor ever diagnose the patient with Epilepsy?

YES 1
NO Skip to F.6 2
Don't Know Skip to F.6 99

Participant ID:_____

F.5.1 With what type of Epilepsy was the patient diagnosed?

Type of Epilepsy: _____
Don't Know 99

F.5.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.6 Did a doctor ever diagnose the patient with a Heart Disease or Heart Condition?

YES 1
NO Skip to F.7 2
Don't Know Skip to F.7 99

F.6.1 With what type of Heart Disease or Heart Condition was the patient diagnosed?

Type of Heart Disease or Condition: _____
Don't Know 99

F.6.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

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F.7 Did a doctor ever diagnose the patient with <u>High Blood Pressure</u>?

YES 1
NO Skip to **F.8** 2
Don't Know Skip to **F.8** 99

F.7.1 With what type of <u>High Blood Pressure</u> was the patient diagnosed?

Type of High Blood Pressure: _____
Don't Know 99

F.7.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.8 Did a doctor ever diagnose the patient with a <u>Kidney Disease</u>?

YES 1
NO Skip to **F.9** 2
Don't Know Skip to **F.9** 99

F.8.1 With what type of <u>Kidney Disease</u> was the patient diagnosed?

Type of Kidney Disease: _____
Don't Know 99

F.8.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

Participant ID:_____

F.9 Did a doctor ever diagnose the patient with a <u>Liver Disease</u>?

YES 1
NO Skip to **F.10** 2
Don't Know Skip to **F.10** 99

F.9.1 With what type of <u>Liver Disease</u> was the patient diagnosed?

Type of Liver Disease: _____
Don't Know 99

F.9.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.10 Did a doctor ever diagnose the patient with <u>Polio</u>?

YES 1
NO Skip to **F.11** 2
Don't Know Skip to **F.11** 99

F.10.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

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F.11 Did a doctor ever diagnose the patient with Rheumatic Fever or Scarlet Fever?

YES 1
NO Skip to **F.12** 2
Don't Know Skip to **F.12** 99

F.11.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.12 Did a doctor ever diagnose the patient with a Stroke?

YES 1
NO Skip to **F.13** 2
Don't Know Skip to **F.13** 99

F.12.1 Was the patient diagnosed with a Hemorrhagic or Ischemic Type Stroke?

Hemorrhagic 1
Ischemic 2
Don't Know 99

(*For clarification: Hemorrhagic strokes result from an burst blood vessel. Ischemic strokes result from a blood clot.*)

F.12.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.13 Did a doctor ever diagnose the patient with an Autoimmune Disorder?

YES 1
NO Skip to **F.14** 2
Don't Know Skip to **F.14** 99

F.13.1 With what type of Autoimmune Disorder was the patient diagnosed?

Type of Autoimmune Disorder: _____
Don't Know 99

F.13.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.14 Did a doctor ever diagnose the patient with a Thyroid Disease?

YES 1
NO Skip to **F.15** 2
Don't Know Skip to **F.15** 99

F.14.1 With what type of Thyroid Disease was the patient diagnosed?

Type of Thyroid Disease: _____
Don't Know 99

Participant ID:_____

F.14.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.15 Did a doctor ever diagnose the patient with a Motor Neuron Disease other than ALS? *(Examples include: Primary Lateral Sclerosis, Progressive Muscular Atrophy, Kennedy's Disease, and Progressive Bulbar Palsy)*

YES 1
NO Skip to **F.16** 2
Don't Know Skip to **F.16** 99

F.15.1 With what type of Motor Neuron Disease was the patient diagnosed?

Type of Motor Neuron Disease: _____
Don't Know 99

F.15.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.16 Did the patient have any other medical conditions you would like to tell me about?

YES 1
NO Skip to **G.1** 2
Don't Know Skip to **G.1** 99

Participant ID:_____

F.16.1 With what other medical conditions was the patient diagnosed?

Other Medical Condition 1: _____

F.16.1.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.16.2 Other Medical Condition 2: _____

F.16.2.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.16.3 Other Medical Condition 3: _____

F.16.3.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

Participant ID:_____

SECTION G: History of Infection or Trauma

This section contains questions regarding the patient's history of specific infections or trauma in the year prior to the diagnosis of ALS, which you said was [QUESTION D.1.2: ____/_____].

G.1 During the year before [QUESTION D.1.2: ____/_____], did a doctor prescribe the patient antibiotics for an illness or infection?

YES 1
NO Skip to G.2 2
Don't Know Skip to G.2 99

G.1.1 What were the antibiotics for? _____

Don't Know 99

G.1.2 When were the antibiotics prescribed? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

G.1.3 As a result of the illness or infection for which the patient was taking antibiotics, did the patient have to spend the night in a hospital?

YES 1
NO 2
Don't Know 99

Participant ID:_____

G.2 During the year before [QUESTION D.1.2: ____/_____], did the patient have any injury, such as a broken bone, which required a visit to a doctor or an Emergency Room?

YES 1
NO Skip to G.3 2
Don't Know Skip to G.3 99

G.2.1 When did this injury occur? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

G.2.2 Please describe the injury, how the patient was injured and what part of their body was injured.

Type of Injury: _____

Cause of Injury: _____

Body Part Injured: _____

G.2.3 Did the patient have to spend at least one night in the hospital because of the injury?

YES 1
NO 2
Don't Know 99

G.2.4 Did the patient have to have surgery because of the injury?

YES 1
NO 2
Don't Know 99

G.3 During the year prior to [QUESTION D.1.2: ____/_____], did the patient have surgery for reasons other than injury?

YES 1
NO Skip to **H.1** 2
Don't Know Skip to **H.1** 99

G.3.1 What kind of surgery?

Type of Surgery: _____

G.3.2 When did you have the surgery? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

G.3.3 Did the patient have to spend at least one night in a hospital?

YES 1
NO 2
Don't Know 99

SECTION H: Immunization History

Now you will be asked some questions about any vaccines the patient may have received in the year prior to the diagnosis of ALS, which you said was [QUESTION D.1.2: ____/_____].

H.1 Was the patient given the MMR (Measles, Mumps, Rubella) shot?

YES 1
NO Skip to **H.2** 2
Don't Know Skip to **H.2** 99

H.1.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.1.2 Did the patient have any side effects you think were related to this shot?

YES 1
NO Skip to **H.2** 2
Don't Know Skip to **H.2** 99

H.1.2.1 What were the side effects?

Side Effects: _____

H.1.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

H.2 Was the patient given the Tetanus/Diptheria shot?

Participant ID:_____

YES 1
NO Skip to H.3 2
Don't Know Skip to H.3 99

H.2.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.2.2 Did the patient have any side effects you think were related to this shot?

YES 1
NO Skip to H.3 2
Don't Know Skip to H.3 99

H.2.2.1 What were the side effects?

Side Effects: _____

H.2.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

Participant ID:_____

H.3 Was the patient given the DPT (Diptheria/Pertussis/Tetanus) shot?

YES 1
NO Skip to H.4 2
Don't Know Skip to H.4 99

H.3.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.3.2 Did the patient have any side effects you think were related to this shot?

YES 1
NO Skip to H.4 2
Don't Know Skip to H.4 99

H.3.2.1 What were the side effects?

Side Effects: _____

H.3.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

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H.4 Was the patient given the Flu shot?

YES		1
NO	Skip to **H.5**	2
Don't Know	Skip to **H.5**	99

H.4.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.4.2 Did the patient have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.5**	2
Don't Know	Skip to **H.5**	99

H.4.2.1 What were the side effects?

Side Effects: _____

H.4.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID:_____

H.5 Was the patient given the Polio shot?

YES		1
NO	Skip to **H.6**	2
Don't Know	Skip to **H.6**	99

H.5.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.5.2 Did the patient have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.6**	2
Don't Know	Skip to **H.6**	99

H.5.2.1 What were the side effects?

Side Effects: _____

H.5.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID:_____

H.6 Was the patient given the Chicken Pox or Varicella shot?

YES		1
NO	Skip to **H.7**	2
Don't Know	Skip to **H.7**	99

H.6.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.6.2 Did the patient have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.7**	2
Don't Know	Skip to **H.7**	99

H.6.2.1 What were the side effects?

Side Effects: _____

H.6.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID:_____

H.7 Was the patient given the Hepatitis A shot?

YES		1
NO	Skip to **H.8**	2
Don't Know	Skip to **H.8**	99

H.7.1 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.7.2 Did the patient have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.8**	2
Don't Know	Skip to **H.8**	99

H.7.2.1 What were the side effects?

Side Effects: _____

H.7.2.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

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H.8 Did the patient start or complete the Hepatitis B series of shots?

YES		1
NO	Skip to **H.9**	2
Don't Know	Skip to **H.9**	99

H.8.1 How many shots had the patient already received?

1.....1
2.....2
3.....3

H.8.2 When did the patient receive the last shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.8.3 Did the patient have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.9**	2
Don't Know	Skip to **H.9**	99

H.8.3.1 What were the side effects, and with which shot did the patient have them?

Side Effects: _____
Shot Number(s): ___
Don't Know 99

Participant ID:_____

H.8.3.2 How long after receiving the shot did the patient experience this side effect? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

H.9 Was the patient given any other vaccine during the year prior to [QUESTION D.1.2: ____/_____]?

YES		1
NO	Skip to **H.10**	2
Don't Know	Skip to **H.10**	99

H.9.1 What shot did the patient get?_____

H.9.2 When was the patient given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.9.3 Did the patient have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.10**	2
Don't Know	Skip to **H.10**	99

H.9.3.1 What were the side effects?

Side Effects: _____

Participant ID:_____

H.9.3.2 How long after receiving the shot did the patient experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

H.10 Has the patient ever been given the Anthrax vaccine?

YES		1
NO	Skip to **I.1**	2
Don't Know	Skip to **I.1**	99

H.10.1 Why did the patient receive the anthrax vaccine?

Military	1
Job	2
Other: _____ *(specify)*	3
Don't Know	99

H.10.2 How many shots had the patient been given?

1.....1	5.....5
2.....2	6.....6
3.....3	7+.....7
4.....4	Don't Know....99

H.10.3 When did the patient get the last shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

Participant ID:_____

H.10.4 Did the patient have any side effects you think were related to the anthrax shot?

YES		1
NO	Skip to **I.1**	2
Don't Know	Skip to **I.1**	99

H.10.4.1 What were the side effects?

Side Effects: _____

H.10.4.2 How long after receiving the shot did the patient experience this side effect? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

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SECTION I

Family Medical History

Now you will be asked some questions about the patient's family members and their medical histories. Please answer the questions regarding medical history to the best of your knowledge for all blood-related family members, including those who are no longer alive.
We would like to know which family member was diagnosed with each condition. If the condition has multiple types, we would also like to know with which type the patient's family member was diagnosed. For example, Arthritis has two types: Rheumatoid and Osteo. *(For the questions about the family member diagnosed and the type of disease diagnosed, circle the appropriate number and fill in the blank with the appropriate type)*

I.1 Was the patient adopted by the family who raised him/her?

YES	1
NO	2
Don't Know	99

I.2 Has a doctor diagnosed anyone in the patient's family with ALS

YES		1
NO	Skip to **I.3**	2
Don't Know	Skip to **I.3**	99

I.2.1 Which family member was diagnosed, and what type did they have (*Sporadic or Familial*)?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.3 Has a Doctor diagnosed anyone in the patient's family with Arthritis?

YES		1
NO	Skip to **I.4**	2
Don't Know	Skip to **I.4**	99

I.3.1 Which family member was diagnosed, and what type did they have? *(Rheumatoid or Osteo)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.4 Has a Doctor diagnosed anyone in the patient's family with Cancer?

YES		1
NO	Skip to **I.5**	2
Don't Know	Skip to **I.5**	99

I.4.1 Which family member was diagnosed, and what type did they have? *(Prostate, Lung, Liver, etc.)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID:_____

I.5 Has a Doctor diagnosed anyone in the patient's family with Diabetes?

YES		1
NO	Skip to I.6	2
Don't Know	Skip to I.6	99

I.5.1 Which family member was diagnosed, and what type did they have? *(Type I or Type II)*

Father 1	_____	Grandmother 6	_____
Mother.....2	_____	Grandfather 7	_____
Brother.....3	_____	Grandchild 8	_____
Sister 4	_____	Other 9	_____
Child 5	_____	Don't Know 99	

I.6 Has a Doctor diagnosed anyone in the patient's family with Asthma or Reactive Airway Disease?

YES		1
NO	Skip to I.7	2
Don't Know	Skip to I.7	99

I.6.1 Which family member was diagnosed?

Father 1	Grandmother 6
Mother.....2	Grandfather 7
Brother.....3	Grandchild 8
Sister 4	Other 9
Child 5	Don't Know 99

Participant ID:_____

I.7 Has a Doctor diagnosed anyone in the patient's family with Epilepsy?

YES		1
NO	Skip to I.8	2
Don't Know	Skip to I.8	99

I.7.1 Which family member was diagnosed, and what type did they have?
(Partial or Generalized Seizures, Grand Mal or Petit Mal Seizures)

Father 1	_____	Grandmother 6	_____
Mother.....2	_____	Grandfather 7	_____
Brother.....3	_____	Grandchild 8	_____
Sister 4	_____	Other 9	_____
Child 5	_____	Don't Know 99	

I.8 Has a Doctor diagnosed anyone in the patient's family with Heart Disease or Heart Condition?

YES		1
NO	Skip to I.9	2
Don't Know	Skip to I.9	99

I.8.1 Which family member was diagnosed, and what type did they have?
(Coronary Artery Disease, Arrhythmia, Murmur, etc.)

Father 1	_____	Grandmother 6	_____
Mother.....2	_____	Grandfather 7	_____
Brother.....3	_____	Grandchild 8	_____
Sister 4	_____	Other 9	_____
Child 5	_____	Don't Know 99	

Participant ID:_____

I.9 Has a Doctor diagnosed anyone in the patient's family with High Blood Pressure?

YES		1
NO	Skip to **I.10**	2
Don't Know	Skip to **I.10**	99

I.9.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

I.10 Has a Doctor diagnosed anyone in the patient's family with a Kidney Disease?

YES		1
NO	Skip to **I.11**	2
Don't Know	Skip to **I.11**	99

I.10.1 Which family member was diagnosed, and what type did they have?
(Kidney Stones, Renal Failure, Chronic Urinary Tract Infections, etc)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID:_____

I.11 Has a Doctor diagnosed anyone in the patient's family with a Liver Disease?

YES		1
NO	Skip to **I.12**	2
Don't Know	Skip to **I.12**	99

I.11.1 Which family member was diagnosed, and what type did they have? *(Hepatitis, Cirrhosis, etc.)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.12 Has a Doctor diagnosed anyone in the patient's family with Polio?

YES		1
NO	Skip to **I.13**	2
Don't Know	Skip to **I.13**	99

I.12.1 Which family member was diagnosed with Polio?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

Participant ID:_____

I.13 Has a Doctor diagnosed anyone in the patient's family with Rheumatic Fever or Scarlet Fever?

YES		1
NO	Skip to **I.14**	2
Don't Know	Skip to **I.14**	99

I.13.1 Which family member was diagnosed with Rheumatic Fever or Scarlet Fever?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

I.14 Has a Doctor diagnosed anyone in the patient's family with a Stroke?

YES		1
NO	Skip to **I.15**	2
Don't Know	Skip to **I.15**	99

I.14.1 Which family member was diagnosed, and what type did they have (*Hemorrhagic or Ischemic*)?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID:_____

I.15 Has a Doctor diagnosed anyone in the patient's family with an Autoimmune Disorder?

YES		1
NO	Skip to **I.16**	2
Don't Know	Skip to **I.16**	99

I.15.1 Which family member was diagnosed, and what type did they have?
(Lupus, Multiple Sclerosis, Graves Disease)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.16 Has a Doctor diagnosed anyone in the patient's family with Parkinson's Disease?

YES		1
NO	Skip to **I.17**	2
Don't Know	Skip to **I.17**	99

I.16.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

Participant ID:_____

I.17 Has a Doctor diagnosed anyone in the patient's family with Alzheimer's Disease?

YES		1
NO	Skip to **I.18**	2
Don't Know	Skip to **I.18**	99

I.17.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

I.18 Has a Doctor diagnosed anyone in the patient's family with a Motor Neuron Disease, other than ALS?
(Examples include: Primary Lateral Sclerosis, Progressive Muscular Atrophy, Kennedy's Disease, and Progressive Bulbar Palsy)

YES		1
NO	Skip to **I.19**	2
Don't Know	Skip to **I.19**	99

I.18.1 Which family member was diagnosed, and what type did they have?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID:_____

I.19 Has a Doctor diagnosed anyone in the patient's family with a Thyroid Disease?

YES		1
NO	Skip to **I.20**	2
Don't Know	Skip to **I.20**	99

I.19.1 Which family member was diagnosed, and what type did they have?
(Hypothyroidism, Hyperthyroidism, Goiter, etc.)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.20 Are there any other family medical conditions you would like to tell me about?

YES		1
NO	Skip to **J.1**	2
Don't Know	Skip to **J.1**	99

I.20.1 Which family member was diagnosed, and what type of condition did they have?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

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Participant ID:_____

SECTION J

Military Service History

Now you will be asked some questions about time the patient may have spent in the Military. This will include any time spent on Reserves or National Guard status.

J.1 Did the patient ever serve in the Military? *(Includes Army, Air Force, Coast Guard, Marines, Navy, National Guard, Merchant Marines, Public Health Service; Active Duty and Reserves.)*

YES		1
NO	Skip to K.1	2
Don't Know	Skip to K.1	99

J.2 Was the patient ever on Active Duty Military status?

YES		1
NO	Skip to J.3	2
Don't Know	Skip to J.3	99

J.2.1 In what branch did the patient serve and during which years? (yyyy-yyyy)

Army	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Air Force	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Navy	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Marines	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Coast Guard	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Merchant Marines	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Public Health Service	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Other	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __

Participant ID:_____

J.3 Was the patient ever in the Reserves?

YES		1
NO	Skip to J.4	2
Don't Know	Skip to J.4	99

J.3.1 In what branch did the patient serve and during which years? (yyyy-yyyy)

Army	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Air Force	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Navy	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Marines	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Coast Guard	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Merchant Marines	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Public Health Service	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Other	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __

J.4 Was the patient ever in the National Guard?

YES		1
NO	Skip to J.5	2
Don't Know	Skip to J.5	99

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Participant ID:_____

J.4.1 In what branch did the patient serve and during which years? (yyyy-yyyy)

Army	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Air Force	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Navy	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Marines	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Coast Guard	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Merchant Marines	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Public Health Service	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Other	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _

J.5 Did the patient serve in World War II?

YES		1
NO	Skip to J.4	2
Don't Know	Skip to J.4	99

J.5.1 What years did the patient serve in WWII? (yyyy-yyyy) _ _ _ _ - _ _ _ _

Don't Know 99

J.5.2 Where did the patient serve?

Pacific	1	Neither	4
Europe	2	Don't Know	99
Both	3		

J.5.3 What was the patient's primary duty?

Primary Duty: _____

Don't Know 99

Participant ID:_____

J.6 Did the patient serve in the Korean War?

YES		1
NO	Skip to J.7	2
Don't Know	Skip to J.7	99

J.6.1 What years did the patient serve in Korea? (yyyy-yyyy) _ _ _ _ - _ _ _ _

Don't Know 99

J.6.2 What was the patient's primary duty?

Primary Duty: _____

Don't Know 99

J.6.3 If the patient served more than one tour, please list the other years along with primary duties

Tour 2 Dates: (yyyy-yyyy) _ _ _ _ - _ _ _ _

Don't Know 99

Tour 2 Primary Duty: _____

Don't Know 99

Tour 3 Dates: (yyyy-yyyy) _ _ _ _ - _ _ _ _

Don't Know 99

Tour 3 Primary Duty: _____

Don't Know 99

Tour 4 Dates: (yyyy-yyyy) _ _ _ _ - _ _ _ _

Don't Know 99

Tour 4 Primary Duty: _____

Don't Know 99

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Participant ID:_____

J.7 Did the patient serve in the Vietnam War?

YES 1
NO Skip to **J.8** 2
Don't Know Skip to **J.8** 99

J.7.1 What years did the patient serve in Vietnam? (yyyy-yyyy)

Dates: _ _ _ _ - _ _ _ _
Don't Know 99

J.7.2 What was the patient's primary duty?

Primary Duty: _____
Don't Know 99

J.7.3 If the patient served more than one tour, please list the years of the patient's additional tours along with primary duties?

Tour 2 Dates: (yyyy-yyyy) _ _ _ _ - _ _ _ _
Don't Know 99

Tour 2 Primary Duty: _____
Don't Know 99

Tour 3 Dates: (yyyy-yyyy) _ _ _ _ - _ _ _ _
Don't Know 99

Tour 3 Primary Duty: _____
Don't Know 99

Participant ID:_____

Tour 4 Dates: (yyyy-yyyy) _ _ _ _ - _ _ _ _
Don't Know 99

Tour 4 Primary Duty: _____
Don't Know 99

J.8 Did the patient serve in the Gulf War?

YES 1
NO Skip to **J.9** 2
Don't Know Skip to **J.9** 99

J.8.1 What were the dates the patient served? (mm/yyyy)

Began Service: _ _ / _ _ _ _
Don't Know 99
Ended Service : _ _ / _ _ _ _
Don't Know 99

J.8.2 What was the patient primary duty?

Primary Duty: _____
Don't Know 99

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Participant ID:_____

J.9 To the best of your knowledge, was the patient ever exposed to any chemical or biologic agents?

YES		1
NO	Skip to **J.10**	2
Don't Know	Skip to **J.10**	99

J.9.1 If you know the agents the patient was exposed to, please list them.

Agents: _____

Don't Know 99

J.10 To the best of your knowledge, was the patient exposed to any ionizing or non-ionizing radiation?

YES		1
NO	Skip to **J.11**	2
Don't Know	Skip to **J.11**	99

J.10.1 If you know the sources the patient was exposed to, please list them.

Sources: _____

Don't Know 99

J.11 Was the patient ever a Prisoner of War (POW)?

YES		1
NO	Skip to **K.1**	2
Don't Know	Skip to **K.1**	99

J.11.1 What were the years of the patient's imprisonment? (yyyy)

Began: __ __ __ __

Don't Know 99

Ended: __ __ __ __

Don't Know 99

J.11.2 In what war was the patient a POW?

War: _____

Don't Know 99

J.11.3 Where was the patient imprisoned?

City, Country: _____

Don't Know 99

J.11.4 Was the patient imprisoned in any other wars?

YES		1
NO	Skip to **K.1**	2
Don't Know	Skip to **K.1**	99

J.11.4.1 What were the years of the patient's imprisonment? (yyyy)

Began: __ __ __ __

Don't Know 99

Ended: __ __ __ __

Don't Know 99

Participant ID:_____

J.11.4.2 In what war was the patient a POW?

War: _____

Don't Know 99

J.11.4.3 Where was the patient imprisoned?

City, Country: _____

Don't Know 99

Participant ID:_____

SECTION K: Residential History

Beginning with the patient's address at the time the patient was diagnosed with ALS, which you said was **[QUESTION D.1.2: ____/_____]**, and moving back in time, please answer the following questions for each home the patient lived in over the **20** years prior to the diagnosis of ALS.

(Use the RESIDENTIAL HISTORY WORKSHEET to make sure there are no unexplained gaps in the residential history. On the supplemental sheets enter residences lived in prior to the one at the time of ALS diagnosis.)

K.1 Where did the patient live when he/she was diagnosed with ALS?

Street: _____ Apt. # _____

City: _____ State: __ __ Zip _____

K.1.1 When did he/she live there? (mm/yyyy):

Move In Date: __ __ / __ __ __ __

Don't Know 99

Move Out Date: __ __ / __ __ __ __

Don't Know 99

K.1.2 What type of residence was it?

Mobile Home 1
Apartment 2
House 3
Duplex.....4
Other .....5 _____ *(Specify)*

K.1.3 Did the patient's home have an attached garage?

YES		1
NO	Skip to **K.1.4**	2
Don't Know	Skip to **K.1.4**	99

K.1.3.1 Did the patient store his/her car or truck inside?

YES	1
NO	2
Don't Know	99

K.1.4 Was this residence a farm or a ranch?

YES	1
NO	2
Don't Know	99

K.1.5 When was the residence built? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

K.1.6 Did the patient remodel the home while he/she lived there?

YES		1
NO	Skip to **L.1**	2
Don't Know	Skip to **L.1**	99

K.1.6.1 Please describe the changes made:

Changes: _____
_____
_____
_____

(On the supplemental sheets enter residences lived in prior to the one at the time of ALS diagnosis.)

Participant ID:_____

SECTION L: Recreational Activities

We are interested in any recreational activities the patient participated in on a regular basis. Please answer "Yes" for any activity the patient participated in at least 6 times a year. Do not include activities the patient participated in only once in his/her life, or only once or twice a year.
If the patient participated in the activity, we also would like to know if he/she participated in their childhood or their adulthood. Childhood meaning when the patient was less than 18 years old, and adulthood meaning from his/her 18th birthday until they were diagnosed with ALS, which you said was [QUESTION D.1.2: _____/_____]. If the patient participated in the activity during both periods of life, please answer "Yes" for both the child and adult questions.

L.1 Did the patient ever participate in Oil-based Painting on a regular basis?

YES		1
NO	Skip to L.2	2
Don't Know	Skip to L.2	99

L.1.1 Did the patient paint as a child?

YES	1
NO	2
Don't Know	99

L.1.2 Did the patient paint as an adult?

YES	1
NO	2
Don't Know	99

L.2 Did the patient ever Repaired/Maintained a Car or Truck on a regular basis?

YES		1
NO	Skip to L.3	2
Don't Know	Skip to L.3	99

L.2.1 Did the patient work on his/her car or truck as a child?

YES	1
NO	2
Don't Know	99

L.2.2 Did the patient work on his/her car or truck as an adult?

YES	1
NO	2
Don't Know	99

L.3 Did the patient ever participate in Gardening on a regular basis?

YES		1
NO	Skip to L.4	2
Don't Know	Skip to L.4	99

L.3.1 Did the patient participate in gardening as a child?

YES	1
NO	2
Don't Know	99

Participant ID:_____

L.3.2 Did the patient participate in gardening as an adult?

YES	1
NO	2
Don't Know	99

L.4 Did the patient ever participate in any kind of Glasswork (i.e. Stained or Lead) on a regular basis?

YES		1
NO	Skip to L.5	2
Don't Know	Skip to L.5	99

L.4.1 Did the patient participate in glasswork as a child?

YES	1
NO	2
Don't Know	99

L.4.2 Did the patient participate in glasswork as an adult?

YES	1
NO	2
Don't Know	99

L.5 Did the patient ever go Hiking or Camping on a regular basis?

YES		1
NO	Skip to L.6	2
Don't Know	Skip to L.6	99

L.5.1 Did the patient go hiking or camping as a child?

YES	1
NO	2
Don't Know	99

L.5.2 Did the patient go hiking or camping as an adult?

YES	1
NO	2
Don't Know	99

L.6 Did the patient ever participate in Hunting on a regular basis?

YES		1
NO	Skip to L.7	2
Don't Know	Skip to L.7	99

L.6.1 Did the patient participate in hunting as a child?

YES	1
NO	2
Don't Know	99

L.6.2 Did the patient participate in hunting as an adult?

YES	1
NO	2
Don't Know	99

Participant ID:_____

L.7 Did the patient ever participate in Jewelry Making on a regular basis?

YES		1
NO	Skip to **L.8**	2
Don't Know	Skip to **L.8**	99

L.7.1 Did the patient participate in jewelry making as a child?

YES	1
NO	2
Don't Know	99

L.7.2 Did the patient participate in jewelry making as an adult?

YES	1
NO	2
Don't Know	99

L.8 Did the patient ever participate in Model Building (cars, boats, planes, etc.)on a regular basis?

YES		1
NO	Skip to **L.9**	2
Don't Know	Skip to **L.9**	99

L.8.1 Did the patient build models as a child?

YES	1
NO	2
Don't Know	99

Participant ID:_____

L.8.2 Did the patient build models as an adult?

YES	1
NO	2
Don't Know	99

L.9 Did the patient ever participate in Motor Cross/Car Racing on a regular basis?

YES		1
NO	Skip to **L.10**	2
Don't Know	Skip to **L.10**	99

L.9.1 Did the patient participate in Motor Cross/Car Racing as a child?

YES	1
NO	2
Don't Know	99

L.9.2 Did the patient participate in Motor Cross/Car Racing as an adult?

YES	1
NO	2
Don't Know	99

L.10 Did the patient ever participate in Motor Cross/Car Racing, as a spectator on a regular basis?

YES		1
NO	Skip to **L.11**	2
Don't Know	Skip to **L.11**	99

Participant ID:_____

L.10.1 Did the patient attend Motor Cross/Car Races as a child?

YES 1
NO 2
Don't Know 99

L.10.2 Did the patient attend Motor Cross/Car Races as an adult?

YES 1
NO 2
Don't Know 99

L.11 Did the patient ever participate in Photography, this must include developing his/her own pictures, on a regular basis?

YES 1
NO Skip to **L.12** 2
Don't Know Skip to **L.12** 99

L.11.1 Did the patient participate in photography as a child?

YES 1
NO 2
Don't Know 99

L.11.2 Did the patient participate in photography as an adult?

YES 1
NO 2
Don't Know 99

L.12 Did the patient ever participate in Pottery Making on a regular basis?

YES 1
NO Skip to **L.13** 2
Don't Know Skip to **L.13** 99

L.12.1 Did the patient participate in pottery making as a child?

YES 1
NO 2
Don't Know 99

L.12.2 Did the patient participate in pottery making as an adult?

YES 1
NO 2
Don't Know 99

L.13 Did the patient ever participate in furniture refinishing on a regular basis?

YES 1
NO Skip to **L.14** 2
Don't Know Skip to **L.14** 99

L.13.1 Did the patient participate in furniture refinishing as a child?

YES 1
NO 2
Don't Know 99

Participant ID:_____

L.13.2 Did the patient participate in furniture refinishing as an adult?

YES 1
NO 2
Don't Know 99

L.14 Did the patient ever participate in Woodworking or Carpentry on a regular basis?

YES 1
NO Skip to **L.15** 2
Don't Know Skip to **L.15** 99

L.14.1 Did the patient participate in woodworking or carpentry as a child?

YES 1
NO 2
Don't Know 99

L.14.2 Did the patient participate in woodworking or carpentry as an adult?

YES 1
NO 2
Don't Know 99

L.15 Did the patient ever participate in any other type of Arts and Crafts on a regular basis?

YES 1
NO Skip to **L.16** 2
Don't Know Skip to **L.16** 99

L.15.1 Please specify: _____

Participant ID:_____

L.15.2 Did the patient participate in any type of Crafts as a child?

YES 1
NO 2
Don't Know 99

L.15.3 Did the patient participate in any type of crafts as an adult?

YES 1
NO 2
Don't Know 99

L.16 Are there any other activities that the patient participated in on a regular basis?

YES 1
NO Skip to **M.1** 2
Don't Know Skip to **M.1** 99

L.16.1 Please list each activity and whether the patient participated in the activity as a child, adult, or both.

Activity 1: _____
Adult 1
Child 2
Both 3

Activity 2 _____
Adult 1
Child 2
Both 3

Activity 3 _____
Adult 1
Child 2
Both 3

Participant ID:_____

SECTION M: Physical Activity

Now you will be asked some questions regarding the patient's participation in organized sports programs.

M.1 Did the patient participate in organized athletics during high school?

YES		1
NO	Skip to **M.2**	2
Don't Know	Skip to **M.2**	99

M.1.1 Did the patient letter or "make the varsity team" in one or more sports?

YES	1
NO	2
Don't Know	99

M.1.2 Please list the sports the patient lettered in.

Sports List: _____

(If the patient attended college, aswered QUESTIONS **M.2** through **M.3.1.1**. *If the patient did not attend college, skip to* QUESTION **M.4***)*

M.2 Did the patient participate in intramural athletic activities during college?

YES		1
NO	Skip to **M.3**	2
Don't Know	Skip to **M.3**	99

M.2.1 Please list the sports the patient participated in.

Sports List: _____

M.3 Did the patient participate in intercollegiate sports during college?

YES		1
NO	Skip to **M.4**	2
Don't Know	Skip to **M.4**	99

M.3.1 Did the patient letter in one or more sports?

YES	1
NO	2
Don't Know	99

M.3.1.1 Please list the sports the patient lettered in.

Sports List: _____

M.4 Was the patient ever employed as a professional or semi-professional athlete?

YES		1
NO	Skip to **M.5**	2
Don't Know	Skip to **M.5**	99

M.4.1 Please specify the sport or sports:

Sports List: _____

Participant ID:_____

M.5 Did the patient ever participate in any community, church, or other socially sponsored sport on a regular basis as an adult?

YES		1
NO	Skip to N.1	2
Don't Know	Skip to N.1	99

M.5.1 Please specify the sport or sports:

Sports List: _____

Participant ID:_____

SECTION N: Tobacco and Alcohol Use

Now you will be asked some questions about the patient's use of or exposure to tobacco and alcohol.

N.1 Did the patient smoke at least 100 cigarettes in his/her lifetime?

YES		1
NO	Skip to N.2	2
Don't Know	Skip to N.2	99

N.1.1 Was the patient still smoking cigarettes at the time of their death?

YES	Skip to N.1.4	1
NO		2

N.1.2 How old was the patient when he/she had his/her last cigarette?

Age: __ __

N.1.3 Overall, how many years did the patient smoke, excluding any years that he/she quit?

Years Smoked: __ __

N.1.4 What was the average number of Cigarettes that the patient smoked per day? *(A PACK CONTAINS 20 CIGARETTES)*

Average Number of Cigarettes Smoked Per Day: __ __

N.1.5 Was the patient still smoking cigarettes when he/she was diagnosed with ALS?

YES	1
NO	2
Don't Know	99

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Participant ID:_____

N.2 In the patient's lifetime did he/she ever live in the same household with a smoker?

YES		1
NO	Skip to N.3	2
Don't Know	Skip to N.3	99

N.2.1 Did this person or persons smoke in the house while the patient was home?

YES	1
NO	2
Don't Know	99

N.3 Prior to **[QUESTION D.1.2: ____/_____]**, did the patient ever drink an alcoholic beverage?

YES		1
NO	Skip to N.4	2
Don't Know	Skip to N.4	99

N.3.1 When did the patient start drinking alcoholic beverages?

Please answer either: AGE or YEAR (yyyy)

Age: __ __ Year: __ __ __ __

N.3.2 Was the patient still drinking alcoholic beverages at the time of their death?

YES		1
NO	Skip to N.3.2	2

Participant ID:_____

N.3.3 When did the patient stop drinking alcoholic beverages?

Please answer either: AGE or YEAR (yyyy)

Age: __ __ Year: __ __ __ __

N.3.4 On average, how many alcoholic beverages did the patient drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

N.3.5 On average, how many glasses (5 ounces) of wine did the patient drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

N.3.6 On average, how many cans (12 ounces) of beer did the patient drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

N.3.7 On average, how many shots (1.5 ounces) of liquor did the patient drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

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Participant ID:_____

Participant Hypotheses

As you are probably aware, research into the possible causes for ALS has been on going for more than 100 years. This survey, although long and fairly comprehensive, cannot ask questions regarding all potential risk factors. Now, we would like for you to think about the questions you have answered, and then record any ideas you may have regarding how you think the patient's ALS onset might have been triggered. This may include ideas regarding nutrition, exercise, a chemical exposure, or you may elaborate further on those questions already discussed.

(RECORD ANSWER IN THE SPACE BELOW)

PATIENT QUESTIONNAIRE

Participant ID: _____

PALS Patient Questionnaire
Kelly Health Issues Working Group
Version 1/11/01

Please read the Instructions sheet before beginning the questionnaire.

In the following questionnaire, please fill in any blanks that are indicated for your response, or circle the appropriate number to the right of the answer choices.

Date Completed (mm/dd/yyyy): __ __ / __ __ / __ __ __ __

Participant ID: _____

SECTION A: Patient Information

This section refers to the person who has ALS.

A.1 Patient's First Name: _____

A.2 Patient's Middle or Maiden Name: _____

A.3 Patient's Last Name: _____

A.4 Patient's Last Name when Employed at Kelly AFB (If different from A.3):_____

A.5 Patient's Social Security Number: __ __ __ -- __ __ -- __ __ __ __

A.6 Patient's Telephone Number: (__ __ __) __ __ __ -- __ __ __ __

A.7 Patient's Address:

Street: _____ Apartment #: _____

_____

City: _____ State: __ __

Zip Code: __ __ __ __ __ - __ __ __ __

Participant ID: _____

Thank you for taking the time to complete this survey. In this questionnaire you will be asked about many different areas of your life, including questions about your family, your medical history, and your hobbies. The purpose of these questions is to help us determine if there is any one thing or several things that you have in common with other patients who have ALS, and the main purpose of our study is to determine if there are more people who have worked at Kelly Air Force Base that have ALS than would be expected.

Before you begin, it is important to mention a few things. All of your responses are completely confidential, and will only be seen or heard by people directly associated with the investigation. No information about any specific individual will ever be reported. Your name will never appear in any report about this study. You may choose not to answer any question or end the interview at any time.

This questionnaire is very lengthy, but you will not have to answer every question. Feel free to rest or take a break as you need to.

If someone is assisting you, the patient, in completing this questionnaire, skip to <u>SECTION B</u>.
If you are answering this questionnaire alone, skip to <u>SECTION C</u> at the beginning of the questionnaire booklet.

SECTION B: Interpreter Information

This section refers to anyone assisting the patient with ALS in completing this questionnaire.

If you are assisting a patient with ALS in completing this questionnaire, we would like to have some information about you, in case we need your assistance again in the future. Your information will receive the same guarantee of confidentiality that we extend to the person you are assisting today.

B.1 What is your name?

First Name: _____
Middle or Maiden Name: _____
Last Name: _____

B.2 What is your address?

Street: _____ Apartment #: _____

City: _____ State: __ __

Zip Code: __ __ __ __ __

B.3 What is your telephone number?

(__ __ __) __ __ __ -- __ __ __ __

Participant ID: _____

B.4 What is your relationship to the patient?

Husband	1	Brother	5
Wife	2	Sister	6
Son	3	Father	7
Daughter	4	Mother	8
Other Relative	_____ *(specify relationship)*		9
Other	_____ *(specify relationship)*		10

Participant ID: _____

SECTION C: Patient Demographic Information

We are going to begin with some basic questions about you, the patient.

C.1 What is your date of birth? (mm/dd/yyyy)

DOB: __ __ / __ __ / __ __ __ __
Don't Know 99
Declined 50

C.2 What is your place of birth?

City: _____ State: __ __
Country: _____
Don't Know 99
Declined 50

C.3 What is your gender?

Male 1
Female 2

C.4 What is your Race or Ethnicity?

White/Caucasian 1
Black/African-American 2
Hispanic/Latino 3
Native Hawaiian/Pacific Islander 4
Native American/Alaskan Native 5
Asian/Asian-American 6
Other: _____ *(specify)*.....7
Don't Know 99
Declined 50

Participant ID: _____

C.5 What is your marital status?

Married	1	Single, Never Married	5
Separated	2	Don't Know	99
Divorced	3	Declined	50
Widowed	4		

C.6 What was the highest grade in school or level of education you completed?

0	1	GED	14
1	2	Vocational Training / Some College	15
2	3	Associate Degree	16
3	4	College Grad	17
4	5	Master's Degree	18
5	6	doctoral Degree	19
6	7	Some Professional or Graduate School	20
7	8	Don't Know	99
8	9	Declined	50
9	10		
10	11		
11	12		
12	13		

C.7 What was your family's yearly income in the year prior to your diagnosis with ALS? Please include all personal income, income from spouse, and income from other members of your household.

Less than $5,000	1	$30,000 - $39,999	7
$5,000 - $9,999	2	$40,000 - $49,999	8
$10,000 - $14,999	3	$50,000 - $59,999	9
$15,000 - $19,999	4	$60,000 and over	10
$20,000 - $24,999	5	Don't Know	99
$25,000 - $29,999	6	Declined	50

Participant ID: _____

SECTION D: ALS Diagnosis

I would now like to ask you a few questions about ALS.

D.1 Has a doctor diagnosed you with ALS?

YES		1
NO	Skip to E.1	2
Don't Know	Skip to E.1	99

D.1.1 Were you diagnosed with sporadic or familial ALS?

Sporadic	1
Familial	2
Don't Know	99
Declined	50

D.1.2 What month and year were you diagnosed with ALS? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

D.1.3 What is the name of the doctor who first diagnosed you with ALS?

Doctor's Name: _____
Don't Know 99

D.1.4 Where does your doctor practice medicine?

City: _____ State: __ __

Country: _____

Don't Know 99

D.1.5 What was your **first** ALS-related symptom? Please give one.

Symptom: _____

Don't Know 99

D.1.6 What month and year did you notice the first ALS-related symptom? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

*(If "**Fatigue**" is noted as your first symptom, please think of your next noticeable symptom and fill in below. If another symptom or* **Don't Know** *is the reply, skip to* **question E.1***)*

D.1.6.1 What was your **second** ALS-related symptom?

Second Symptom: _____

Don't Know 99

D.1.6.2 What month and year did you notice the second ALS-related symptom? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

SECTION E: Work History

In this next section, we will focus on your work history. Please answer the questions for all jobs you have held, both part-time jobs and full-time jobs, beginning with the current or most recent job, and going back to 20 years **before** the diagnosis of ALS, which you said was [QUESTION D.1.2: _____/_____]. Please include all jobs, not just the jobs worked at Kelly AFB. Also include jobs performed while in the Active Duty Military, Reserves, or National Guard.

Anytime your job description, job title, or your assigned location changed please consider it as a "new" job. We are interested in as much information as you can recall about your duties, responsibilities, and working conditions for each job, including any chemicals or equipment you used to fulfill those responsibilities.

(Please use the JOB HISTORY WORKSHEET to make sure there are no unexplained gaps in your employment history)

Current or most recent job *(Job #1 on the Job History Worksheet)*

We will begin with your current or most recent job.

E.1 Are you currently employed?

YES 1

NO 2

E.2 What is/was your Job Title? _____

(If the answer given in **question E.2** *is* ***mother, housewife, volunteer, or unemployed****, skip to* **question E.7***)*

E.3 What is the name of the company or organization?

Company Name: _____

E.4 What does the company do or make?

Company Purpose or Product: _____

Participant ID: _____

E.5 What does/did your division or section do or make?

Division Purpose or Product: _____

E.6 Where is/was your assigned work location?

City: _____ State: __ __

Country: _____ Military Base: _____

E.6.1 If you are/were assigned to work at a Military Base, what is/was your job status?

Active Duty	1	Civil Service	4
Reserves	2	Contractor	5
National Guard	3	Non-appropriated Funds	6
		Don't Know	99

E.7 What was the month and year you started this job? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

E.8 What was the month and year you ended this job? (mm/yyyy)

Date: __ __ / __ __ __ __

Still Employed 1

Don't Know 99

E.9 On average, how many hours per week do/did you work?

Number of hours per week: __ __ __

Don't Know 99

E.10 What are/ were your primary duties or main tasks in this job? *(Record answer in space below)*

_____

_____

_____

E.11 How do/did you accomplish these duties or tasks?
(For example: Type on a computer, drive a forklift, etc. Record answer in space below)

_____

_____

_____

E.12 Please look at the list of chemicals titled "Materials."
Please indicate the items you worked with or came into contact with while doing your job.

(Circle the appropriate material numbers for your responses, and fill in the blanks if you choose any of the "Other" materials. Please print the job number in the appropriate blanks in the upper left hand corner.)

E.13 Prior to [QUESTION D.1.2: _____/_____], did you ever see a doctor for health problems related to a chemical exposure while working at this job?

YES		1
NO	Skip to **E.14**	2
Don't Know	Skip to **E.14**	99

Participant ID: _____

E.13.1 Please list the agent or agents and describe what happened.

Agent: _____

Incident: _____

_____

_____

(Use the SUPPLEMENTAL SHEETS for all jobs prior to the most recent.)

E.14 Either on or off the job, prior to **[QUESTION D.1.2:** ____/_____**]**, have you ever received a severe electrical shock that resulted in unconsciousness?

YES		1
NO	Skip to **E.15**	2
Don't Know	Skip to **E.15**	99

E.14.1 At what age did you first receive a shock that resulted in unconsciousness?

Age: __ __

Don't Know 99

E.15 Either on or off the job, prior to **[QUESTION D.1.2:** ____/_____**]**, have you ever received a severe electrical shock that resulted in a burn?

YES		1
NO	Skip to **E.16**	2
Don't Know	Skip to **E.16**	99

E.15.1 At what age did you receive a shock that resulted in a burn?

Age: __ __

Don't Know 99

Participant ID: _____

E.16 Either on or off the job, prior to **[QUESTION D.1.2:** ____/_____**]**, had you ever received an electrical shock, but one that did not result in injury?

YES		1
NO	Skip to **F.1**	2
Don't Know	Skip to **F.1**	99

E.16.1 At what age did you receive a shock that did not result in injury?

Age: __ __

Don't Know 99

Participant ID: _____

SECTION F: Medical History

We are now interested in any health condition you have had diagnosed by a doctor prior to the diagnosis of ALS, which you said was [QUESTION D.1.2: ____/_____].

F.1 Has a doctor ever diagnosed you with Arthritis?

YES		1
NO	Skip to F.2	2
Don't Know	Skip to F.2	99

F.1.1 Were you diagnosed with Rheumatoid or Osteo-arthritis?

Rheumatoid	1
Osteo	2
Don't Know	99

F.1.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.2 Has a doctor ever diagnosed you with Cancer?

YES		1
NO	Skip to F.3	2
Don't Know	Skip to F.3	99

F.2.1 With what type or types of Cancer were you diagnosed?

Cancer Type 1: _____
Don't Know 99

Participant ID: _____

F.2.1.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.2.2 Cancer Type 2: _____
Don't Know 99

F.2.2.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.2.3 Cancer Type 3: _____
Don't Know 99

F.2.3.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.3 Has a doctor ever diagnosed you with Diabetes?

YES		1
NO	Skip to F.4	2
Don't Know	Skip to F.4	99

Participant ID: _____

F.3.1 With what type of diabetes were you diagnosed? Type I Diabetes, which is also known as Juvenile Onset Diabetes, or Type II diabetes, which is also known as Adult Onset diabetes?

Type I (Juvenile) 1
Type II (Adult Onset) 2
Don't Know 99

F.3.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.4 Has a doctor ever diagnosed you with Asthma or Reactive Airway Disease?

YES 1
NO Skip to F.5 2
Don't Know Skip to F.5 99

F.4.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.5 Has a doctor ever diagnosed you with Epilepsy?

YES 1
NO Skip to F.6 2
Don't Know Skip to F.6 99

Participant ID: _____

F.5.1 With what type of Epilepsy were you diagnosed?

Type of Epilepsy: _____
Don't Know 99

F.5.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.6 Has a doctor ever diagnosed you with a Heart Disease or Heart Condition?

YES 1
NO Skip to F.7 2
Don't Know Skip to F.7 99

F.6.1 With what type of Heart Disease or Heart Condition were you diagnosed?

Type of Heart Disease or Condition: _____
Don't Know 99

F.6.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

Participant ID: _____

F.7 Has a doctor ever diagnosed you with High Blood Pressure?

YES		1
NO	Skip to **F.8**	2
Don't Know	Skip to **F.8**	99

F.7.1 With what type of High Blood Pressure were you diagnosed?

Type of High Blood Pressure: _____

Don't Know 99

F.7.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

F.8 Has a doctor ever diagnosed you with a Kidney Disease?

YES		1
NO	Skip to **F.9**	2
Don't Know	Skip to **F.9**	99

F.8.1 With what type of Kidney Disease were you diagnosed?

Type of Kidney Disease: _____

Don't Know 99

F.8.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

Participant ID: _____

F.9 Has a doctor ever diagnosed you with a Liver Disease?

YES		1
NO	Skip to **F.10**	2
Don't Know	Skip to **F.10**	99

F.9.1 With what type of Liver Disease were you diagnosed?

Type of Liver Disease: _____

Don't Know 99

F.9.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

F.10 Has a doctor ever diagnosed you with Polio?

YES		1
NO	Skip to **F.11**	2
Don't Know	Skip to **F.11**	99

F.10.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

Participant ID: _____

F.11 Has a doctor ever diagnosed you with Rheumatic Fever or Scarlet Fever?

YES		1
NO	Skip to **F.12**	2
Don't Know	Skip to **F.12**	99

F.11.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.12 Has a doctor ever diagnosed you with a Stroke?

YES		1
NO	Skip to **F.13**	2
Don't Know	Skip to **F.13**	99

F.12.1 Were you diagnosed with a Hemorrhagic or Ischemic Type Stroke?

Hemorrhagic 1
Ischemic 2
Don't Know 99

(For clarification: Hemorrhagic strokes result from an burst blood vessel. Ischemic strokes result from a blood clot.)

F.12.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

Participant ID: _____

F.13 Has a doctor ever diagnosed you with an Autoimmune Disorder?

YES		1
NO	Skip to **F.14**	2
Don't Know	Skip to **F.14**	99

F.13.1 With what type of Autoimmune Disorder were you diagnosed?

Type of Autoimmune Disorder: _____
Don't Know 99

F.13.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.14 Has a doctor ever diagnosed you with a Thyroid Disease?

YES		1
NO	Skip to **F.15**	2
Don't Know	Skip to **F.15**	99

F.14.1 With what type of Thyroid Disease were you diagnosed?

Type of Thyroid Disease: _____
Don't Know 99

Participant ID: _____

F.14.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.15 Has a doctor ever diagnosed you with a Motor Neuron Disease other than ALS?
(Examples include: Primary Lateral Sclerosis, Progressive Muscular Atrophy, Kennedy's Disease, and Progressive Bulbar Palsy)

YES 1
NO Skip to **F.16** 2
Don't Know Skip to **F.16** 99

F.15.1 With what type of Motor Neuron Disease were you diagnosed?

Type of Motor Neuron Disease: _____
Don't Know 99

F.15.2 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.16 Do you have any other medical conditions you would like to tell me about?

YES 1
NO Skip to **G.1** 2
Don't Know Skip to **G.1** 99

Participant ID: _____

F.16.1 With what other medical conditions were you diagnosed?

Other Medical Condition 1: _____

F.16.1.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.16.2 Other Medical Condition 2: _____

F.16.2.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

F.16.3 Other Medical Condition 3: _____

F.16.3.1 What was the date of diagnosis? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

Participant ID: _____

SECTION G: History of Infection or Trauma

This section contains questions regarding your history of specific infections or trauma in the year prior to the diagnosis of ALS, which you said was [QUESTION D.1.2: ____/_____].

G.1 During the year before [QUESTION D.1.2: ____/_____], did a doctor prescribe antibiotics for an illness or infection?

YES		1
NO	Skip to G.2	2
Don't Know	Skip to G.2	99

G.1.1 What were the antibiotics for? _____

Don't Know 99

G.1.2 When were the antibiotics prescribed? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

G.1.3 As a result of the illness or infection for which you were taking antibiotics, did you have to spend the night in a hospital?

YES	1
NO	2
Don't Know	99

G.2 During the year before [QUESTION D.1.2: ____/_____], did you have any injury, such as a broken bone, which required a visit to a doctor or an Emergency Room?

YES		1
NO	Skip to G.3	2
Don't Know	Skip to G.3	99

G.2.1 When did this injury occur? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

G.2.2 Please describe the injury, how you were injured and what part of your body was injured.

Type of Injury: _____

Cause of Injury: _____

Body Part Injured: _____

G.2.3 Did you have to spend at least one night in the hospital because of the injury?

YES	1
NO	2
Don't Know	99

G.2.4 Did you have to have surgery because of the injury?

YES 1
NO 2
Don't Know 99

G.3 During the year prior to [QUESTION D.1.2: ____/_____], did you have surgery for reasons other than injury?

YES 1
NO Skip to H.1 2
Don't Know Skip to H.1 99

G.3.1 What kind of surgery?

Type of Surgery: _____

G.3.2 When did you have the surgery? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

G.3.3 Did you have to spend at least one night in a hospital?

YES 1
NO 2
Don't Know 99

SECTION H: Immunization History

Now I am going to ask you some questions about any vaccines you may have received in the year prior to the diagnosis of ALS, which you said was [QUESTION D.1.2: ____/_____].

H.1 Were you given the MMR (Measles, Mumps, Rubella) shot?

YES 1
NO Skip to H.2 2
Don't Know Skip to H.2 99

H.1.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.1.2 Did you have any side effects you think were related to this shot?

YES 1
NO Skip to H.2 2
Don't Know Skip to H.2 99

H.1.2.1 What were the side effects?

Side Effects: _____

H.1.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

Participant ID: _____

H.2 Were you given the Tetanus/Diptheria shot?

YES 1
NO Skip to **H.3** 2
Don't Know Skip to **H.3** 99

H.2.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.2.2 Did you have any side effects you think were related to this shot?

YES 1
NO Skip to **H.3** 2
Don't Know Skip to **H.3** 99

H.2.2.1 What were the side effects?

Side Effects: _____

H.2.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

Participant ID: _____

H.3 Were you given the DPT (Diptheria/Pertussis/Tetanus) shot?

YES 1
NO Skip to **H.4** 2
Don't Know Skip to **H.4** 99

H.3.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.3.2 Did you have any side effects you think were related to this shot?

YES 1
NO Skip to **H.4** 2
Don't Know Skip to **H.4** 99

H.3.2.1 What were the side effects?

Side Effects: _____

H.3.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

Participant ID: _____

H.4 Were you given the Flu shot?

YES		1
NO	Skip to **H.5**	2
Don't Know	Skip to **H.5**	99

H.4.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.4.2 Did you have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.5**	2
Don't Know	Skip to **H.5**	99

H.4.2.1 What were the side effects?

Side Effects: _____

H.4.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID: _____

H.5 Were you given the Polio shot?

YES		1
NO	Skip to **H.6**	2
Don't Know	Skip to **H.6**	99

H.5.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.5.2 Did you have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.6**	2
Don't Know	Skip to **H.6**	99

H.5.2.1 What were the side effects?

Side Effects: _____

H.5.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID: _____

H.6 Were you given the Chicken Pox or Varicella shot?

YES		1
NO	Skip to **H.7**	2
Don't Know	Skip to **H.7**	99

H.6.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.6.2 Did you have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.7**	2
Don't Know	Skip to **H.7**	99

H.6.2.1 What were the side effects?

Side Effects: _____

H.6.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID: _____

H.7 Were you given the Hepatitis A shot?

YES		1
NO	Skip to **H.8**	2
Don't Know	Skip to **H.8**	99

H.7.1 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

H.7.2 Did you have any side effects you think were related to this shot?

YES		1
NO	Skip to **H.8**	2
Don't Know	Skip to **H.8**	99

H.7.2.1 What were the side effects?

Side Effects: _____

H.7.2.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days	1
Weeks	2
Months	3

Participant ID: _____

H.8 Did you start or complete the Hepatitis B series of shots?

YES 1
NO Skip to **H.9** 2
Don't Know Skip to **H.9** 99

H.8.1 How many shots have you already received?

1.....1
2.....2
3.....3

H.8.2 When did you receive the last shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.8.3 Did you have any side effects you think were related to this shot?

YES 1
NO Skip to **H.9** 2
Don't Know Skip to **H.9** 99

H.8.3.1 What were the side effects, and with which shot did you have them?

Side Effects: _____
Shot Number(s): ___
Don't Know 99

Participant ID: _____

H.8.3.2 How long after receiving the shot did you experience this side effect? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

H.9 Were you given any other vaccine during the year prior to **[QUESTION D.1.2:** ____/_____**]**?

YES 1
NO Skip to **H.10** 2
Don't Know Skip to **H.10** 99

H.9.1 What shot did you get? _____

H.9.2 When were you given the shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.9.3 Did you have any side effects you think were related to this shot?

YES 1
NO Skip to **H.10** 2
Don't Know Skip to **H.10** 99

H.9.3.1 What were the side effects?

Side Effects: _____

Participant ID: _____

H.9.3.2 How long after receiving the shot did you experience the side effects? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

H.10 Have you ever been given the Anthrax vaccine?

YES 1
NO Skip to I.1 2
Don't Know Skip to I.1 99

H.10.1 Why did you receive the anthrax vaccine?

Military 1
Job 2
Other: _____ *(specify)* 3
Don't Know 99

H.10.2 How many shots have you been given?

1.....1 5.....5
2.....2 6.....6
3.....3 7+.....7
4.....4 Don't Know....99

Participant ID: _____

H.10.3 When did you get the last shot? (mm/yyyy)

Date: __ __ / __ __ __ __
Don't Know 99

H.10.4 Did you have any side effects you think were related to the anthrax shot?

YES 1
NO Skip to I.1 2
Don't Know Skip to I.1 99

H.10.4.1 What were the side effects?

Side Effects: _____

H.10.4.2 How long after receiving the shot did you experience this side effect? Please specify as days, weeks, or months.

Days 1
Weeks 2
Months 3

Participant ID: _____

SECTION I

Family Medical History

Now you will be answering questions about your family members and their medical histories. Please answer the questions regarding medical history to the best of your knowledge for all blood-related family members, including those who are no longer alive.
We would also like to know which family member was diagnosed with each condition. If the condition has multiple types, I would also like to know with which type your family member was diagnosed. For example, Arthritis has two types: Rheumatoid and Osteo. *(For the questions about the family member diagnosed and the type of disease diagnosed, circle the appropriate number and fill in the blank with the appropriate type)*

I.1 Did the family who raised you adopt you?

YES		1
NO		2
Don't Know		99

I.2 Has a doctor diagnosed anyone in your family with ALS

YES		1
NO	Skip to **I.3**	2
Don't Know	Skip to **I.3**	99

I.2.1 Which family member was diagnosed, and what type did they have (*Sporadic or Familial*)?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

I.3 Has a doctor diagnosed anyone in your family with Arthritis?

YES		1
NO	Skip to **I.4**	2
Don't Know	Skip to **I.4**	99

I.3.1 Which family member was diagnosed, and what type did they have? *(Rheumatoid or Osteo)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.4 Has a doctor diagnosed anyone in your family with Cancer?

YES		1
NO	Skip to **I.5**	2
Don't Know	Skip to **I.5**	99

I.4.1 Which family member was diagnosed, and what type did they have? *(Prostate, Lung, Liver, etc.)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

I.5 Has a doctor diagnosed anyone in your family with Diabetes?

YES		1
NO	Skip to **I.6**	2
Don't Know	Skip to **I.6**	99

I.5.1 Which family member was diagnosed, and what type did they have? *(Type I or Type II)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.6 Has a doctor diagnosed anyone in your family with Asthma or Reactive Airway Disease?

YES		1
NO	Skip to **I.7**	2
Don't Know	Skip to **I.7**	99

I.6.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

Participant ID: _____

I.7 Has a doctor diagnosed anyone in your family with Epilepsy?

YES		1
NO	Skip to **I.8**	2
Don't Know	Skip to **I.8**	99

I.7.1 Which family member was diagnosed, and what type did they have?
(Partial or Generalized Seizures, Grand Mal or Petit Mal Seizures)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.8 Has a doctor diagnosed anyone in your family with Heart Disease or Heart Condition?

YES		1
NO	Skip to **I.9**	2
Don't Know	Skip to **I.9**	99

I.8.1 Which family member was diagnosed, and what type did they have?
(Coronary Artery Disease, Arrhythmia, Murmur, etc.)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

I.9 Has a doctor diagnosed anyone in your family with High Blood Pressure?

YES		1
NO	Skip to **I.10**	2
Don't Know	Skip to **I.10**	99

I.9.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

I.10 Has a doctor diagnosed anyone in your family with a Kidney Disease?

YES		1
NO	Skip to **I.11**	2
Don't Know	Skip to **I.11**	99

I.10.1 Which family member was diagnosed, and what type did they have?
(Kidney Stones, Renal Failure, Chronic Urinary Tract Infections, etc)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

I.11 Has a doctor diagnosed anyone in your family with a Liver Disease?

YES		1
NO	Skip to **I.12**	2
Don't Know	Skip to **I.12**	99

I.11.1 Which family member was diagnosed, and what type did they have? *(Hepatitis, Cirrhosis, etc.)*

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.12 Has a doctor diagnosed anyone in your family with Polio?

YES		1
NO	Skip to **I.13**	2
Don't Know	Skip to **I.13**	99

I.12.1 Which family member was diagnosed with Polio?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

Participant ID: _____

I.13 Has a doctor diagnosed anyone in your family with Rheumatic Fever or Scarlet Fever?

YES		1
NO	Skip to **I.14**	2
Don't Know	Skip to **I.14**	99

I.13.1 Which family member was diagnosed with Rheumatic Fever or Scarlet Fever?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

I.14 Has a doctor diagnosed anyone in your family with a Stroke?

YES		1
NO	Skip to **I.15**	2
Don't Know	Skip to **I.15**	99

I.14.1 Which family member was diagnosed, and what type did they have (*Hemorrhagic or Ischemic*)?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

I.15 Has a doctor diagnosed anyone in your family with an Autoimmune Disorder?

YES		1
NO	Skip to **I.16**	2
Don't Know	Skip to **I.16**	99

I.15.1 Which family member was diagnosed, and what type did they have?
(Lupus, Multiple Sclerosis, Graves Disease, etc.)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.16 Has a doctor diagnosed anyone in your family with Parkinson's disease?

YES		1
NO	Skip to **I.17**	2
Don't Know	Skip to **I.17**	99

I.16.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

Participant ID: _____

I.17 Has a doctor diagnosed anyone in your family with Alzheimer's disease?

YES		1
NO	Skip to **I.18**	2
Don't Know	Skip to **I.18**	99

I.17.1 Which family member was diagnosed?

Father	1	Grandmother	6
Mother	2	Grandfather	7
Brother	3	Grandchild	8
Sister	4	Other	9
Child	5	Don't Know	99

I.18 Has a doctor diagnosed anyone in your family with a Motor Neuron Disease, other than ALS?

(Examples include: Primary Lateral Sclerosis, Progressive Muscular Atrophy, Kennedy's Disease, and Progressive Bulbar Palsy)

YES		1
NO	Skip to **I.19**	2
Don't Know	Skip to **I.19**	99

I.18.1 Which family member was diagnosed, and what type did they have?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

I.19 Has a doctor diagnosed anyone in your family with a Thyroid Disease?

YES		1
NO	Skip to **I.20**	2
Don't Know	Skip to **I.20**	99

I.19.1 Which family member was diagnosed, and what type did they have?
(Hypothyroidism, Hyperthyroidism, Goiter, etc.)

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

I.20 Are there any other family medical conditions you would like to tell me about?

YES		1
NO	Skip to **J.1**	2
Don't Know	Skip to **J.1**	99

I.20.1 Which family member was diagnosed, and what type of condition did they have?

Father	.....1 _____	Grandmother	.....6 _____
Mother	.....2 _____	Grandfather	.....7 _____
Brother	.....3 _____	Grandchild	.....8 _____
Sister	.....4 _____	Other	.....9 _____
Child	.....5 _____	Don't Know	99

Participant ID: _____

SECTION J

Military Service History

Now you will be asked some questions about time you may have spent in the Military. This will include any time spent on Reserves or National Guard status.

J.1 Have you ever served in the Military? *(Includes Army, Air Force, Coast Guard, Marines, Navy, National Guard, Merchant Marines, Public Health Service; Active Duty and Reserves.)*

YES		1
NO	Skip to K.1	2
Don't Know	Skip to K.1	99

J.2 Were you ever on Active Duty Military status?

YES		1
NO	Skip to J.3	2
Don't Know	Skip to J.3	99

J.2.1 In what branch did you serve and during which years? (yyyy – yyyy)

Army	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Air Force	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Navy	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Marines	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Coast Guard	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Merchant Marines	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Public Health Service	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Other	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _

Participant ID: _____

J.3 Were you ever in the Reserves?

YES		1
NO	Skip to J.4	2
Don't Know	Skip to J.4	99

J.3.1 In what branch did you serve and during which years?

Army	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Air Force	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Navy	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Marines	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Coast Guard	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Merchant Marines	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Public Health Service	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _
Other	_ _ _ _ - _ _ _ _	_ _ _ _ - _ _ _ _

J.4 Were you ever in the National Guard?

YES		1
NO	Skip to J.5	2
Don't Know	Skip to J.5	99

Participant ID: _____

J.4.1 In what branch did you serve and during which years?

Army	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Air Force	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Navy	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Marines	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Coast Guard	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Merchant Marines	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Public Health Service	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __
Other	__ __ __ __ - __ __ __ __	__ __ __ __ - __ __ __ __

J.5 Did you serve in World War II?

YES		1
NO	Skip to J.6	2
Don't Know	Skip to J.6	99

J.5.1 What years did you serve in WWII? (yyyy - yyyy) __ __ __ __ - __ __ __ __

Don't Know 99

J.5.2 Where did you serve?

Pacific	1	Neither	4
Europe	2	Don't Know	99
Both	3		

J.5.3 What was your primary duty?

Primary Duty: _____

Don't Know 99

Participant ID: _____

J.6 Did you serve in the Korean War?

YES		1
NO	Skip to J.7	2
Don't Know	Skip to J.7	99

J.6.1 What years did you serve in Korea? (yyyy - yyyy) __ __ __ __ - __ __ __ __

Don't Know 99

J.6.2 What was your primary duty?

Primary Duty: _____

Don't Know 99

J.6.3 If you served more than one tour, please list the other years along with primary duties

Tour 2 Dates: (yyyy – yyyy) __ __ __ __ - __ __ __ __

Don't Know 99

Tour 2 Primary Duty: _____

Don't Know 99

Tour 3 Dates: (yyyy – yyyy) __ __ __ __ - __ __ __ __

Don't Know 99

Tour 3 Primary Duty: _____

Don't Know 99

Tour 4 Dates: (yyyy – yyyy) __ __ __ __ - __ __ __ __

Don't Know 99

Participant ID: _____

Tour 4 Primary Duty: _____
Don't Know 99

J.7 Did you serve in the Vietnam War?

YES 1
NO Skip to **J.8** 2
Don't Know Skip to **J.8** 99

J.7.1 What years did you serve in Vietnam? (yyyy – yyyy)

Dates: __ __ __ __ - __ __ __ __
Don't Know 99

J.7.2 What was your primary duty?

Primary Duty: _____
Don't Know 99

J.7.3 If you served more than one tour, please list the years of your additional tours along with primary duties?

Tour 2 Dates: (yyyy – yyyy) __ __ __ __ - __ __ __ __
Don't Know 99

Tour 2 Primary Duty: _____
Don't Know 99

Tour 3 Dates: (yyyy – yyyy) __ __ __ __ - __ __ __ __
Don't Know 99

Participant ID: _____

Tour 3 Primary Duty: _____
Don't Know 99

Tour 4 Dates: (yyyy – yyyy) __ __ __ __ - __ __ __ __
Don't Know 99

Tour 4 Primary Duty: _____
Don't Know 99

J.8 Did you serve in the Gulf War?

YES 1
NO Skip to **J.9** 2
Don't Know Skip to **J.9** 99

J.8.1 What were the dates you served? (mm/yyyy)

Began Service: __ __ / __ __ __ __
Don't Know 99
Ended Service : __ __ / __ __ __ __
Don't Know 99

J.8.2 What was your primary duty?

Primary Duty: _____
Don't Know 99

Participant ID: _____

J.9 To the best of your knowledge, were you ever exposed to any chemical or biologic agents?

YES		1
NO	Skip to **J.10**	2
Don't Know	Skip to **J.10**	99

J.9.1 If you know the agents you were exposed to, please list them.

Agents: _____

Don't Know 99

J.10 To the best of your knowledge, were you exposed to any ionizing or non-ionizing radiation?

YES		1
NO	Skip to **J.11**	2
Don't Know	Skip to **J.11**	99

J.10.1 If you know the sources you were exposed to, please list them.

Sources: _____

Don't Know 99

J.11 Have you ever been a Prisoner of War (POW)?

YES		1
NO	Skip to **K.1**	2
Don't Know	Skip to **K.1**	99

Participant ID: _____

J.11.1 What were the years of your imprisonment? (yyyy)

Began: __ __ __ __

Don't Know 99

Ended: __ __ __ __

Don't Know 99

J.11.2 In what war were you a POW?

War: _____

Don't Know 99

J.11.3 Where were you imprisoned?

City, Country: _____

Don't Know 99

J.11.4 Have you been imprisoned in any other wars?

YES		1
NO	Skip to **K.1**	2
Don't Know	Skip to **K.1**	99

J.11.4.1 What were the years of your imprisonment? (yyyy)

Began: __ __ __ __

Don't Know 99

Ended: __ __ __ __

Don't Know 99

Participant ID: _____

J.11.4.2 In what war were you a POW?

War: _____

Don't Know 99

J.11.4.3 Where were you imprisoned?

City, Country: _____

Don't Know 99

Participant ID: _____

SECTION K: Residential History

Beginning with your address at the time you were diagnosed with ALS, which you said was [**QUESTION D.1.2:** ____/_____], and moving back in time, please answer the following questions for each home you lived in over the 20 years prior to the diagnosis of ALS.
(Use the RESIDENTIAL HISTORY WORKSHEET to make sure there are no unexplained gaps in your residential history. On the supplemental sheets enter residences lived in prior to the one at the time of ALS diagnosis.)

K.1 Where did you live when you were diagnosed with ALS?

Street: _____ Apt. # ____

City: _____ State: __ __ Zip _____

K.1.1 When did you live there? (mm/yyyy):

Move In Date: __ __ / __ __ __ __

Don't Know 99

Move Out Date: __ __ / __ __ __ __

Don't Know 99

K.1.2 What type of residence was it?

Mobile Home 1
Apartment 2
House 3
Duplex.....4
Other .....5 _____ *(Specify)*

K.1.3 Did your home have an attached garage?

YES 1
NO Skip to K.1.4 2
Don't Know Skip to K.1.4 99

Participant ID: _____

K.1.3.1 Did you store your car or truck inside?

YES	1
NO	2
Don't Know	99

K.1.4 Was this residence a farm or a ranch?

YES	1
NO	2
Don't Know	99

K.1.5 When was the residence built? (mm/yyyy)

Date: __ __ / __ __ __ __

Don't Know 99

K.1.6 Did you remodel the home while you lived there?

YES		1
NO	Skip to L.1	2
Don't Know	Skip to L.1	99

Participant ID: _____

K.1.6.1 Please describe the changes made:

Changes: _____
_____
_____
_____

(On the supplemental sheets enter residences lived in prior to the one at the time of ALS diagnosis.)

Participant ID: _____

SECTION L: Recreational Activities

We are interested in any recreational activities you have ever participated in on a regular basis. Please answer "Yes" for any activity you participated in at least 6 times a year. Do not include activities you participated in only once in your life, or only once or twice a year.
If you participated in the activity, we also would like to know if you participated in your childhood or your adulthood. Childhood meaning when you were less than 18 years old, and adulthood meaning from your 18th birthday until you were diagnosed with ALS, which you said was [QUESTION D.1.2: ____/_____]. If you participated in the activity during both periods of life, please answer "Yes" for both the child and adult questions.

L.1 Have you ever participated in oil-based painting on a regular basis?

YES		1
NO	Skip to L.2	2
Don't Know	Skip to L.2	99

L.1.1 Did you paint as a child?

YES	1
NO	2
Don't Know	99

L.1.2 Did you paint as an adult?

YES	1
NO	2
Don't Know	99

L.2 Have you ever repaired/maintained a car or truck on a regular basis?

YES		1
NO	Skip to L.3	2
Don't Know	Skip to L.3	99

L.2.1 Did you work on your car or truck as a child?

YES	1
NO	2
Don't Know	99

L.2.2 Did you work on your car or truck as an adult?

YES	1
NO	2
Don't Know	99

L.3 Have you ever participated in gardening on a regular basis?

YES		1
NO	Skip to L.4	2
Don't Know	Skip to L.4	99

L.3.1 Did you participate in gardening as a child?

YES	1
NO	2
Don't Know	99

Participant ID: _____

L.3.2 Did you participate in gardening as an adult?

YES	1
NO	2
Don't Know	99

L.4 Have you ever participated in any kind of glasswork (e.g. Stained or Lead) on a regular basis?

YES		1
NO	Skip to **L.5**	2
Don't Know	Skip to **L.5**	99

L.4.1 Did you participate in glasswork as a child?

YES	1
NO	2
Don't Know	99

L.4.2 Did you participate in glasswork as an adult?

YES	1
NO	2
Don't Know	99

L.5 Have you ever gone hiking or camping on a regular basis?

YES		1
NO	Skip to **L.6**	2
Don't Know	Skip to **L.6**	99

Participant ID: _____

L.5.1 Did you go hiking or camping as a child?

YES	1
NO	2
Don't Know	99

L.5.2 Did you go hiking or camping as an adult?

YES	1
NO	2
Don't Know	99

L.6 Have you ever participated in hunting on a regular basis?

YES		1
NO	Skip to **L.7**	2
Don't Know	Skip to **L.7**	99

L.6.1 Did you participate in hunting as a child?

YES	1
NO	2
Don't Know	99

L.6.2 Did you participate in hunting as an adult?

YES	1
NO	2
Don't Know	99

Participant ID: _____

L.7 Have you ever participated in jewelry making on a regular basis?

YES		1
NO	Skip to L.8	2
Don't Know	Skip to L.8	99

L.7.1 Did you participate in jewelry making as a child?

YES	1
NO	2
Don't Know	99

L.7.2 Did you participate in jewelry making as an adult?

YES	1
NO	2
Don't Know	99

L.8 Have you ever participated in model building (cars, boats, planes, etc.)on a regular basis?

YES		1
NO	Skip to L.9	2
Don't Know	Skip to L.9	99

L.8.1 Did you build models as a child?

YES	1
NO	2
Don't Know	99

Participant ID: _____

L.8.2 Did you build models as an adult?

YES	1
NO	2
Don't Know	99

L.9 Have you ever participated in Motor Cross/Car Racing on a regular basis?

YES		1
NO	Skip to L.10	2
Don't Know	Skip to L.10	99

L.9.1 Did you participate in Motor Cross/Car Racing as a child?

YES	1
NO	2
Don't Know	99

L.9.2 Did you participate in Motor Cross/Car Racing as an adult?

YES	1
NO	2
Don't Know	99

L.10 Have you ever participated in Motor Cross/Car Racing, as a spectator on a regular basis?

YES		1
NO	Skip to L.11	2
Don't Know	Skip to L.11	99

Participant ID: _____

L.10.1 Did you attend Motor Cross/Car Races as a child?

YES	1
NO	2
Don't Know	99

L.10.2 Did you attend Motor Cross/Car Races as an adult?

YES	1
NO	2
Don't Know	99

L.11 Have you ever participated in photography, this must include developing your own pictures, on a regular basis?

YES		1
NO	Skip to **L.12**	2
Don't Know	Skip to **L.12**	99

L.11.1 Did you participate in photography as a child?

YES	1
NO	2
Don't Know	99

L.11.2 Did you participate in photography as an adult?

YES	1
NO	2
Don't Know	99

Participant ID: _____

L.12 Have you ever participated in pottery making on a regular basis?

YES		1
NO	Skip to **L.13**	2
Don't Know	Skip to **L.13**	99

L.12.1 Did you participate in pottery making as a child?

YES	1
NO	2
Don't Know	99

L.12.2 Did you participate in pottery making as an adult?

YES	1
NO	2
Don't Know	99

L.13 Have you ever participated in furniture refinishing on a regular basis?

YES		1
NO	Skip to **L.14**	2
Don't Know	Skip to **L.14**	99

L.13.1 Did you participate in furniture refinishing as a child?

YES	1
NO	2
Don't Know	99

Participant ID: _____

L.13.2 Did you participate in furniture refinishing as an adult?

YES 1
NO 2
Don't Know 99

L.14 Have you ever participated in <u>woodworking or carpentry</u> on a regular basis?

YES 1
NO Skip to **L.15** 2
Don't Know Skip to **L.15** 99

L.14.1 Did you participate in woodworking or carpentry as a child?

YES 1
NO 2
Don't Know 99

L.14.2 Did you participate in woodworking or carpentry as an adult?

YES 1
NO 2
Don't Know 99

L.15 Have you ever participated in any other type of <u>arts and crafts</u> on a regular basis?

YES 1
NO Skip to **L.16** 2
Don't Know Skip to **L.16** 99

L.15.1 Please specify: _____

Participant ID: _____

L.15.2 Did you participate in any type of crafts as a child?

YES 1
NO 2
Don't Know 99

L.15.3 Did you participate in any type of crafts as an adult?

YES 1
NO 2
Don't Know 99

L.16 Are there any other activities that you participated in on a regular basis?

YES 1
NO Skip to **M.1** 2
Don't Know Skip to **M.1** 99

L.16.1 Please list each activity and whether you participated in the activity as a child, adult, or both.

Activity 1: _____
Adult 1
Child 2
Both 3

Activity 2 _____
Adult 1
Child 2
Both 3

Activity 3 _____
Adult 1
Child 2
Both 3

Participant ID: _____

SECTION M: Physical Activity

Now you will be asked some questions regarding your participation in organized sports programs.

M.1 Did you participate in organized athletics during high school?

YES		1
NO	Skip to **M.2**	2
Don't Know	Skip to **M.2**	99

M.1.1 Did you letter or "make the varsity team" in one or more sports?

YES	1
NO	2
Don't Know	99

M.1.2 Please list the sports lettered in.

Sports List: _____

(If you attended college, answer QUESTIONS **M.2** through **M.3.1.1**. *If you did not attend college, skip to* QUESTION **M.4***)*

M.2 Did you participate in intramural athletic activities during college?

YES		1
NO	Skip to **M.3**	2
Don't Know	Skip to **M.3**	99

M.2.1 Please list the sports you participated in.

Sports List: _____

M.3 Did you participate in intercollegiate sports during college?

YES		1
NO	Skip to **M.4**	2
Don't Know	Skip to **M.4**	99

M.3.1 Did you letter in one or more sports?

YES	1
NO	2
Don't Know	99

M.3.1.1 Please list the sports you lettered in.

Sports List: _____

M.4 Have you ever been employed as a professional or semi-professional athlete?

YES		1
NO	Skip to **M.5**	2
Don't Know	Skip to **M.5**	99

M.4.1 Please specify the sport or sports:

Sports List: _____

Participant ID: _____

M.5 Have you ever participated in any community, church, or other socially sponsored sport on a regular basis as an adult?

YES		1
NO	Skip to N.1	2
Don't Know	Skip to N.1	99

M.5.1 Please specify the sport or sports:

Sports List: _____

Participant ID: _____

SECTION N: Tobacco and Alcohol Use

Now you will be asked some questions about your use of or exposure to tobacco and alcohol.

N.1 Have you smoked at least 100 cigarettes in your lifetime?

YES		1
NO	Skip to N.2	2
Don't Know	Skip to N.2	99

N.1.1 Do you still smoke cigarettes?

YES	Skip to N.1.4	1
NO		2

N.1.2 How old were you when you had your last cigarette?

Age: ___ ___

N.1.3 Overall, how many years did/have you smoke/smoked, excluding any years that you quit?

Years Smoked: ___ ___

N.1.4 What is/was the average number of Cigarettes that you smoked per day? *(A PACK CONTAINS 20 CIGARETTES)*

Average Number of Cigarettes Smoked Per Day: ___ ___

N.1.5 Were you still smoking cigarettes when you were diagnosed with ALS?

YES	1
NO	2
Don't Know	99

Participant ID: _____

N.2 In your lifetime did you ever live in the same household with a smoker?

YES		1
NO	Skip to N.3	2
Don't Know	Skip to N.3	99

N.2.1 Did this person or persons smoke in the house while you were home?

YES	1
NO	2
Don't Know	99

N.3 Prior to the date that you were diagnosed with ALS, which you said was [**QUESTION D.1.2:** ____/_____], did you ever drink an alcoholic beverage?

YES		1
NO	Skip to **Participant Hypothesis**	2
Don't Know	Skip to **Participant Hypothesis**	99

N.3.1 When did you start drinking alcoholic beverages?

Please answer either: AGE or YEAR (yyyy)

AGE: __ __ YEAR: __ __ __ __

N.3.2 Do you still drink alcoholic beverages?

YES	Skip to N.3.3 1
NO	Skip to N.3.2 2

N.3.3 When did you stop drinking alcoholic beverages?

Please answer either : AGE or YEARS (yyyy)

AGE: __ __ YEAR: __ __ __ __

N.3.4 On average, how many alcoholic beverages do/did you drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

N.3.5 On average, how many glasses (5 ounces) of wine do/did you drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

N.3.6 On average, how many cans (12 ounces) of beer do/did you drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

N.3.7 On average, how many shots (1.5 ounces) of liquor do/did you drink per **week**?

< 1	1	8-14	4
1-4	2	15+	5
5-7	3	Don't Know	99

Participant ID: _____

Participant Hypotheses

As you are probably aware, research into the possible causes for ALS has been on going for more than 100 years. This survey, although long and fairly comprehensive, cannot ask questions regarding all potential risk factors. Now, we would like for you to think about the questions you have answered, and then record any ideas you may have regarding how you think the ALS disease onset might have been triggered. This may include ideas regarding nutrition, exercise, a chemical exposure, or you may elaborate further on those questions already discussed.

(RECORD ANSWER IN THE SPACE BELOW)

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APPENDIX C—ADDITIONAL TABLES

TABLE C1. Agents Contacted by ALS Case Series Respondents Over 20-Year Work History, Self-Report

By Total Number of Agents/Jobs:							
Agents contacted at the 228 jobs held in 20 years prior to ALS diagnosis: (n=76 PALS)	**No. all jobs (n=228)**	**% all jobs (n=228)**	**No. Kelly-jobs (n=60)**	**% Kelly-jobs (n=60)**	***No. other S.A. base***	***No. base jobs not in S.A.***	***No. outside military***
Total # of mentions by respondents	*693*	*100*	*279*	*100*	*58*	*181*	*175*
Cleaning solvents, degreaser	47	20.6	18	30.0	*8*	*8*	*13*
Cutting, lubricating oils	39	17.1	13	21.7	*7*	*6*	*13*
Aluminum	38	16.7	17	28.3	*8*	*7*	*6*
Paint, varnish, stain	37	16.2	16	26.7	*5*	*7*	*9*
Jet fuel fumes	35	15.4	16	26.7	*4*	*13*	*2*
Adhesives, glues, coatings	34	14.9	11	18.3	*3*	*6*	*14*
Metal dust, metal fumes	32	14.0	12	20.0	*2*	*6*	*12*
Lead-containing paint	30	13.2	11	18.3	*6*	*8*	*5*
Welding fumes	27	11.8	13	21.7	*4*	*4*	*6*
Alcohols, ketones	25	11.0	11	18.3	*1*	*5*	*8*
Leaded gasoline fumes	24	10.5	11	18.3	*1*	*7*	*5*
Fertilizers	23	10.1	9	15.0	*3*	*5*	*6*
Herbicides	20	8.8	9	15.0	*2*	*5*	*4*
Insecticides	20	8.8	8	13.3	*1*	*5*	*6*
Lead	19	8.3	10	16.7	*0*	*6*	*3*
Machine fuels	18	7.9	10	16.7	*0*	*5*	*3*
Pesticides (name unknown)	18	7.9	8	13.3	*1*	*5*	*4*
Plastic fumes, plastic resins	17	7.5	5	8.3	*0*	*5*	*7*
Mercury	15	6.6	5	8.3	*0*	*5*	*5*
Solvent-based inks, dyes	15	6.6	5	8.3	*0*	*5*	*5*
Benzene, toluene, xylene	14	6.1	6	10.0	*0*	*6*	*2*
Metals (name unknown)	14	6.1	4	6.7	*1*	*6*	*3*
Cadmium	13	5.7	7	11.7	*0*	*5*	*1*
Chromium	13	5.7	8	13.3	*0*	*5*	*0*
Fungicides	13	5.7	5	8.3	*0*	*5*	*3*
Organic solvents (name unknown)	13	5.7	2	3.3	*1*	*5*	*5*
Beryllium	12	5.3	6	10.0	*0*	*5*	*1*
Manganese	12	5.3	4	6.7	*0*	*5*	*3*
Radium	9	3.9	4	6.7	*0*	*4*	*1*
Phenols	8	3.5	5	8.3	*0*	*2*	*1*
Uranium	8	3.5	3	5.0	*0*	*4*	*1*
Plutonium	7	3.1	2	3.3	*0*	*4*	*1*
Copper	6	2.6	0	0.0	*0*	*0*	*6*
Silver	4	1.8	0	0.0	*0*	*0*	*4*
Nickel	3	1.3	0	0.0	*0*	*0*	*3*
Missile fuel fumes	2	0.9	0	0.0	*0*	*2*	*0*
Other metals (specify)	2	0.9	2	3.3	*0*	*0*	*0*
Other organic solvents	2	0.9	2	3.3	*0*	*0*	*0*
Chlorine Bleach	1	0.4	0	0.0	*0*	*0*	*1*
Gold	1	0.4	0	0.0	*0*	*0*	*1*
Steel	1	0.4	0	0.0	*0*	*0*	*1*

TABLE C1. Agents Contacted by ALS Case Series Respondents Over 20-Year Work History, Self-Report (Cont.)

By Total Number of Agents/Jobs:							
Styrene	1	0.4	1	1.7	*0*	*0*	*0*
Zinc	1	0.4	0	0.0	*0*	*0*	*1*

By number of PALS				
Agents contacted during 20-year work history preceding diagnosis (n=76 PALS)	**No. PALS w/exposure (n=76 PALS)**	**% PALS w/exposure (n=76 PALS)**	**No. PALS w/ Kelly exposure (n=40 PALS)**	**% PALS w/ Kelly exposure (n=40 PALS)**
Leaded gasoline fumes	17	22.4	9	22.5
Adhesives, glues, coatings	15	19.7	7	17.5
Aluminum	15	19.7	10	25.0
Cleaning solvents, degreaser	15	19.7	11	27.5
Paint, varnish, stain	15	19.7	9	22.5
Metal dust, metal fumes	14	18.4	7	17.5
Alcohols, ketones	13	17.1	9	22.5
Jet fuel fumes	13	17.1	12	30.0
Cutting, lubricating oils	12	15.8	6	15.0
Insecticides	12	15.8	6	15.0
Lead	12	15.8	8	20.0
Welding fumes	12	15.8	6	15.0
Machine fuels	11	14.5	8	20.0
Fertilizers	10	13.2	3	7.5
Lead-containing paint	10	13.2	4	10.0
Benzene, toluene, xylene	8	10.5	6	15.0
Herbicides	8	10.5	3	7.5
Beryllium	6	7.9	6	15.0
Cadmium	6	7.9	5	12.5
Chromium	6	7.9	6	15.0
Fungicides	6	7.9	3	7.5
Pesticides (name unknown)	6	7.9	1	2.5
Plastic fumes, plastic resins	6	7.9	3	7.5
Solvent-based inks, dyes	6	7.9	3	7.5
Manganese	5	6.6	2	5.0
Metals (name unknown)	5	6.6	2	5.0
Phenols	5	6.6	5	12.5
Mercury	4	5.3	3	7.5
Radium	4	5.3	4	10.0
Organic solvents (name unknown)	3	3.9	0	0.0
Uranium	3	3.9	3	7.5
Copper	2	2.6	0	0.0
Other metals (specify)	2	2.6	2	5.0
Other organic solvents	2	2.6	2	5.0
Plutonium	2	2.6	2	5.0
Chlorine Bleach	1	1.3	0	0.0
Gold	1	1.3	0	0.0
Steel	1	1.3	0	0.0
Styrene	1	1.3	1	2.5
Zinc	1	1.3	0	0.0

TABLE C2. Jobs Not Included in Work History Analysis

Job ID*	Job Title	Job ID*	Job Title
o *Jobs provided by the 17 PALS not included in the 20-year work history analysis (jobs were either outside of 20-year time frame or dates of employment were not provided)*			
12	Unemployed	63	Air Reserve Technician
12	****Branch Chief**	70	Pilot
13	****Aircraft Engine Repairer**	71	Attorney
14	Purchasing	71	Student
22	****Supervisor/Air Traffic Controller**	71	Pilot
22	Air Traffic Controller	72	Meat Inspection
46	****Electronics equipment specialist**	74	Picked up wrecked autos for salvage
46	****Radar/Radio Repair**	83	****Boiler Inspector**
46	****Radar Inspector**	83	Operator
49	****Supply Technician**	83	Operator
52	***Branch Chief Engine Repair**	88	****GS-13**
56	Volunteer	91	****Retired**
63	****Major**	92	Soil Scientist
63	Navigator/C-130	92	Clerk
63	Air Force Reserve Technician		
o *Other jobs provided by the 76 PALS otherwise included in 20-year work history analysis (jobs were*			
4	****Mechanic**	37	Office Manager
6	Maintenance Manager	37	Key Punch
6	Store Manager	37	****Loan Officer**
6	Telecommunications Specialist	44	****Aircraft mechanic**
6	Telecommunications Specialist	54	Machinist
6	****Telecommunications Specialist**	54	Gofer
6	Telecommunications Specialist	55	****Air Traffic Controller**
6	Telecommunication Specialist	58	Secure movement of C-130 gunship
6	Telecommunications Specialist	58	Security
7	Retired	58	Security
8	Don't Know	65	Lt Col
11	Computer Systems Analyst	65	Part-time Assistant @ Mortuary
11	Computer Systems Analyst	65	Unknown
11	Computer Systems Analyst	65	Bombardier
11	Computer Systems Analyst	66	Operations Manager
11	Accounting - Finance	66	Pilot
15	****Equipment Specialist**	66	Major
15	****Aircraft Jet Engine Mechanic**	67	Unknown
15	****Aircraft piston jet engine mechanic**	68	****Clerk**
15	****Apprentice aircraft engine mechanic**	68	Engineer

TABLE C2. Jobs Not Included in Work History Analysis (Cont.)

Job ID*	Job Title	Job ID*	Job Title
18	Assembly Supervisor	68	Sergeant Major
18	SGT	73	Bottler
18	Maintenance Control	79	****USAF**
18	Don't Know	79	USAF
18	SGT US Air Force	79	USAF
18	****SGT US Air Force**	79	USAF
18	SGT USAF	79	Electronic Counter Measure Technician
18	SGT UASF	79	Student
21	Supervisor Procurement Agent	79	Desk Clerk
23	Foreman	79	Helper
23	Lathe Operator	80	****USAF**
25	Owner	84	Broadcast Engineer
25	Salesman	84	****Major**
25	Basic Airman to Tech Sgt	87	Recruiter/MSG
25	Mechanic	87	Car Salesman
26	Repairman	90	****Dept. of Defense Police TNT (Tactical**
28	Machinist	90	****Aircraft Electrician**
29	Dairy Farming/ Apple Orchard farming	90	Upholstery
31	Research Assistant	95	Produce Manager
31	Nuclear Reactor Operator	95	Part-time Movie Manager
31	Nuclear Reactor Operator	95	Sales
31	Don't Know	95	Base Movie Manager
33	****Top Secret Security Agent**	95	Drive-In Movie Manager
36	Aircraft Mechanic	95	Sales
36	Aircraft Mechanic		

*Arbitrary ID used to distinguish between cases (e.g. all of jobs with Job ID #71 belonged to one case)
**Denotes job listed as being at Kelly AFB

TABLE C3. Workplace Locations Mentioned by Respondents to the ALS Association Questionnaire and/or Case Series Questionnaire

Building	No. of mentions*	%**	Building	No. of mentions*	%**	Building	No. of mentions*	%**
12	1	1.1	1536	1	1.1	HQ AIA	1	1.1
43	6	6.5	1537	1	1.1	HQ USAFSS	10	10.9
59	1	1.1	1556	3	3.3	HQ. Afcoms	1	1.1
73	1	1.1	1562	1	1.1	Hangar	4	4.3
100	1	1.1	1636	1	1.1	Hanger near flight line	1	1.1
121	1	1.1	2000	3	3.3	Hangers by Loop 13	1	1.1
138	1	1.1	2001	1	1.1	Headquarters Electronic Security Command	3	3.3
143	1	1.1	2008	1	1.1	Little Pentagon	1	1.1
157	1	1.1	2028	1	1.1	MATS Headquarters	1	1.1
162	1	1.1	3030	1	1.1	Motor Pool Division	1	1.1
171	21	22.8	3822	1	1.1	NCO Club	1	1.1
172	1	1.1	4001	1	1.1	Nuclear Weapons Systems	1	1.1
178	1	1.1	4041	1	1.1	Occupational Medical Clinic	1	1.1
200	1	1.1	AF Cadet Program	1	1.1	Only at Kelly AFB for 2- 3 week periods	1	1.1
205	1	1.1	Adage Inc. contract Fairchild Aircraft	1	1.1	Operations Building	1	1.1
206	1	1.1	Administration Building	1	1.1	Parts Department	1	1.1
207	4	4.3	Air & Boiler Room	1	1.1	Physician's Assistant Program	1	1.1
211	1	1.1	All over base in cafeterias/snack bars	1	1.1	Roofs	1	1.1
232	1	1.1	Bldg once housed bombs (no windows)	1	1.1	Security Service Federal Credit Union	1	1.1
308	2	2.2	Cadet Program	1	1.1	Sheet Metal Section, Shops Division	1	1.1
314	1	1.1	Civil Service Building	1	1.1	Sheet metal school hangar	1	1.1
317	1	1.1	Computer Center	1	1.1	Shipping and Receiving	1	1.1

TABLE C3. Workplace Locations Mentioned by Respondents to the ALS Association Questionnaire and/or Case Series Questionnaire (Cont.)

Building	No. of mentions*	%**	Building	No. of mentions*	%**	Building	No. of mentions*	%**
324	7	7.6	Continental DVSN	1	1.1	South Kelly Field	1	1.1
325	1	1.1	Control Tower	2	2.2	Terminal Bldg	1	1.1
329	2	2.2	Cryptological Depot on Security Hill	1	1.1	Test Cell	1	1.1
351	1	1.1	DRMD- Disposal Office	1	1.1	Training Facility	1	1.1
360	3	3.3	Dining Hall	1	1.1	Training program	1	1.1
361	1	1.1	Electrical School, US Army Aircorp	1	1.1	USAF Band	1	1.1
375	13	14.1	Flier	1	1.1	Warehouse Buildings	1	1.1
1091	1	1.1	Flight Line	3	3.3	Procurement	1	1.1
1500	1	1.1	GCA Trailer	1	1.1			
1534	1	1.1						

*All building/location data were provided by 92 of the 142 PALS initially identified
**Percent of the 92 potential PALS who reported working in particular buildings (note: 50 potential PALS did not provide any information on buildings

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