

**100058 Interviewer:** We would like to start by asking you to state your name and a little bit about personal background: where you grew up, your education, and then what were some things you were interested in as a young person that led you to a decision to have a career in science.

**100115 Susan:** My name is Susan Pinney and I grew up in Pennsylvania, in Berks County, Pennsylvania near the town of Reading, Pennsylvania. Actually, that's part of an area called the Reading prong, which is an area high in radon exposure, naturally occurring radon. Didn't know that at the time I was growing up, but uh it's an interesting coincidence. And I went to a public high school there and always was interested in science, science fair projects, science experiments, uh, but this was quite a while ago. And I remember going to my high school guidance counselor and saying I wanted to be a scientist and she said, "Oh no, you need to be either a nurse or a teacher." So I was somewhat bound and determined and rather than going to a three-year nursing program, I found a college program in nursing, a university program, and they were not, there were not very many of those programs at the time. And I went to the University of Pennsylvania in Philadelphia in their four-year baccalaureate program in nursing which has also had a research component and I've always kind of gravitated toward research. And after I graduated there I worked a short time in the Reading Hospital but then went on to the University of Michigan and I worked there in the cardiovascular nursing. In fact, was a nurse in their three-bed coronary care unit and was part of the first heart transplant that occurred at the University of Michigan. And, uh, that was interesting to me. And my other job there, in addition to my regular full time job, another job I held there during the five years I was at Michigan was that I was on the cardiac arrest team for the Michigan Stadium during the football games. So that was a fun job. I got my Master's degree in nursing as a cardiovascular clinical specialist at Michigan and taught in their undergraduate program in nursing, and then came to Cincinnati around about the time I had my first child. And started teaching here at the University of Cincinnati College of Nursing, first in the undergraduate program and then in the graduate program. Several years later after I had my third child, I decided that I wanted to go back to school and obtain a Ph.D. in research, with looking forward to doing nursing research, and was looking for a good program to learn research methodology and obtain a Ph.D. Here at the time, here in Cincinnati, the only program that really met my needs was here at Kettering Lab at the Department of Environmental Health. There were other programs in nursing research in Indianapolis or Columbus but since at the time I had three small children they weren't good options. So I started in the program here in epidemiology and soon realized, about twenty years ago, that I really enjoyed epidemiology. So as part of my dissertation research, as part of that program I worked on studies of ceramic fibers, going around the country and collecting data. My dissertation research was a study of reproductive outcomes, pregnancy outcomes, among women who worked in the semi-conductor industry. And I found that women, particularly in this one facility, who had handled a lot of glycol-ethers and other solvents had an increased rate of miscarriages or spontaneous abortions and an increased rate of stillbirth. Uh, and then I started working as a Research Associate in the Department of Environmental Health and soon became a faculty member and have continued my research here ever since.

**100530 Interviewer:** Could you give us a sort of definition of epidemiology for the layperson and then a little a bit of why that area of work has fascinated you?

**100543 Susan:** Well, epidemiology is simply the study of factors which cause disease in large populations, using population data. Most people when they think of epidemiology think of infectious disease epidemiology, and I know a little about that, but my training in the Department of Environmental Health has been primarily in toxic epidemiology, occupational and especially environmental. So, uh and that fascinated me, I believe, going back to my basic science interest which tended to be in chemistry and physics when I was, way back in high school.

**100632 Interviewer:** And when you say toxic epidemiology, what do you mean by that?

**100637 Susan:** Uh, studying the effects of dust, metals, chemicals, and obviously radiation also on the occurrence of disease, whether in what ways they are risk factors for the occurrence of disease.

**100654 Interviewer:** Can you tell us the story about how you first got involved in research surrounding the Fernald site?

**100701 Susan:** Yes, that's kind of an interesting story. Uh, I was doing some other research studies here in the Department of Environmental Health, and actually at that time my office was near the Occupational Medicine Clinic. Our former chair of the Department, Dr. Raymond Suskind, who was an occupational dermatologist, had an office in the clinic. And I had known Dr. Suskind when I was a student in the Department and also knew him through the proximity of our offices in the clinic. And I remember one day, I know exactly where I stood, uh, standing by the fax machine, and Dr. Suskind came up and said that there was a new project that would be a medical surveillance program with research possibilities for Fernald area residents. And he said, "I've spoken to Bob Wones and I've recommended to him that you be the epidemiologist on that program and I hope you will be interested in doing that." And we talked a few more minutes and I mean I was thrilled to be asked because I realized soon the research possibilities and the pioneering work, really, that was going to be done with this program.

**100838 Interviewer:** Before that encounter had you heard much about Fernald just in the media or just paying attention to local, I don't know, environmental or health issues or what was your familiarity with that?

**100849 Susan:** Some, but not a lot. You'll remember that I'm not a Cincinnati native. I came here at the time when there was a lot about Fernald in the paper, in the mid-'70s on, but I live east of Cincinnati and, you know, other than reading about it in the paper and in the news I didn't know much about the project at all scientifically. At that point in the Department of Environmental Health there was very little involvement in Fernald, there was some involvement among our Industrial Hygiene Department and some other departments had some small projects out there but not, not anything in epidemiology, uh, a little bit from occupational medicine. So it was a new project.

**100945 Interviewer:** Do you remember the first time you went to the site?

**100949 Susan:** Oh, yes, I do remember the first time I went to the site. Uh, although I guess I've been there so many times, the specifics of the different visits kind of run together. Uh, the first time I went to the site I was impressed, at that time buildings were still up nothing had come down, and so I was impressed by the size of the site. As you approach it uh seeing the number of buildings, I mean it really looks like a very large site out there in the midst of nowhere. The other thing that obviously impresses lots of people or makes an impression is driving up to the site and the close proximity of the dairy farm with the cows right out there. So those are the things that I remember most.

**101039 Interviewer:** Can you talk a little bit about some of the first work when you just started getting involved with the medical monitoring program and what your role was in relationship to health screening activities on the patient care side of the house and you're looking at epidemiological issues, what were some of your roles and responsibilities?

**101101 Susan:** Well, let me tell you some things I remember first. There was you know, the court, the settlement with DOE occurred, and then because the residents were very interested in getting a medical monitoring program going quickly, things were happening pretty quickly to get it going. And at the time I was approached to be the epidemiologist, the exams were ready to begin. So it was a time of really frenzy, a lot of activity to get the questionnaires together, to get all the data collection forms together, uh to design how we would do this. And uh, we got things together, I think pretty well. I think that some very wise decisions were made. Dr. Wones had had a lot of experience with screening and he really knew how to run a program like this. He had a philosophy of providing a benefit to everyone, so the screening was more comprehensive and general rather than focused on certain health outcomes or diseases that might result from the exposures, which was a really a guidance to our entire approach. And so our entire approach was designed as a comprehensive approach. Uh, the other piece that both Dr. Wones and I felt strongly about was providing good feedback to community residents. One of the downfalls of lots of screening programs is that the screening tests are done, results are given to people, and then they either don't know how to do anything about them, where to go, or choose not to for whatever reason. We together developed a program where participants would not just get the results of certain tests that were abnormal, but get copies of all their test results, get a comprehensive letter from the physician, so they'd have, they were full participants in terms of information. They had literally all the information that we had, all the pieces of paper. And then the second thing that we did was to provide follow-up by nurses, follow-up phone calls, uh which I think has been very important in health outcomes and that people do get further testing and treatment for any abnormalities we detect. And I think that it's that follow-up and that relationship with the follow-up nurses that has kept people in the program. Our continuing participation rates are very high for programs like this. So that's been very important. The comprehensive approach has also been important in allowing us to have, now, a very rich database for study. And to be able to look at outcomes that, health outcomes, diseases that we may not have, we certainly would not have anticipated being important back in 1990. So there are a number of benefits. There were some other parts to that question but I forgotten what they were.

**101432 Interviewer:** What was your role early on, now you've got data, but at the time you were just trying to mount the overall program, what were some of the things you were thinking about in terms of potential future research that what you tried to design into the thing to start with?

**101447 Susan:** Uh, well one thing I tried to do was to make sure we would have the data we needed in the future to do the kind of statistical analyses. For example, uh, in designing questionnaires we wanted to make sure if we wanted to study breast cancer that we had information on other risk factors for cancer other than radiation or chemical exposure. That we knew the age of a woman at the birth of her first child, that we knew how long she had used contraceptives, because to do any kind of credible scientific analysis you need all that information. And one of the challenges was creating a questionnaire that was short enough to be palatable to people, that they would be willing to sit down and fill out, yet long enough that we got the information we needed. So each year we would think about what we used, yearly questionnaires, what additional questions we would ask that year until we had a bank of data that contained data on all the risk factors we needed. Another challenge was designing a database that would house all these data and in a way so when we had questionnaires each year for data that we collected repeatedly every year, we had a database structure that was a good structure for housing all those data. And, uh, I think early on also to make sure that we had good epidemiologic methods in place for data collection, including the things we do to encourage return of questionnaires, postcard reminders, phone calls to remind people to ask if they have questions, developing databases that would automatically issue reports of who needed that kind of intervention, items like that; working on things like to that to make sure that we had a fairly smooth program in place and that we were using our resources, our people resources, as efficiently as we could.

**101712 Interviewer:** ... thinking of looking at Fernald

**101717 Susan:** You mean in terms of research?

**101720 Interviewer:** What were, again for students or researchers who don't know anything about, what an epidemiologist does in this type of situation. Just describe a little bit the goal, if there is such a thing, of your research might have?

**101737 Susan:** Well the original concerns of the residents were cancers. When you think of radiation and most people think of cancer. So, that certainly was the original concern, and from the beginning our data collection system was designed so that we would get information about cancers and medical record documents about cancers and pathology reports about cancers. Uh, so that was the initial thought. Uh, I think though the cancer that people were most concerned about was lung cancer uh, and I think the surprise for us was that it wasn't lung cancer where we saw an elevation in cancer incidence. It was in the urinary system cancers, which when we went back and thought about it made a lot of sense, but it was not the primary concern at the time when we began the project.

**101847 Interviewer:** Interesting. Could you talk a little bit more about, again going from the past and kind of up to the present what you, you were, talking about the data collection what you were, talk a little bit more about the process of the research within the community? Tell us a little bit about how that went. You said you had follow up that were very helpful you got a lot of ...

**101910 Susan:** Well, the follow-up was very helpful for care, for the diagnostic process, and for moving people from an abnormal test, what we call an elevated risk factor, to getting some treatment from community physicians. Our program is a screening program where we do a certain set of screening tests, but any abnormalities in those tests, we can do a few more tests sometimes, but beyond that people are sent back to their own primary physician for further testing or for treatment. Uh, however, we also as part of the program send out yearly questionnaires, we send out a questionnaire each year. And the first few questionnaires were fairly long and since then we've tried to keep the questionnaire to a manageable length so that people will fill it out and return it and we've had good success with that. So each year we ask the same set of questions, about have you had any new medical problems, have you been hospitalized, have you had any surgeries. But then we also ask each year a couple of additional questions and have planned those questions so that we would be ready to do the data analyses that are needed. For example, we asked a set of questions about risk factors for a particular kind of skin cancer called malignant melanoma, it's probably one of the most serious types of skin cancer, so we ask about risk factors for malignant melanoma. We've asked questions about the amount of time people spend outside because that would be a determinant in their radon exposure. We ask questions about how much food they ate from local gardens, which would increase their ingestion, possibly, of radioactive contaminants. So, planning what questions were going to be asked, I felt, was an important part of my job. And another thing that we did about a year into the program that I think has made this a much more successful program was to do a second wave of recruitment. What had happened was we had done about one year's worth of exams, done about 2,500 exams, and we knew there were a lot of people who are eligible for the program but who had not applied. So we planned with the help of a lot of people a media campaign to distribute information about the program and actually got some cooperation from area banks in having the applications available at the bank, and the banks agreed to notarize without charge the applications. And at that time we went from about 3,000 participants to now we are over 9,600 participants, over nine thousand six hundred participants. So that was a very successful part both in terms that the benefit of health screening now is available to many, many more people than it would have been originally and the database is much richer. We have, the database gives us guidance both for where the medical monitoring program should go in the future. By looking at the data we've collected we can see what diseases seem to be in excess and then plan our efforts for screening based on that. The database will also be a very rich resource in doing research and looking at what diseases are in excess and whether that excess is related to any of the exposures.

**102315 Interviewer:** Can you describe for us a little bit what you perceived the community's concerns were about the, or were there any questions they might have asked regarding the research itself or participating. Were there any concerns that they had or did it change over time?

**102335 Susan:** Oh yes, I think they definitely had some concerns about research and what it would mean to do research, what would it mean for the medical monitoring program data to be used for research. And they had some very good questions about the confidentiality of their information. Uh, they had good questions about what would be the benefits of the research, what would be the benefits to them as a group of community residents who had lived around Fernald, would there be any direct benefits to them. You know, and then also appreciating that there would be more general scientific benefits. Uh, because of the experience they had had with government agencies, they also were, uh, they didn't have a lot of trust in people who were receiving government funding. Researchers at universities do most of their research based with funds from the federal government, that's just how it's done. So there was that kind of concern because I received federal funding from my other research and others who participated in our research projects do also. So we had to take our time, begin slowly, explain the research process. We started with three fairly small studies of genetic mutation and did them as pilot studies in small groups of people, actually using 56 Fernald area residents and did studies of three genetic mutations as a pilot study. The sample size really wasn't large enough to be able to detect the small differences that would have been there had there been an effect. But I think those first studies certainly established a sense of trust in how we do research, how we communicate with the advisory group, we have an advisory group of community residents, about what we're going to do and how we communicate back our results. At the end, we were very honest with them and said we had not found any statistically significant differences, and the most likely reason that we didn't find any statistically significant difference was that our sample size was not large enough. The variation from individual to individual within the group was large enough that we really would not allow us to see any variation based on different levels of exposure. But their concerns about being identifiable in publications certainly, I think, were allayed by the way we handled the research and we presented our data in publications. And I think since then it's just been a gradual process of community residents learning how the research process works and developing a dialogue with them. We do also have a program of an application for access to data, which means that anyone who wants to use Fernald Medical Monitoring Program data to do research has to complete a written application and submit it first to the citizens advisory group and then it goes on to the trustees to be approved for access to data. Even though I have been involved in the program all along, was, you know, a person who was directly involved with the design of the database and works with Fernald data every day, every time I want to do a research project or one of my students would like to do a research project, we complete and file an application for access to data and then report back periodically on how our research is going.

**102748 Interviewer:** Do you want to talk a little bit about FCAB at this point, was it FCAB?

**102753 Susan:** No, I think you're talking about the Fernald Health Effects Subcommittee.

**102757 Interviewer:** Yes, could you talk a little bit about your involvement with that and the history of that?

**102804 Susan:** Yes.

**102805 Interviewer:** How did it start? How did you get involved?

**102809 Susan:** Well, the Fernald Health Effects Subcommittee is actually a committee of the executive branch of the United States government, but it has been administered, the administrative activities have been conducted from the Centers for Disease Control. So I was asked a number of years ago, when the Health Effects Subcommittee began, to be a member of the Health Effects Subcommittee and to serve in that capacity as a scientist, as an epidemiologist, who would understand the issues of epidemiology. And the purpose of the committee is to advise the federal government on what are the health concerns of community and to advise the federal government on what types of research should be done. Part of my role was to help interpret, for the committee, what types of research questions were there and what was the feasibility of addressing those research questions to help in the communication from the federal agencies to the committee members.

**110025 Interviewer:** O.K., so how did you see, how you got involved, how did you see your role change wearing the hat of a community advisory board member versus a researcher?

**110038 Susan:** A scientist.

**110039 Interviewer:** A scientist.

**110041 Susan:** ... versus a scientist doing Fernald research. You know, it's difficult to switch from someone who is doing research myself and interested in the research that I would like to be doing to also be acting as an advocate for a community, as part as a member of the community, to be an advocate for what types of research the federal government should be doing. Uh, it was difficult because there were some research questions that were truly outside the bounds of what would be feasible to carry out as a quality research project. An example of that would be to do a large cohort study. There were probably about 40,000 people who lived within the exposure domain during the time that the plant was in operation. Any thought of trying to track down a high enough proportion of that group and get data from them, you would need a high proportion of the group to have a credible body of data as being representative of that population to do research studies. You know, as a researcher, knowing that that was just not feasible, you know, with the amount of time that had elapsed, just would not be feasible to do. Although that would be the gold standard study to do the very best study, it just was not feasible. And uh, that was hard for some people to understand because I believe going into the first meetings of the Health Effects Subcommittee that's what the community wanted. Uh, on the other hand, there were times when I felt that I could be an effective advocate for asking federal agencies to do more, to come back with more data, to look a little harder, especially with exposure assessments that were done of the area to see what contaminants remained. So it helped me actually a lot. I found it exciting in that I felt much more in a public health role than a research role, looking at public health implications and what's best for this community now, given all we know, what's the next best thing to do. And I guess it goes back to when I was deciding upon a career in nursing, if I didn't go into critical care the other piece that had fascinated me and that I really enjoyed was public health nursing on the streets of urban Philadelphia. This was an entirely different setting, but the issues of what's best for health of a population were there, the same issues were there.

**110348 Interviewer:** Can you talk a little bit about what some of the positive results of the activities of the FHES and some of the limitations or the negatives of the outcomes?

**110415 Susan:** Well, I think there had been certainly some positive effects of the Health Effects Subcommittee and certainly some limitations too. Uh, I think one very positive effect of the Health Effects Subcommittee was the completion of a Dosimetry Reconstruction Project. Certainly, CDC started that project before the Health Effects Subcommittee was formed and CDC certainly funded that whole project outside of the auspices of the Health Effects Subcommittee. But at the end of the project the risk estimation, the risk modeling that was done for community residents, I believe was done to the extent it was done somewhat through the input received from the Health Effects Subcommittee. What the project did, this Dosimetry Reconstruction Project did at the end was to estimate doses of different types of radiation to individuals who lived certain distances from the plant, who worked at a certain place, who were of a certain age, who maybe ate fish from Paddy's Run Creek, all those different variables uh, and the assumptions that went into that and the need for doing that kind of research came from the Health Effects Subcommittee. So the Health Effects Subcommittee said yes, we really do need some risk modeling, some risk estimates and then CDC came back and said well we're trying to do this, can you tell us what's the likelihood that people ate locally grown beef? What's the likelihood that people ate from fruit and vegetable stands, bought produce there? And so that kind of interchange assisted in that project. So that's some of the positives

Uh, I think that the sharing of information that went on there was critical to developing a good working relationship with federal agencies and their knowing what we were doing in the Medical Monitoring Program and we knowing what their plans were and I can give you two examples of that. One thing that happened was as CDC was doing their Dosimetry Reconstruction Project, John Till, Dr. John Till, was the head of that project from the Radiological Assessment Corporation Group. And he would come periodically to Cincinnati to present their progress in their project to the Health Effects Subcommittee. When he came, he and I would meet or Owen Divine, Dr. Owen Divine, and Dr. Till and I would meet and we would talk about the factors that they were including in their computations of radiation dose. And I knew the factors and I knew how they going to be in the models, the equations and therefore we could plan to ask questions in our questionnaires so that we would have precisely the data to fit into the algorithms or the equations for calculating organ doses. So that worked very well. Another example is through ATSDR's knowledge (pause tape- Interviewer) Well I can give you a second example. A second example of that was that by my presence on the Health Effects Subcommittee I could update the agencies periodically on what we were doing with the Medical Monitoring Program, what kinds of data we were collecting and really allow them to know the rich database we were developing and the possibilities for research. ATSDR, the Agency for Toxic Substances and Disease Registry, which is an agency of the Department of Health and Human Services of the U.S. government, that agency decided to fund us, to give us some money to do a data analysis of some of the Medical Monitoring Program data. We used funding that came from the Fernald trustees to do the first analysis of cancer incidence, and that's where we saw an increase in urinary system cancer. But with funding from ATSDR we have conducted an analysis of non-cancers or non-malignant disease, such as chronic kidney disease, thyroid disease, diseases that aren't cancers.



And in fact, they are going to publish that as a report of their agency, a fairly detailed report, and right now we're in the editing process and that report will become public this summer.

**110930 Interviewer:** Uh, can you want to talk about some of the limitations or some of the negatives ...

**110935 Susan:** Can I just say something? That report will be the first report of health effects of communities around any DOE site. So in that way, the Fernald community has really contributed to the body of knowledge about health effects around a nuclear weapons site.

**111057 Interviewer:** Would you like to share with us some of the analysis that you found, or you can't do that yet?

**111002 Susan:** Can't do that yet, that'll have to wait.

**111005 Interviewer:** What about the other analysis that you did ...

**111009 Susan:** The cancer incidences?

**111009 Interviewer:** Yes, the cancers would you discuss a little bit ...

**111011 Susan:** Yes, well, uh, there's somewhat of an interesting story to that. Since this Medical Monitoring Program is funded through the settlement agreement or the settlement fund, which is actually there is still oversight by the federal court, we periodically, the trustees need to go back, the Fernald trustees need to go back and report to the judge how things are going. And most of those court hearings focus on how the money is being spent, but the judge is always interested in what is happening in the Medical Monitoring Program, and usually at most court hearings asks Dr. Wones to get up and give him a direct report. And the judge always asked, "Have you found any excess cancers, have you found more cancers?" So we took the data we had, that we had collected, the diagnosis data, made sure that all our cancer diagnoses were verified with outside records and did a data analysis to see if new cases of cancers, since the beginning of the program, were occurring at a higher rate than you would expect compared to U.S. population rates, compared to Ohio rates, you know, several comparisons. And in doing that data analysis, we found that there was no excess in lung cancer incidence, new cases of lung cancer. In fact, the rate of lung cancers in the Fernald Medical Monitoring Program group was just about exactly what you would expect compared to U.S. rates, compared to Ohio rates. But what we did find was that there was about a 70% increase in urinary system cancers, those are cancers of the kidney and bladder, and we also found an increase of about the same amount in malignant melanoma. A third cancer where there was an increase in new cases of cancer, since the beginning of the program, beginning of the Medical Monitoring Program, was prostate cancer. Although as scientists we weren't sure that that was a true or a real increase, and the reason for that is that our screening program probably checked men for signs of prostate cancer more thoroughly than a general office visit. And we also used a special test for prostate cancer called a PSA or a Prostatic Specific Antigen test that had not been used or was not used everywhere at the time when comparison data from the U.S. databases, from the Ohio databases, were

collected. So prostate cancer is a very slowly growing cancer and therefore in doing our types of examinations we might have found cases earlier than our comparison data or the clinicians where the comparison data came from. So that might not be a real increase, but since we found the increase in urinary system cancers, there actually had been some other data that came out that confirmed or confirm our data. For example, there was a plant outside of St. Louis, another plant in the nuclear weapons complex called the Mallinckrodt Chemical Works, and at that plant they found among their workers an increase in kidney cancer. And there was a study of cancers in women who worked at various nuclear weapon sites, and in that study, in the women from Fernald in that study, the only cancer that was elevated was urinary system cancer.

**1114 29 Interviewer:** Could you just describe for us why that, how that in terms of Fernald might have been, what is a, what's it called, the pathway. How did possibly happen to the urinary track ...

**111445 Susan:** The piece of research that we haven't done yet is what we call exposure modeling. What we've done so far is just taken a group of people, a population, and looked at them and said, "As a group are their cancer rates higher than what we would expect?" We have not yet calculated, for example, organ doses to the kidney of various radioactive contaminants and then looked to see if those people who lived there longer, lived closer to the plant, and therefore got more radioactive contaminants to their kidneys, whether they were more likely to develop kidney cancer than people who lived far out, less time. Uh, but the reason why urinary system cancer might be a plausible health effect from exposures to Fernald is because of uranium, and especially what we call the chemical properties of uranium. Uh, uranium has some radioactivity naturally, there is some natural radioactivity to uranium, but it also is a metal and its metal properties can be irritating and damaging to the kidney. We know that a large proportion of people who lived around Fernald in past years drank from private wells or even used water from cisterns where the water was first collected on rooftops went into the cistern and they used that as drinking water. We know that from the questions we asked them on the questionnaires about each place that they lived. Uh, we have also found in some research done by one of my graduate students, Ron Qui, she found that people who, she found that the risk for developing urinary system cancer when she looked just at people who drank from wells. So, we're looking just to people who drank from wells, the risk of developing urinary system cancer was much higher for people who lived close to the plant and that risk, that level of risk that we calculate fell off rapidly until about two and a half miles from the plant and at point there was no excess risk. So statistically we found a relationship among those who drank from wells that living closer to the plant put someone at a much higher risk for developing urinary system cancer.

**111725 Interviewer:** Just to clarify for the laypeople, including myself, so the water would collect on the roofs and it would have some traces of uranium in it and then they would drink it and then it would, could you just describe a little bit ...

**111736 Susan:** Well, we don't know that piece for sure. We do know is that when you use a cistern water collects on roofs and then drains into a cistern, a holding tank, and people drank from those cisterns. Uh, we do know that dust came from the stacks at the plant and was carried by the wind and distributed across the area, uh, so it's very plausible to believe that there was

dust on roofs and therefore that dust could get into cisterns. At this point, we haven't done research that would tell us whether people who drank from cisterns and whose homes were in the pathway of the dust are at greater risk for developing urinary system cancers. We haven't done that piece yet.

**111829 Interviewer:** And did your research look at male and female gender rates? Do you want to talk about that a little?

**111837 Susan:** Yes, uh, actually that's an interesting question because when we were looking at urinary system cancer, kidney and bladder cancer, bladder cancer especially, usually is found much more in men than in women. Uh, one interesting piece of our research, we found that among those who drank from wells, and I think actually among all of the urinary system cancers, we found it to be higher rates in women than men. And uh, we found, we feel that that might be due to the fact that women at that time were more likely to stay home and so weren't going away during the day to drink water some place else.

**111921 Interviewer:** And is that risk, are you still continuing to study in that area?

**111925 Susan:** Yes, yes.

**111928 Interviewer:** What period of time also was it that you were continuing to study this thing?

**111932 Susan:** The first study of cancer incidence that I've been speaking about, that study we looked at new cancer cases during the time that people had been in the Medical Monitoring Program because we had excellent medical records. We had excellent ascertainment and we knew that we were looking at very high quality data. So we looked at the first four years of participation in the Medical Monitoring Program in that first analysis. Uh, we have, the judge has approved almost a half a million dollars of funding for us to continue cancer research. This time, though, we will be doing that precise dose estimation for various organs of the body and because of the good working relationship we've developed with the Center for Disease Control, they are giving us the algorithm they developed, the equation that they developed, through their Dosimetry Reconstruction Project. So we actually will be using that equation. We have included as a consultant in the project, George Kelow, who actually developed that equation. In the first year of research, will be devoted to calculating organ doses of radioactive contaminants for each participant in the medical monitoring program. So we'll have very precise data. The second year will be devoted to using that exposure information, those doses and to see, we're looking at five cancers. We're looking at lung cancer, breast cancer, prostate cancer, urinary system cancer, and malignant melanoma and to see if there is what we call a dose-response relationship. And that means that people with higher doses, and in this case with higher doses to the specific organ involved, were more likely to develop a cancer.

**112137 Interviewer:** You said that there was a, I think you said what a 70% increase above, could you describe, is that per 1,000, what's the average versus what? Give us a sense of what that means, or is that hard to do?

**112200 Susan:** It's hard to explain. Uh, I'm trying to think of a way to answer your question. The way we do this kind of research is that we take rates that have come from national databases and we apply those rates to the Fernald population, but they're what we call age- and sex-specific rates. So for each five-year age group in the Fernald population, so you have five years males who are 40 to 44, we take the lung cancer rate that was developed from the national database, from the Ohio database, and calculate how many cases of lung cancer we would expect in that group based on those national rates and then add each group's expected number together and then look at how many actual cases we have in the Fernald population. So that's how we do the research. So I can't off of the top of my ..., and we looked at it over multiple years so it's hard to equate what you're asking me, which is a yearly incidence rate which is generated for a general population, whereas we have a Fernald medical monitoring population doesn't necessarily have the same age distribution or sex distribution as the general population. So it's a complicated process and that's why I can't answer that question directly.

**112341 Interviewer:** You had mentioned, could you tell us a little bit more about the other two types of cancer elevations that you found? You mentioned prostate, (**Susan:** I think I pretty well told you about prostate) yes, but there was another one.

**112352 Susan:** Malignant melanoma is ...

**112354 Interviewer:** And why would that be?

**112356 Susan:** We don't know really, but malignant melanoma, the excess that we saw, remember that we didn't use radiation or radioactive contaminant doses in that analysis. So the excess that we saw may just be due to lots of sunlight exposure, which is a very well-known risk factor for developing malignant melanoma. The excess may just be due to the ethnic background of the population. People who have fair hair and fair skin, blue eyes are at additional risk for developing malignant melanoma. So there may be a lot of people with those characteristics in the Fernald population, so that could explain the excess. But there have also been some research studies again, workers at laboratories, at laboratories that were part of the nuclear weapons systems, where they worked with a lot of radioactive materials, and research looking at mortality studies of the cause of death of those workers, have noted some increase in malignant melanoma. So there may possibly be some connection here, we will only know when we do some additional research.

**112521 Interviewer:** O.K., can you recall any memorable accounts or exchanges between residents and researchers at any of the meetings of the FHES ...?

**112537 Susan:** Well, I'm having a tough time remembering a specific incident. I think that the discussions of the Health Effects Subcommittee meeting have been to the point, have been focused. Certainly, challenging questions have been raised. Uh, but I think certainly on the part of the committee members and I think also the federal agencies, the goal has been to share information, to try to identify the best approach for doing research, and to learn from each other. I really do believe that. I think it has been an excellent arena for sharing ideas. I think that the

idea sharing that went on there that would have not occurred had not the Health Effects Subcommittee been there. Uh, and I think also the community was able to articulate their concerns in a way that the federal agencies really heard them because there's an initial articulation, and then the federal agencies didn't understand exactly what people were concerned about. There was a chance for a full discussion and to bring in history, talking about wells, obviously with the urinary system effect that we've seen there's been concern about wells. And so there's been an exchange of information, what kind of well testing has been done in the past, who has those records, what people, what kind of permission slips people had to sign to have their well tested. Uh, public water system when it came in, the fact that some people still do not have public water because of the cost of bringing the water line to their home from the street, those kinds of information have been shared. This is just one example. Our Health Effects Subcommittee, I've observed some other Health Effects Subcommittees at some other DOE sites, and our Health Effects Subcommittee certainly doesn't have the conflict, the number of contentious discussions that other Health Effects Subcommittees have had. But I really think that it has allowed us to work very effectively with federal agencies.

**112808 Interviewer:** In your opinion, who should set the agenda for health related research at DOE facilities and who should pay for that research?

**112823 Susan:** Well that's two questions. Who should set the agenda? Certainly the agenda setting should be a collaborative effort between those who were exposed or those who lived in the area those worked at that site. I've kind of missed out talking about the workers in this discussion and that's a big piece, it shouldn't be neglected at all. The workers have brought tremendous input to the Health Effects Subcommittee uh, and the history that they bring to the Health Effects Subcommittee, and not just what their experiences were but where data were collected and where those data might be have been tremendous. I think the agenda setting needs to be a joint effort, and I think that worked well within the Health Effects Sub-Committee arena. I think it's an ongoing process. Certainly, as research is finished and findings, research findings or results, become available that alters the agenda. It has to. And therefore it needs to be an ongoing process, it can't be setting an agenda and that's it. I really fear that that's the piece we're going to be missing once the Health Effects Subcommittee is no longer in existence. It's that ongoing discussion and being able to use scientific findings, as they become available, use those scientific findings in agenda setting.

**120024 Interviewer:** Who do you think should be paying for the research?

**120030 Susan:** I think the only group that has the resources to pay for the research that needs to be done is the federal government. I think the data we have collected both in the resident medical monitoring program and the worker medical monitoring program provide opportunities to ask and answer scientific questions that have never been answered. For the workers, through the worker medical monitoring program we have collected not only a large volume of medical data and lots of diagnostic testing exactly as we did with residents, but we also have collected very detailed occupational histories on those workers. The government through NIOSH, the National Institute for Occupational Safety and Health, has funded us to use that occupational history data in a project to calculate radon doses, or radon levels of exposure, to Fernald workers. And

through funding for that project we are able to computerize much of that occupational history data so it's now in computer files, and we can use for data analysis. And that's very important. You know, as I said we will have levels of radon for Fernald workers which will then allow us to make estimates of what levels correspond to an increase in risk for developing lung cancer. I mentioned that we've seen no excess in lung cancer among residents, but among workers, in a study done by NIOSH, there was definitely an excess of lung cancer, lung cancer deaths in Fernald workers. NIOSH is updating that study and should have some additional results out fairly soon. But there is a concern about radon exposure and inhaling radon gas among Fernald workers and what health effects that might cause. And hopefully the federal government, through NIOSH, will fund additional research once we have these radon doses calculated so that we can see exactly at what level there is additional risk. Now they're having previous studies of radon exposure in workers and what levels cause excess risk in lung cancer, but they have been done mainly in uranium miners and that's a different situation. It's an enclosed space down in the mine. And calculating our radon doses in Fernald workers, we've had to cope with all different kinds of questions about radon exposure. For example, uh, there's a tremendous variation in levels between day and night. At the Fernald plant most of the radon came from waste silos, known as the K-65 silos, and large amounts of radium bearing ore and other kinds of waste with lots of radioactive contaminants were put into those silos. And for many years, until the early '70s, the silos had no coverings were wide open and were emitting radon gas and the radon gas would then dissipate through the atmosphere. And because the prevalent winds went generally from west to east and these silos were to the west of the plant buildings, it's reasonable to believe that the general direction of dissipation would be over the plant buildings. There were also some activities at the plant that might have contributed to additional radon exposure, but this will be interesting because people who were in the administration building, who really did not work in production, had some amount of radon exposure. Once we finish our dose estimation project, we'll know how much and then we'll know by using those data, we can tell what level of radon exposure will lead to an additional risk of getting lung cancer. But, as I said, we've already learned that during the night time when the air did not move over the site, you know when there was not much breeze at night, the radon sat there and the exposure levels were much higher. We're also looking at what the differences between outside and inside a building, what gradient you would apply. I mentioned uranium miners. The other group that we know about radon exposure are people in their homes, again with inside a house. This is a different model. The radon is coming from an source, an external source, an outside source, and we're asking as it dissipates what kind of exposure might there be to other people who are working outside in the area, and then how much of it gets inside a building from an outside source.

**120555 Interviewer:** Has your work at all involved chemical exposure, because I know there were a lot of chemicals that were used in the manufacturing process? Is there a way or can you discuss that at all? Is that a known health threat?

**120611 Susan:** There were a large amounts of chemicals used at the Fernald site. The process of removing uranium metal from ore was a chemical extraction process, that's the process that was used at Fernald. Lots of chemicals were used in that process, and then as you know later on down the process these metals were formed into rods and other forms that were milled there at the plant. And in cleaning that equipment, in cleaning the rods, lots of solvents were used in cleaning

the equipment as well as being used in the chemical extraction process. There actually is not nearly, there is little information known about levels of chemical exposure. Since the focus was primarily radiation and workers wore radiation badges, we actually know quite a bit about certain types of radiation exposure, less about radon gas monitoring. But there was almost no monitoring for chemical fume levels in the air, and so we have very little data about that. Also, although they kept good track about how they stored radioactive waste, there is much less information about how chemical waste was disposed of at the plant. As part of this newly funded project that I mentioned a few minutes ago, we are going to try to do some reconstruction of the chemical exposures to community residents. NIOSH has done an exposure estimate project, an exposure assessment project, where they were trying to reconstruct what might have been chemical exposures to workers, but in the area of exposure assessment there has been much less done with chemicals than has been done with radiation.

**120813 Interviewer:** Can you describe your recent current research project, looking at what are your findings, can you do that? Two more questions then we're done. What advice would you give to Congress concerning the management and funding of health research related to DOE sites? This is your big chance.

**120852 Susan:** Well, I think one specific piece of advice that comes to my mind right now is that there is a great need to fund a database, a medical database for Fernald workers, a computer database. Uh, their medical monitoring program did not include any funds for that database and not having those data computerized and not having resources to do that sizeable project has really blocked any kind of data analysis of cancers or anything else we can do with this group. So my first advice would be that there is an opportunity there to answer a lot of research questions and either, and also just to guide the efforts of their medical surveillance program where we really do need some resources. So that would be a very specific request, but you were asking a much more general question. What would be my advice? Any type of program there are two prongs. There's the prong of delivering screening or health benefits to people who lived at these sites or worked at these sites. And there's a second prong of what can we learn from, what are our learnings from what has happened at these sites. I think my advice to Congress would be to look at the Fernald model for surveillance programs. I think that we have been amazingly successful in the kind of data we've gathered and the quality of those data and in the continuing participation we have with the people who are in those programs. And I go back to what I said at the very beginning of this interview. I think a lot of key to that success is the follow up that occurs after screening and the continuing contact that we have with our participants. They see the health benefit, you know, for some the health benefit is knowing that they have a clean bill of health and that's always reassuring and that is definitely a health benefit. But for many people who either are ..., have been found to have an abnormality in a diagnostic test or to have an elevated risk factor, to have a high cholesterol, to be smoking, those kinds of things, the health benefit is in our interest and our care about that and the fact that we work hard to make sure that people understand what all that means to their future health, find a practitioner, if they don't have one who can help them, and make sure they get that problem taken care of. And that should be the model and I think that's what I would say to Congress. I would say that when there is a need for medical screening, look at this model and fund this kind of model. Uh, for research questions, my advice to Congress would be to fund activities that use state-of-the-art methods. In looking at

worker's studies we definitely need to get beyond doing studies that we're just basing our exposure estimation on the personnel record. On knowing, you know, what the personnel record says about that person's job title and what department they were in. Uh, we have the ability to ask focused questions about what pieces of equipment people worked with, what materials they handled, what they actually did in their job. And we now have methods where we can use the information. If we don't have information from everyone, we can use the information we have to develop exposure profiles from those people where we don't have individual information. In doing all of that, we can come up with much more precise exposure estimates and therefore get a much better answer to what kind of exposures really contribute to disease or factor in causing disease. And the same with community residents, there are a lot of opportunities here to answer questions about various kinds of radiation exposure and how they contribute to disease.

**121354 Interviewer:** Final question: what would you like future generations, like for instance, one of the things as the site gets cleaned up, even though we're not quite sure when is going to happen, one of the reasons that we wanted to do this was to keep a record. And already, students who never went through the Cold War who were five or six or seven or eight years old, say 20 years from now, what would you like them to be thinking about, the next generation, what would you like them to remember about the lessons learned from Fernald as an epidemiologist? I guess would be to learn about the possible health-related effects of nuclear weapons production at Fernald.

**121350 Susan:** You know Fernald, when Fernald was built and production started there, it was the time of the Cold War and the people who worked there really saw their service as service to their country. Many of them were World War II veterans, and they felt that what they were doing was really doing something very valuable in protecting their country, supporting the defense of their country. The ..., some was known about the hazards of handling the materials that they handled. There were also materials that they handled that we didn't really know a lot about the hazards, the chemicals that you mentioned or you asked me about earlier. But I think the learnings are that in our enthusiasm about doing good works, producing new products, developing technology, we need always to be vigilant about the fact that we are handling materials that are foreign to the human body, that are not meant to enter the human body, and have a potential for causing health effects. And to remind ourselves that we need to allocate resources to protect our health even when we don't know that there is definitely a health effect from that substance. If we're using a lot of something, I think just good wisdom tells us that we need to protect ourselves, whether it be workers or community residents. You know, I have concerns about the things I see going on around me. You know, we're all part of the computer generation and we sit more and more hours in front of our computers and keyboards, no matter who we are, I'm a scientist I do a lot. I see my physician colleagues sitting more and more in front of computers, everyone. And I also know some of the ergonomics, or what that does to our muscular skeletal system, I think that probably what is happening right now is that we who are users have not used computers enough, lots of us, to start developing muscular skeletal effects from all that use. There are people who have studied this and have come out with what height your keyboard should be at, how you should sit, what posture you should use, the exercises to get up and walk around, but almost no one adheres to that. It's going to take people developing muscular skeletal disease from years and years of computer use and then finally, I think, people



will pay attention and do all the things they're supposed to be doing. Now that's somewhat what happened at Fernald. It took a number of years of experience and people became more aware from what was happening in other populations at other sites, learning about other research that had been done involving radiation. And it was fairly late in the history of the site that controls were placed on a lot of the, that the silos were covered, and other controls were placed so that the contaminants would not get out to the community and that the workers would be better protected. It was really in the '80s that a lot of the worker protection came into place. So, you know, it's always better when you have hindsight, when you have the results of your experience, but I'm concerned that we're doing in the same thing in lots of other areas of our lives. Another concern I have is the use of glycol-ethers. When I did my research on glycol-ethers they were used heavily in the semi-conductor industry in making computer chips. Glycol-ethers are now used in all kinds of paints, lots and lots of ways glycol-ethers are used in different types of industries. I don't think we still know a lot about the health effects of glycol-ethers, and there may be few, I mean we may be perfectly safe, but we're using this chemical very widely.

**121936 Interviewer:** One final thing related to that. Are there still need to continue research for current potentially, at Fernald, are there still potential health risks to the community and to the workers with the current state that might need to be researched down the line? I mean, I know there have been past exposures, but I'm wondering if there's still potential.

**122007 Susan:** Well most of my knowledge is about historical exposures. I really, my background on research is such that I'm not really very knowledgeable about current effort. I will say that everything that I know tells me that workers are very well protected, that although it's clean-up and we're in a clean-up phase and people getting rid of radioactive contaminants the means to do that that have been put in place are very protective of workers. And I think that certainly, there are no, there is nothing being released from the site, at the present time that to my knowledge that poses any hazard to community residents. You know we have some questions about whether there are remnants from previous releases that are still out there that may be affecting, that may be causing some low levels of exposures to community residents such as wells, people still using cisterns. You know, there could be possibly some remnants of concern about exposure but, you know, I think currently things are in pretty good shape. I forget what the rest of that question.

**122133 Interviewer:** That's fine. Is there anything else that you'd like to add that you would like to talk about that we didn't cover that may be of some interest to people looking at Fernald? I'm really curious to know why there wasn't more emphasis on the worker health studies than community.

**122154 Susan:** Well there really was but the way your questions came that I think Steve has had much more contact with the residents. So the questions led me to talk about residents, which I think is unfortunate.

**122210 Interviewer:** Do you want to talk a little bit more about the workers? We have about four more minutes; we could do a little bit more about the workers issues and studies. I'm not quite sure I don't know enough about it.

**122226 Susan:** Well, the Workers' Medical Monitoring Program, the workers also, there was a class action suit of workers against the Department of Energy, which I believe was settled in '94 or '95. But in 1995, the Workers' Medical Monitoring Program started, which provides yearly exams to workers, and not only do we collect the same kind of health data and risk factor data, all those kinds of things from workers as we do from residents. We also collected very extensive occupational histories asking them, it's kind of interesting how we developed those interviews and questionnaires. Because people at the plant did such a variety of things but we wanted specific information about who worked with which piece of equipment and who handled what, we developed a method of questionnaire modules. And so we developed a module for people who worked in Plant 1, we developed a module for people who worked in Plant 8, we developed a module for people who worked in the laundry, we developed a module for people who worked in health and safety, you know, lots of modules. And what this allowed us to do, the traditional approach to collecting occupational histories, to do occupational questionnaires, you create one questionnaire that you give to everyone at the plant, at the site. And you can ask so many questions, usually people can tolerate having so many questions, but sometimes they have to be fairly general questions so that they're applicable to all different kinds of workers. By taking this approach we could give people exactly the modules that asked specific questions about the area that they worked in or the jobs they did and were able to get specific information. So sometimes it gets a little crazy in my office as we try to assemble these questionnaires for these people, and they're color coded and they get what looks like a sandwich really with, you know, a layer of green, and a layer of blue, and a layer of salmon depending on the areas they worked. But it really has allowed us to very precisely be able to say who stood where and what they did and at different years in time. And that's been very valuable.

**122446 Interviewer:** Have you had any preliminary analysis yet of any of this or ...

**122449 Susan:** Well we're just beginning with the radon project. But the other piece that we developed as that project which was fascinating to me and I don't have time to tell you about it, was the way we triggered their memories. Remember these guys, primarily, men and women, had worked at that plant back until the early '50s and we had to come up with a way of helping them remember what they did. We had help from DAAP, the department at the University of Cincinnati, and they helped us, an architect from DAAP helped us, with a project of creating collage boards for each building. She had done research about aspects of buildings that help people remember, doorways, windows, cornices, that kind of thing. And so we had a collage for each building to help them remember which of the old buildings they had worked in. In addition to that we developed what we call our scrapbooks, but they were big books of pictures from the interior of each building and workers doing various tasks. And we put those, one set of books in the waiting room and so they could look through them and the collages were up there to, but they could look through them as they were waiting for their interview. And then we started the interviews using some of the knowledge we know about memory and learning by just taking the book for Plant 1 or the book for Plant 5 and going through the pictures and just saying, "Tell me what do you remember about that, tell me what you remember about that." We weren't collecting any data at the time, but we used the pictures and their talking about the pictures to help them move their memory back in time. And I'll never forget I was training some

interviewers and I said to the nurse Pam, at the clinic, "I need to demonstrate an interview," I said, "Find someone for me you know whose worked there awhile." She comes, it was time for me to do my demonstration interview and the door opens and she rolls in this old fellow in a wheelchair and I said, "Oh my Pam, you've given me quite a challenge." I thought this was going to be good, and, but we started out with the collage boards, and he talked slowly he didn't have a lot to say, and he talked some more and then we got to the scrapbook and started talking about the pictures. And it was just amazing how he got into it and started remembering and went on and on and on. So it was a wonderful demonstration of how those pictorial memory prompts can work.

**122731 Interviewer:** When might you have some analysis or and what kind of potential health risks were there to being exposed to the radon and to the ...

**122740 Susan:** Well, the radon exposure estimation project ends the end of June, the beginning of July. Probably our report won't be written till later on that fall. So that will give some radon levels, we hope to obtain additional funding then to use the mortality data that NIOSH is accumulating and to use that with our radon data to see how predictive radon levels, radon exposure was, of lung cancer mortality and possibly some other disease outcomes. We still keep hoping to obtain funding from the federal government to computerize the rest of the medical monitoring medical data so we can look at data analyses there. But until we have funds to do that, there really isn't much we can do, which is very sad.

**122841 Interviewer:** I think we've covered and we've actually ....