

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA

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University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford University
Dana-Farber Cancer Institute
Emory University School of Medicine
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
University of California at San Francisco
*Seattle Children's Hospital &
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Mayo Clinic
Children's Health Care - Minneapolis
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Children's Hospital of Los Angeles
UCLA Medical Center
Miller Children's Hospital
Children's Hospital of Orange County
*Riley Hospital for Children-
Indiana University*
UAB/The Children's Hospital of Alabama
*University of Michigan-
Mott Children's Hospital*
Children's Medical Center of Dallas

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About the Study

The Long-Term Follow-Up Study is designed to examine many different aspects of health care for people treated for cancer or similar illnesses. Questions that may interest you are:

- What will be the result of the treatment you receive?
- Are there any nonmedical effects associated with having cancer or similar illnesses?
- What long-term side effects might arise from one treatment compared to another?

We have asked 20,000 people treated for a variety of serious illnesses in childhood and adolescence to complete a questionnaire regarding their health, their children, and other experiences. Study participants range in age from 10 to 45 years old, with a broad range of experiences which will help define very important issues about the physical and psychosocial effects of a serious childhood illness.

Funded by the National Institutes of Health, this study is the largest of its kind to date. Doctors, nurses, scientists, and their colleagues at 28 institutions across the United States and Canada have participated in its design because they see the need to answer these questions, not only for current patients, but for those beginning therapy. Researchers will develop new therapies using this information and design approaches that will not only cure, but may have fewer unwanted long-term side effects.

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Insurance Issues

People who had a significant childhood illness encounter difficulty obtaining health insurance. Many study participants have been rejected for insurance. You may be covered by the Americans with Disabilities Act (ADA), and if so, you have rights and protections. For information about insurance or other issues and the ADA, call the National Coalition for Cancer Survivorship (NCCS), (301) 650-8868.

Meet the Coordinating Center Team



Front row, seated left to right: Pauline, Ann, Marie, Ann, John, Aleisha, Darnell, Jonathan. Back row: Scott, David, Dave, Heather, Molly, Maureen, Kathy. Not pictured: Lindsay, Irene, and Jack.

Self Examination

It's important to be aware of things we can do to improve and maintain our health. Some types of disease such as breast and testicular cancer, if caught early enough, can often be successfully treated. Simple screening measures are one way to identify potential problems. Enclosed is a card from the American Cancer Society (ACS) which provides instruction for breast and testicular self exam. Hang it in your shower as a monthly exam reminder. For more information, contact the ACS at 1-800-ACS-2345.

From the Editor

Welcome to the Long-Term Follow-up Study Newsletter. If you have completed the LTFU Study questionnaire, thank you! With your help we can make strides in the fight against cancer, leukemia, tumors, and similar illnesses. If you have yet to respond, please give us a call at 1-800-775-2167, and we'll send you another questionnaire. If you have moved or plan to move, let us know so we can update our records.

As we analyze data, we will share our findings. However, as with most research studies, the final report will require several years of analysis. We want this newsletter to reflect issues that are important to you, and we hope you'll find this interesting and helpful.

If you have a story you would like to tell, or have ideas for future articles, drop us a line. Although we can't promise to use all contributions, you can mail letters to:

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Fertility in Survivors of Childhood Illness

Many young adults who were treated for childhood cancer, leukemia, or similar illness have concerns regarding fertility. Over the past few years, we have learned a great deal about the treatment effects on a person's ability to have children. But there is still the need for more research. Here are some general facts about fertility after treatment with chemotherapy or radiation. *It is important, however, to keep in mind that every individual is different and that no two people react in exactly the same way to a specific treatment.*

Your ability to have children will be affected mostly by the type of treatment you received. Certain types of surgery, chemotherapy, and radiation can cause fertility problems. Women need a normal uterus (womb) and at least one functional ovary to become pregnant; men need at least one functioning testicle. Thus, surgical removal of only one ovary or testicle should preserve fertility.

The group of drugs called "alkylating agents" are the ones most often associated with fertility problems, especially in men. The more common alkylating agents include cyclophosphamide (Cytosan), procarbazine, nitrogen mustard, busulfan, BCNU, and CCNU. Individuals treated with high dosages and a combination of two or more of these drugs are more likely to encounter difficulty having children.

Radiation therapy to the groin area, lower abdomen, pelvis, or the spine can also cause fertility problems; this appears to be dose-related. In addition, individuals with brain tumors near the pituitary gland, or who received high doses of radiation or injury to this area, can occasionally have fertility problems.

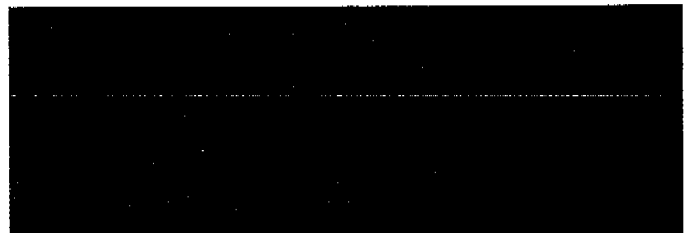
While fertility problems are often permanent, they can also be temporary. Normal function can return, even years after treatment.

Recovery has occurred most often in women treated with chemotherapy alone. In contrast, some women who are currently able to get pregnant may enter menopause early, thus losing their ability to have children. Women treated with alkylating agents and those who received radiation to the pelvic area also appear to have a greater chance of early menopause.

You may need to be tested to determine if you are able to have children. It is relatively easy to tell if a woman's ovaries are functioning normally. Women having regular menstrual periods on their own, without hormonal intervention or birth control pills, are generally able to get pregnant. Your doctor or health care provider can also perform a simple blood test to see if your ovaries are normal.

Men should have a sperm count to determine their fertility. This can be done at a clinic where semen analyses are done. Most large hospitals are able to do this. Speak with your health care provider about resources.

Many new advances are being made in the area of human fertility. Modern techniques such as *in vitro* fertilization and intracytoplasmic sperm injection have enabled couples considered infertile a few years ago to have children. Discuss options with your health care providers or seek consultation with a fertility specialist.



You and Your Doctor

As a survivor of cancer, leukemia, a tumor, or similar illness in childhood, it is important to develop a relationship with a doctor who knows your medical history. This will enable him or her to accurately assess your current health condition. If you don't know the details of your previous illness, ask someone who does such as a parent or sibling or call the hospital or clinic where you were treated. Make an appointment with the doctor who treated you to review your records. Some things to ask include:

- What disease did I have?
- How old was I when I was diagnosed?
- Where was it?
- Which chemotherapy drugs were used?
- What was the radiation site and dosage?
- What surgery was done?

Now you can address the following:

- Are there any known long-term side effects associated with the treatment I received?
- Am I at risk for a recurrence or developing another illness?
- Are there any warning signs or health practices I should be aware of?

Write down your questions before you meet with your doctor. Remember that no matter how minor your question may seem, don't be embarrassed to ask. *After all, this is one way to increase your awareness and take responsibility for your own health care.*

What's Next?

Now that the baseline questionnaire is complete, what's next? One way to analyze data is to compare responses to a national sample of individuals who have never had these illnesses. This is done with data from the National Center for Health Statistics. Another way is to collect information on siblings of study participants. This accounts for biological and family factors which allows us to focus on differences resulting from previous illness and treatment.

We will contact 10,000 participants to see if they have a brother or sister we may contact. If selected, we will approach you for permission to contact your sibling; we then mail him or her an introductory letter and consent form. If they participate, they will receive a questionnaire similar to yours, without reference to your disease. Your sibling has the choice to participate or not, and their decision will not change your involvement in any way.

Gotten a Phone Message Lately?



LTFU Interviewers: Back row, standing left to right: Ursula, Deantha, Marie, Margaret, Janice, Brenda. Front row, sitting: Jamie, Joan. Not pictured: Susan.