

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 &
Medical Center
Toronto Hospital for Sick Children
St. Jude Children's Research Hospital
Children's Hospital of Columbus
Roswell Park Cancer Institute
Mayo Clinic
Children's Health Care - Minneapolis
Children's Hospital of Philadelphia
St. Louis Children's Hospital
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*

The Long-Term Follow-Up Study newsletter is written and published by the University of Minnesota Department of Pediatrics, Division of Pediatric Epidemiology & Clinical Research.

From the Editor

In this second edition of the Long-Term Follow-Up Study newsletter, we present some of the information we've gathered so far, and introduce you to some of our new undertakings. We're excited to share findings with you, but as with most large studies like this, a final report will require many years of analysis. Please see the Study Stats section on page 2 of this issue for details of our preliminary findings. Also on page 2, we introduce Lit Watch, a new feature of the newsletter devoted to highlighting current medical literature or research you may be interested in.

As part of the Long-Term Follow-Up Study we are beginning to collect information on the use of growth hormone. We're asking doctors who treated children with growth hormone to give us information about the exact dates of treatment, the dose received, and how well the children treated with growth hormone responded. With this information we hope to add to our understanding of the usefulness of growth hormone for treating children and young adults.

Cigarette smoking among study participants is another area we are investigating. So far, we have found that about 28% of study participants over the age of 18 have smoked. Of those, more than half are still smoking. Some previous studies have shown that although childhood cancer survivors are less likely to experiment with smoking, they are also less likely to quit once they have started. Because of this, effective strategies for reducing smoking among survivors are greatly needed. Researchers at the Dana-Farber

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Study Stats

We get many calls on the toll-free number requesting results from this study. Though final analysis cannot begin until our cohort is complete, we are able to present some preliminary information to you.

Participants in this study are members of a cohort, which is a group of people sharing similar attributes, such as surviving a childhood cancer, tumor, leukemia, or similar illness. The information presented in this section was compiled from the first 11,202 returned questionnaires.

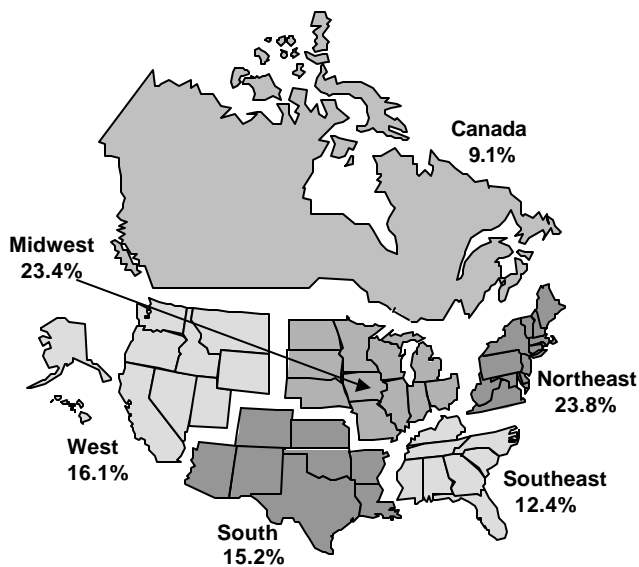
Of all participants. . .

- 87% currently have health insurance.
- 44% had exercised for 20 minutes at least 3 times in the previous week.
- 54% have received a general physical exam from a physician in the last year.
- 67% have seen a dentist within the last year.

Of participants who are 20 years of age or older. . .

- 52% are currently married.
- 34% have ever been pregnant or gotten a partner pregnant.
- 93% have completed high school.
- 17% of males regularly perform monthly testicular self-examinations.
- 27% of females regularly perform monthly breast self-examinations.
- 20% of females have ever had a mammogram.

Current residence of participants



This graph shows the proportion of participants by current residence. It does not reflect the rate or incidence of cancer in various regions, but rather, the region where a person lived when filling out the questionnaire. Some areas may seem to have a larger concentration of participants than others, but this is mainly due to the location of hospitals and their patients taking part in this study.

Lit Watch

Researchers from the Children's Cancer Group, a group of hospitals in the US and Canada that share treatment strategies, recently published a paper about adults successfully treated for childhood acute lymphoblastic leukemia (ALL) and birth defects in their offspring. In the largest group of ALL survivors studied to date, scientists found that adult survivors did not have an increased risk of having offspring with birth defects, despite their earlier therapies for ALL.

"Birth Defects in Offspring of Adult Survivors of Childhood Acute Lymphoblastic Leukemia" can be found in: *Cancer*, July 1, 1996, Volume 78, Number 1, page 169.

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Cancer Institute in Boston have joined other investigators from the Long-Term Follow-Up Study in applying for a grant from the National Cancer Institute. The grant would be used to plan and implement new smoking intervention strategies focused on these smokers, who could be at an even higher than normal risk for the harmful effects of cigarette smoke.

You may receive mailings about, or be asked to participate in one of these studies. As always, you have the final say in whether or not you want to participate.

We hope you enjoy this edition of the Long-Term Follow-Up Study newsletter. If you have any questions or comments, please contact us at 1-800-775-2167. If you have an email account or access to the World Wide Web, let us know: ccss@epivax.epi.umn.edu.

What about My Kids?

by Dr. John Mulvihill

Some survivors of childhood and adolescent cancer cannot have babies or start pregnancies because of their cancer experience. But, if a pregnancy does take place, will the baby and growing child be healthy? Will there be an unusual risk of cancer, birth defects or genetic defects? Such questions are on the minds of many survivors, and they are a major reason the Long-Term Follow-Up Study was launched, because there is very limited information right now.

The reproductive organs can be injured by a tumor itself, or by the surgery necessary to remove it. Radiotherapy can kill normal tissue needed for producing eggs or sperm or for maintaining a pregnancy, and chemotherapy interferes with DNA, the genetic material that we pass on in a pregnancy. These are serious threats to normal reproduction.

In laboratory animals, x-rays and cancer drugs before or during pregnancy clearly can cause birth defects, genetic disease, and even cancer

in the offspring. These laboratory results have not been seen in human studies, however. Among the survivors of the radiation from the atomic bombs in Japan, for example, years of study have revealed NO excess of genetic disease.

With a few exceptions, when a man or woman who survived cancer succeeds in starting a pregnancy, the outcome is not any worse, according to current information, than in the general population in terms of cancer and birth and developmental defects in the children. Data from 15 studies of children of survivors of cancer show that among 3687 live births that took place, the overall rate of birth defects and genetic diseases was 4%, the same as the rate in the general population.

If you have concerns about a pregnancy underway or planned, or about trouble getting pregnant, you may want to consult with the oncologist who treated your illness. You might also consider requesting a genetics consultation. Most university medical centers have a genetics unit, either in the Department of Pediatrics or the Department of Obstetrics and Gynecology. Or you could contact the National Society of Genetic Counselors for a place near you. Their address is: 233 Canterbury Drive, Wallingford, PA 19086-6617; telephone: 610-872-7608.

Save Your Smile

Visits to your dentist are an important part of your overall health. That's why we asked you how long it had been since you last went for a dental check-up. Almost 90% of you answered you had been to the dentist in the past one to two years or less. The following article is from the After Completion of Therapy (ACT) Clinic at St. Jude's Research Hospital, Melissa Hudson, M.D., director.

If you had chemotherapy or radiation to your face area when you were very young, some of your permanent teeth may have shorter roots than normal, or some of your teeth may be smaller than usual. Taking care of the gums properly is especially important when the

tooth roots are short. Lack of good mouth care can lead to gum inflammation and disease. If the gums remain diseased, they may shrink away from the teeth causing the bone supporting the roots to also become infected. The bone may dissolve away slowly causing the teeth to become loose.

If you had high doses of radiation to your face and jaws, you may have some permanent mouth dryness, called xerostomia. A continual dryness in the mouth can cause more cavities to form than is expected. If you do have this condition, you may need to apply a fluoride gel to your teeth at least once a day. The fluoride

acts on the enamel of your teeth to make it more resistant to decay. You should ask your dentist if he/she thinks you should use daily fluoride. Proper brushing habits are very important in this situation as is watching how much candy and other sweets you eat. Also, you should probably see your dentist more often than other people do.

Finally, if you have had a splenectomy, you should always inform your dentist. He/she may wish to give you some antibiotics before doing dental treatment as a precaution against infection.

..... **Please Stay in Touch with Us!**

Remember our 800 number

Did you receive something in the mail from us and are uncertain how to respond? Have you been asked to participate in research and are not quite sure if it is related to the Long-Term Follow-Up Study? Are you planning to move?

You can call the study office free of charge 24 hours a day if you have a question or need information. Usually, the line is answered by a member of the study staff during regular office hours. If you get a recorded message, please leave us a message including your name and telephone number. A staff member will call you back as soon as possible.

Permission for release of information from medical records

As many of you know, it is important for us to obtain information from your medical records. We ask each study participant to provide written consent (Medical Release Form) to obtain copies of records from hospitals and/or doctors you have previously seen or may see in the future.

If you have not signed a medical release form, we will be contacting you to ask for your help in providing the permission needed by your doctors to release information about your previous treatment. Without this information we will not be able to use the information you provided in the questionnaire to help us better

understand the health of individuals like yourself who were treated for a serious illness as a child.

Have you moved in the past year?

If you have moved in the past year, we would like to make sure we have your current address. Please drop us a note or call us with your new address. Keeping in touch will be even more important in the future as the study begins to generate results that may be of importance to you and your health.

Are you willing to volunteer for future research studies?

From time to time we would like to ask participants in the Long-Term Follow-Up Study to be involved in additional studies to help address important research issues. If you are interested, please call us at 1-800-775-2167. You will always have an opportunity to decide which projects you do or do not want to be involved with.

The information you provide is always confidential

Your participation in the Long-Term Follow-Up Study is vital to the study's success. All the information you provide is considered totally confidential and will never be released to anyone without your permission. The results of the research are always presented in such a way that no participant can be identified.