

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA
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From the Editor

We are very pleased to inform you that the National Cancer Institute has funded the Long-Term Follow-Up Study for another five years of research. It is hard to believe that this is our fourth newsletter and that the study has been running for nearly five years already. Recruitment of study participants is now complete, with more than 14,000 survivors and 3,000 siblings agreeing to be part of this important project. We are extremely grateful for your continuing participation. You are part of the largest and most comprehensive research project involving individuals treated for cancer or similar illnesses during childhood. Because of your generous participation great strides will be made in understanding the factors that affect your health and the current and future health of children treated for serious illnesses.

Our goals for the next five years are to continue analyzing the information you have given us, and to publish and keep you informed of our findings. To help with this, we have set up an Education Committee, a group of study investigators who will provide answers to some of your specific questions in upcoming issues of the newsletter.

We will also be contacting everyone next year to see how you are doing and to gather information on topics of importance to study participants. One of the issues we will be focusing on is the difficulties that survivors of cancer and similar illnesses may have in obtaining

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If you want to contact us. . .

Our mailing address is:

Long-Term Follow-Up Study
1300 S. Second Street, Suite 300

Minneapolis, MN 55454

Toll-free phone number:

1-800-775-2167

email:

ccss@epi.umn.edu

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Staying healthy after childhood cancers

by *Melissa Hudson, M.D.*

Reducing the risk of health problems

Childhood cancer survivors may experience health problems resulting from their cancer treatment, and can be at higher risk of some diseases, including other cancers. Practicing behaviors that protect health can reduce the risk of developing these problems. A healthy lifestyle foremost involves avoiding cancer-promoting health habits like tobacco use and unprotected sun exposure. Survivors should not smoke or chew tobacco and should avoid exposure to secondhand smoke when at all possible. Because skin cancers are one of the most common second cancers after childhood cancer, survivors, especially those treated with radiation therapy, should routinely practice sun protection. This includes regularly using sun screen with a sun protection factor (SPF) of 15 or more, wearing protective clothing, avoiding outdoor activities from 10 am to 2 pm when the sun's rays are most intense, and not tanning.

The practice of other protective behaviors will reduce the risk of second cancers and cardiovascular disease. These behaviors include common sense health habits like maintaining an appropriate body weight, exercising regularly, and eating a healthy diet. Obesity (weight 40% or more above the ideal for your height) is linked to many health problems. Being obese may increase the risk of colon, breast, and uterine cancer. Weight reduction—preferably to your ideal body weight—may lower your cancer risk while improving your overall health.

Eat right to reduce your risk of cancer

Dietary practices may affect cancer and heart disease risk negatively or positively. A high intake of dietary fat has been linked to the risk of several common adult cancers. People who eat high-fat diets have a greater risk of getting colon cancer; this may also be true for breast and prostate cancer. High-fat diets are also associated with obesity, heart

disease, and other health problems. To reduce all of these risks, daily fat intake should be limited to 30% or less of your total calories.

Some chemicals used to preserve foods are cancer-promoting (carcinogenic) in large quantities. Diets high in salt-cured and pickled foods and lunchmeats that contain preservatives like nitrites can increase the risk of cancer in the stomach and esophagus. Some of these foods, especially lunchmeats are also high in fat. Foods of this kind should be eaten rarely and in small portions.

Heavy drinkers, especially those who use tobacco, have a high risk of cancer of the mouth, throat, and esophagus. The risk of breast cancer may be increased in women who drink alcohol. Limiting the use of alcohol can reduce these cancer risks and decrease the chances of other alcohol-related problems, such as liver disease.

People who eat high-fiber foods have lower rates of colon cancer. Dietary fiber is found in whole grains, several types of vegetables, and certain fruits. Fiber reduces the time it takes for wastes to pass through the intestinal tract. High-fiber foods also tend to be low in fat.

Eating cruciferous vegetables also helps reduce cancer risk. Cruciferous vegetables include cabbage, brussel sprouts, broccoli, and cauliflower. Eating these vegetables is thought to protect against cancer by blocking the effects of cancer-causing chemicals in other foods. Cruciferous vegetables are also high in fiber and low in fat. These foods should be included frequently in the diet.

Diets rich in vitamins C and A have been shown to reduce cancer risk in animal studies. People whose diets are rich in vitamin C appear less likely to get cancer, especially cancer of the stomach and esophagus. The

best way to get these nutrients is to eat lots of fresh fruits and vegetables. Citrus fruits, melons, cruciferous vegetables, and greens are high in vitamin C. Good sources of vitamin A are dark green and deep yellow vegetables and certain fruits. If your diet is poor, vitamin supplements may help, but extra high doses can cause serious side effects.

Pursue regular medical check-ups

Practicing health maintenance behaviors can improve your awareness of changes in your body and increase the likelihood that problems will be detected at earlier stages. Health maintenance involves having regular medical check-ups, including cancer screening evaluations, appropriate for age, gender, and treatment history. In addition, survivors should perform monthly self-examination of the breast or testes and alert their physicians of suspicious changes. Knowing the details of your previous medical history, including exposures to chemotherapy, radiation, and surgery, is also vital to your future health. This information should be available to you or your physician from the hospital or clinic where you received your therapy. Developing a relationship with a primary care doctor who knows your cancer treatment history, risks of late effects, and recommended screening evaluations will improve the chances of catching problems at earlier, more treatable stages.

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access to health care. The Robert Wood Johnson Foundation has given us a grant that will be used to help us identify the barriers to long-term preventive and cancer-related care facing adult survivors. We will use our findings to develop strategies for improving access to care for those affected.

We hope you find this edition of the newsletter informative. As always, if you have any questions or comments, please call us at our toll-free number **(1-800-775-2167)**, or send an email to ccss@epi.umn.edu.

6 steps you can take to promote a healthier life

(1) DO NOT SMOKE!

DO NOT DIP OR CHEW TOBACCO!

TRY TO AVOID SMOKE-FILLED ROOMS!

(2) EAT RIGHT

Eat more fruits and vegetables every day.

Eat more low-fat and low-cholesterol foods.

Eat foods high in fiber every day.

(3) WATCH YOU WEIGHT

Reduce if you are overweight.

(4) GET REGULAR EXERCISE

At least 3 times a week for 20-30 minutes.

(5) USE SUNSCREEN

Sun protection factor (SPF) of 15 or more.

(6) HAVE REGULAR SCREENING EXAMS

Yearly check-ups.

Monthly breast/testicular self-exams.

Routine pap smears.

Update on study findings

Marriage and divorce among cohort members

Study researchers recently published a paper analyzing the marital status of 10,425 members of the cohort who were over the age of 15 when they completed the study questionnaire. They found that 62% of the cohort members had never married, 32% were married or living as married, 6% were divorced or separated, and less than 0.1% were widowed. Women in the cohort were slightly less likely to have married and also less likely to have divorced or separated than women in the U.S. general population; men had about the same rates of marriage as the general population but were more likely to have divorced or separated. Fewer individuals with brain tumors reported ever being married than other members of the cohort. *Comment:* The data presented in this paper are preliminary and we will continue to follow marriage trends in the cohort. Marital

status can be a useful indicator of the impact of cancer diagnosis and treatment on the quality of life of survivors. *"Marriage in the survivors of childhood cancer: a preliminary description"* can be found in: Medical and Pediatric Oncology, Vol 33, pp 60-63, 1999.

Upcoming reports

Our investigators are currently working on several other reports of study findings. In the next year, we will publish papers on the following topics relating to individuals treated for cancer, leukemia, tumors, or similar illnesses:

- *Pregnancy outcomes*
- *Cancer risk*
- *Thyroid function*
- *Risk behaviors*
- *Chronic pain*
- *Heart function*
- *Smoking frequency and patterns*
- *Use of special education services*
- *Insurance issues*

We will be presenting some of these results in upcoming issues of the newsletter. In the meantime, please contact us if you would like information about where you can find these articles published.

The "Scope" mouthwash study

As we told you in the last newsletter, the Long-Term Follow-Up Study has a new project underway to collect DNA from study participants. Study members are being invited to use a small bottle of Scope mouthwash, mailed to their homes, spit out into a sterile cup, and mail the sample back to the University of Minnesota. There, in the lab of Dr. Stella Davies, the DNA will be extracted and stored in a study DNA bank. It will be used to study genes that might influence late complications of cancer chemotherapy, such as effects on the heart and lung, osteoporosis, etc.

We will be studying genes that have a modest impact on the risk of side effects, not ones that can pick out people with very high risks of severe effects. Samples stored in the

bank will be identified only by a number and will be handled with complete confidentiality. Over 1200 participants have sent in their samples so far and mailings are going out each week. Some participants have asked if we can use this material to clone them. *We promise that we can't and we won't!!* Please look out for your mailing when it comes and don't hesitate to call 1-800-775-2167 if you have questions.

Editor's Note: We received the following letter at the study Coordinating Center recently, and the letter's author has kindly given us permission to share it with you. Donna Nave was diagnosed with acute myelocytic leukemia (AML) in 1976 when she was a freshman in high school. She received her treatment at St. Jude Children's Research Hospital in Memphis. Since that time, Donna has experienced hepatitis C, seizures, and other late effects of her disease and treatment, but today she is vibrantly healthy, and happy to be alive. As is evident from her letter, she is an enthusiastic participant in the "Scope" research project. Thanks, Donna, for your generosity in participating in this important aspect of the Long-Term Follow-Up Study.

September 19, 1999

Dear Dr. Leslie,

I returned home late last night to find a small box dangling from my mailbox. I was excited - "who could possibly be sending me a gift," I thought. When I saw the name, Long-Term Follow-Up Study, I immediately thought "a specimen bottle," and became somewhat disappointed. Then I excitedly realized the study must be over and a small gift is enclosed! How we all love to receive gifts! I hurriedly opened the box only to find a specimen bottle!

Enclosed I am returning your specimen bottle with fresh parts of my body inside! I hope you enjoy the contents and they help you in your cause.

I do appreciate all the hard work you have done in this study. I know how important it is and how it may potentially help others in the future.

Take care and contact me should you need any more of "me!"

Donna Nave

P.S. I enjoy reading your newsletter regarding the progress of the study.

