

LTFU

Long-Term Follow-Up Study

www.cancer.umn.edu/ltfu

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UNIVERSITY OF MINNESOTA
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From the editor

Long-term survivors are making news. In its December 8 issue, *Newsweek* magazine published an article on the top 10 health stories of 2003. Cancer was number four on the magazine's list and the article included a special report on the long-term effects of children's cancer treatments, called "Growing Up Healthy, Afterward." This report featured results of a major LTFU research study, headed by Dr. Melissa Hudson, that were



recently published in *JAMA* (the Journal of the American Medical Association). *JAMA* is one of the most widely circulated medical journals in the country. It is received every week by the membership of the American Medical Association. The author of the *Newsweek* article comments that the LTFU research - which is based on the data you have provided - demonstrates "survivors of childhood cancer are a resilient group. . . . Despite the long-term problems caused by treatment, the vast majority of adults [in the study] rated their health as good or excellent."

Making the most of your health. In the study update section on page two of this newsletter we review Dr. Hudson's findings. We also report on another project, led by Dr. Mark Yeazel, about the cancer screening practices of our participants. Both these studies point out the need for timely screening measures to ensure that survivors who are at risk for health problems get the care they need to maintain their health. The goal of the LTFU is to increase understanding of the long-term effects of therapy, both to minimize side effects for future patients and to provide information to survivors to help them cope with or prevent late effects of the treatments they received. We hope that the information provided by these two studies will help you make the most of your health.

Update on Follow-Up 2002 survey. Thank you to everyone who has already returned the Follow-Up 2002 survey or responded over the phone. The majority of our participants have now completed the survey. If you haven't returned yours yet, however, it's not too late! If you've misplaced the questionnaire and would like us to send you a replacement, or if you would prefer to do the survey with an interviewer over the phone, call our toll-free number: **1-800-775-2167**. Please be aware that your participation is important to assure that our study results are accurate. We appreciate your time and effort in responding.

Follow-Up 2004. Study investigators are beginning to put together the next comprehensive LTFU questionnaire, which we will be mailing out to you starting at the end of 2004. The upcoming survey will be much shorter than preceding ones. We will only be asking you to update us about major medical events you may have experienced. We hope you'll find it quick and easy to complete. Thank you for your help.

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Study updates: Health status; cancer screening

In the Spring 2003 edition of the Long-Term Follow-Up Study newsletter, we reported on some work, led by Dr. Kevin Oeffinger, that looked at the use of outpatient medical care by study participants. That study found that our participants tended to have fewer medical checkups related to their previous cancer or similar illness as they got older and further out from diagnosis. They also tended to have fewer and fewer general physical exams.

LTFU investigators recently published results of two additional studies of the health of our participants, which we review below.

Health status of adult long-term survivors of childhood cancer. Hudson et al, *JAMA* 2003;290:1583-1592. This study looked at the general health of adults who were treated for childhood cancer or a similar serious illness by comparing our study participants to the members of the LTFU sibling group.

Participants reported that many factors influenced how they felt about their health. Certain survivors had physical problems, which in some cases limited their activity or ability to perform well at school or work, or caused chronic pain. Others reported that cancer caused negative effects on mood or resulted in periods of anxiety or fearfulness related to concerns about recurrence or long-term health problems.

Since both physical and emotional factors seemed to influence a survivor's sense of well-being, the overall health of adult survivors in the LTFU study was judged by their responses to questions about how cancer affected many aspects of their physical and psychological health. The areas of health studied included general health, mental health, functional problems, activity limitations, and cancer-related pain and anxiety. Almost 44 percent of the participants reported a negative effect on some aspect of health. Surprisingly though, despite the frequency of specific health problems, only 11 percent of survivors felt that their general health was fair or poor. This encouraging statistic tells us that the vast majority of survivors adjust well after the physical and emotional effects of cancer treatment.

An important focus of the study was to identify factors that are more frequently seen in survivors reporting health problems. Recognizing factors that increase the risk of health problems after childhood cancer helps researchers identify patients who need interventions to correct or prevent these problems. The investigators looked at the survivors' sex

and current age, the specific type of cancer and treatment (surgery, chemotherapy, or radiation), and other factors like household income and access to insurance. In this study, being female, having a low income, and not graduating from high school were associated with poor health. These same factors are linked to having a higher rate of health problems in adults who have not been treated for childhood cancer. Survivors of certain specific childhood cancers were more prone to have problems after treatment than others, including those treated for brain tumors, bone tumors and sarcomas. This information helps increase awareness about the impact of intensive therapy in these groups and their need for extra attention to maintain good health.

The cancer screening practices of adult survivors of childhood cancer. Yeazel et al, *Cancer* 2004;100:631-40. This study, led by LTFU investigator Dr. Mark Yeazel of the University of Minnesota, examined cancer screening practices of study participants. They looked at the frequency of testicular self-exam in male participants. For female participants they looked at how often they practiced breast self-exam and how often they had a pap smear, a mammogram, and a breast exam by a doctor. These are tests that many physician groups recommend for all adults.

They found that many adult survivors were not having the regular cancer screening check-ups that are recommended for all adults to increase the chances of detecting breast, cervical, or testicular cancer at early stages. They also found that the survivors who were least likely to perform cancer screening practices were those who were younger at the time of the study, had lower education levels, or lacked health insurance.

"Surprisingly, despite the frequency of specific health problems, only 11 percent of survivors felt that their general health was fair or poor. This encouraging statistic tells us that the vast majority of survivors adjust well after the physical and emotional effects of cancer treatment."

In his paper, Dr. Yeazel states,

"Survivors of childhood cancer and their primary care physicians need information regarding their future cancer risks and appropriate screening guidelines . . . [Doctors] need to understand that cancer screening recommendations for survivors of childhood cancer may differ from those recommended for the general population."

He also emphasizes the importance for survivors of knowing their treatment history and sharing it with their health care providers. This is one of the most important things an individual can do to minimize the risk of cancer and other serious health problems.

To stay healthy: Have a follow-up plan

by Dr. Melissa Hudson

Are questions and stories about the health of people who had childhood cancer or a similar illness discouraging to you? These health surveys and articles so often seem to focus on problems that can occur after childhood cancer that one may choose not to read further because thinking about these issues is depressing and anxiety-provoking. How does participating in research about childhood cancer survivors and learning about the long-term effects of cancer help you as an individual survivor? The short answer is that it can make you aware of possible risks to your health so you can take steps to prevent health problems.

Research about health issues affecting survivors is important because the knowledge gained alerts health care providers about potential problems that can result from cancer treatment. In some cases, increased awareness may lead to interventions to prevent a problem. In other cases, understanding the risk factors for developing a health problem can increase the likelihood of screening, early diagnosis, and corrective therapy. It is important that survivors work with their health care providers to be aware of their risk factors for health problems and to develop a plan of follow-up that includes both periodic screening for health risks and methods of risk reduction.

You should ask yourself the following questions to find out if you have a proper follow-up plan to deal with health risks following cancer:

Do I have risk factors that have been identified in research studies that increase my chances of health problems after childhood cancer?

The most important factors to consider are your cancer treatment and age at treatment. Knowing the details about your treatment-specific chemotherapy drugs and doses, radiation treatment fields and dose, and type(s) of surgery will help your health care provider better estimate your risk for health problems and organize a plan of follow-up. If you do not know these details, contact your cancer treatment center to request a treatment summary or a form to release a copy of the medical records about your treatment to your current doctor. If you need help getting a copy of your records, call the LTFU study line: 1-800-775-2167.

Do I have a follow-up plan that includes periodic screening tests based on my cancer treatment?

Your follow-up plan should include regular check-ups with a complete physical and specific tests of organ function based on your cancer treatment. For example, survivors treated with anthracycline chemotherapy like doxorubicin or daunorubicin should have periodic heart tests since these drugs may affect heart muscle function. Guidelines for

screening tests after treatment with specific chemotherapy, radiation therapy, and surgery are available on the Children's Oncology Group (COG) public website that can be accessed by both survivors and their health care providers. The COG guidelines are written for health care professionals, so you should review them with your doctor. He or she can help you put the information into perspective and relate it to your treatment history. The web address is:

www.survivorshipguidelines.org

Do I have a follow-up plan for reducing the risk of health problems after cancer?

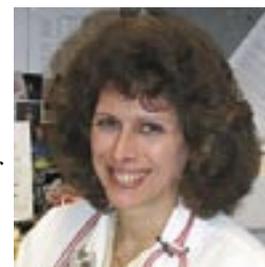
For most survivors, reducing the risk of health problems after cancer involves changing lifestyle and behaviors. The key areas to address include tobacco use, diet and weight control, regular exercise, and sun protection. In some cases, prevention of cancer-related health problems may involve taking medicines, for example, a medication to control high blood pressure or replace thyroid hormone. Regular preventive dental care should also be included in this plan. The COG has developed "Health Links" that review other ways to stay healthy after specific cancer treatments. They can be found at the website listed above.

Do I have a follow-up plan that includes regular screening for cancers that are common among everyone - not just survivors - as they age?

As people get older, the risk of certain cancers becomes higher. For this reason, regular screening is recommended to check for cervical cancer, breast cancer, colon cancer, and prostate cancer. The screening test(s) and frequency varies by age and cancer type. The American Academy of Family Physicians provides a table of recommended screening tests on their website. The recommendations they provide are for low-risk patients. Survivors of childhood cancer or other serious childhood illness may need more frequent screenings depending on their treatment history. The Academy's recommendations can be found on the web at:

<http://www.aafp.org/afp/20010315/1101.html>

LTFU investigator, Dr. Melissa Hudson is the director of the After Completion of Therapy (ACT) Clinic at St. Jude Children's Research Hospital in Memphis, Tennessee. She is the author of the research study that was recently reviewed in Newsweek magazine. Dr. Hudson's research interests include late effects of cancer therapy and health education and promotion in childhood cancer survivors.



ACOR online support groups: "I understand"

We recently added a link on the LTFU website to the Association of Cancer Online Resources (ACOR). The ACOR site hosts several discussion lists on all aspects of cancer. The site's long-term survivors' list provides a place where people can connect with others who have had childhood cancer. Linda Goettina Zame, a survivor of adolescent Hodgkin's disease, runs the list. She believes that joining in the discussion can help people realize that they are not alone: 'Someone on this list will understand,' she says, 'someone on this list will have similar experiences.' The list has members from nearly all of the childhood cancers. Many health care professionals also participate in the discussion list, including some LTFU investigators, such as Dr. Kevin Oeffinger of UT-Southwestern Medical Center in Dallas. Please read below about how this online community helps survivors connect with one another.

A view from a long-term survivor

by Linda Goettina Zame

Every morning when I log on to my computer and read through a new series of letters from strangers—soon to become friends, I want to say, "You are not alone anymore." These letters are from long-term survivors of childhood/adolescent cancer who have signed on to our internet discussion group. When a new member comes along we love to welcome them in to our extended family and help them find a place to share with us some part of our common, sometimes lonely journey. Most newcomers find that someone on the list will have experiences similar to theirs and will be glad to share them.

When we pass from being acutely ill to being free from treatment and illness we are often told to put the past behind us and to get on with our lives, and to a very great extent we do. We grow up, finish school, have careers, marry and have children – or sometimes adopt children if we were left infertile by treatments. But somewhere, someplace, there is always the need to talk and share with others like ourselves.

Many come to the list because for years they have had increasing health problems. They feel guilty about complaining, frustrated in their efforts to get adequate care, and may feel like a burden to spouses and families. There is a flood of relief when they find that others share similar health problems and with some hunting there are health care professionals that understand and can begin to bring relief. Finding others with similar experiences can be a powerful moment.

I want to invite those of you who receive this newsletter to come join us. We are survivors together and our discussion group provides a place to meet and talk honestly about surviving and all that comes with it. Someone will always be there and very likely you will find more than one who will say, "I understand!"

To find the ACOR link on the LTFU website, go to www.cancer.umn.edu/ltfu and click on:

"Additional sources of information (links to other sites)"

The URL to go directly to the long-term survivors' list is:

<http://listserv.acor.org/archives/lt-survivors.html>

Notes from study participants

LTFU study participants often communicate with the study staff through our toll-free line as well as through the comments sections of the questionnaires. The individuals profiled below have given us permission to share some of their experiences with our readers. Several of them have experienced serious late effects from their childhood illness and treatment. While the majority of survivors do not develop these kinds of problems, it is encouraging to learn how resourceful our participants can be when faced with major health challenges.

Californian **Mark Sampietro** was diagnosed with Hodgkin's disease (HD) when he was 16 years old. After reading about the increased risk of thyroid cancer former HD patients may have, Mark contacted his doctor to schedule an exam. A thyroid cancer was found and the thyroid removed. Mark is now doing great on thyroid replacement medications. He credits his successful treatment to reading the LTFU newsletter. *Editor's note: We think the real credit should go to Mark for bringing the information to his own doctor!*

Michele Anthony of Arkansas was also diagnosed with HD at age 16. After treatment, she completed a degree in oncology nursing from the University of Arkansas because she wanted to help others with cancer. Today she works for a pharmaceutical company and also staffs the triage line at a local hospital. As an adult, Michele was diagnosed with breast cancer. She has successfully recovered.

After **Brandon Maas** spoke at a recent cancer survivor's convention in Ohio, the Colorado resident realized that "I really am someone with something to share with other survivors . . . giving others hope and the feeling that they can overcome anything." He recently wrote us about his participation in the LTFU study: "This study, once a painful reminder, is now something I look forward to doing, and reading about in the newsletter." Brandon was diagnosed with bone cancer when he was 14.

Rodney Kornegay teaches high school math in Alabama. He is currently working on his education specialist degree. Rodney was diagnosed with HD when he was 15. He suffered a heart attack six years ago but is now off medication. He has some advice for study participants: "You need to take care of yourself and be aware of what your body is telling you. If you feel like there's a problem, go see someone immediately!"

LTFU toll-free line: 1-800-775-2167