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- Children's Hospital of Columbus
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- St. Louis Children's Hospital
- Children's Hospital of Los Angeles
- UCLA Mattel Children's Hospital
- 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

## From the editor

Greetings from St. Jude Children's Research Hospital! This is the first edition of the LTFU newsletter that is being sent out from the new Study Coordinating Center in Memphis. As of December 1, 2006, all activities involved in coordinating the LTFU Study will take place at St. Jude. Our thanks go out to the staff at the University of Minnesota who have coordinated the study for more than 12 years, since it began in 1994. We have relied on their wealth of experience to achieve a smooth transition for the study. We are pleased that the University of Minnesota will stay active in the study as a member of the group of participating institutions.

As you can see from this newsletter, not much has changed. Starting December 1 we will have a new email address and the study website will have a new address on the Web (*please see the box on page 4*). You can continue to use the same toll-free number to call us, though there will be new voices at the end of the line. And we'll continue to send you a questionnaire about every two years. We hope and expect that participants will notice little change in their contacts with the study.

**Living with chronic disease.** In this edition's study update section we report the results of an important study of LTFU participants' experience of chronic illness. Chronic health problems such as high blood pressure, heart disease, and diabetes are an unfortunate part of aging for just about everyone in our society. The study findings show that people who had childhood cancer or a similar illness are at increased risk of developing chronic health problems. However, it is one of the great success stories of contemporary medicine that so many of these chronic problems can be successfully managed, especially if they are caught early. That's why it is so important for survivors (and their doctors) to know the specific issues they may be facing based on the treatment they received for their childhood illness. We can't emphasize enough the importance of regular follow-up and screening for potential treatment-related problems. Prompt screening preserves health and saves lives.

**Follow-Up 2007.** Mailings of the next comprehensive follow-up questionnaire are scheduled to begin in the first half of next year. Follow-Up 2007 will be somewhat longer than the previous very short survey but we will keep it as brief as we can.

**Happy Holidays!** Everyone on the LTFU Study team wishes you health and happiness during the upcoming holiday season. Thank you, once again, for your continued participation in the study.

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## Study update: Chronic health problems



Dr. Kevin Oeffinger led the study

Chronic health conditions such as heart and lung disease, diabetes, high blood pressure, low hormone levels, osteoporosis, and cancers of the breasts, lungs, and colon are common among older adults. And the likelihood of developing a chronic health problem increases for everyone as they grow older.

Survivors of cancer and other serious diseases in childhood are also at increased risk of developing chronic health problems because of the treatment they received to cure their illness. LTFU researchers wanted to learn more about how treatment for cancer and similar illnesses

- **Risk is related to childhood diagnosis and treatment.**
- People who were treated for illnesses that required stronger therapy and combinations of different types of therapy are the most likely to have chronic health conditions. These include survivors of bone tumors, central nervous system tumors, and Hodgkin's disease. The chance of having a severe or life-threatening condition is related to the type of treatment used to cure a person's original childhood illness. Survivors who received combinations of specific treatments including radiation to the chest, abdomen or pelvis, and chemotherapy drugs known to affect the heart (anthracyclines), the lungs (bleomycin), or the ovaries or testicles (alkylating agents) were shown to be more likely than siblings to have a severe or life-threatening chronic health condition. Female survivors and those who were older when they were diagnosed are more likely to have chronic health concerns compared to other survivors.

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**Know your treatment history.** The results of this study underscore the need for people to know their treatment history and to inform their doctors and other health care providers. Increasingly, chronic health conditions can be successfully managed, especially when they are discovered early. But survivors must know their risks so they can be screened and if necessary treated for these problems in a timely manner.

### TYPES OF CHRONIC CONDITIONS REPORTED BY LTFU STUDY PARTICIPANTS

Common mild-moderate problems	Survivors with this condition	Siblings with this condition
Problems with balance or vertigo	11%	4%
Underactive thyroid	9%	Less than 2%
Chronic cough/shortness of breath	6%	4%
Problems with swallowing	6%	1%
Hearing loss	5%	2%
Hepatitis	1%	Less than half of 1%
Common severe problems	Survivors with this condition	Siblings with this condition
Ovarian failure (for women)	3%	1%
Second cancers	3%	Less than half of 1%
Heart disease (includes heart attack, heart failure, stroke)	3%	Less than half of 1%
Major joint replacement	2%	—

during childhood affects health risks in aging adults. They compared how often survivors and a group of their siblings reported having chronic health conditions. The severity of these health problems was graded as 1 (mild), 2 (moderate), 3 (severe) and 4 (life-threatening). The research team analyzed questionnaire responses that were provided by over 10,000 survivors and 3,000 siblings about 137 chronic health conditions. Survivors ranged in age from 18 to 48 years (average, 27 years); siblings ranged in age from 18 to 56 years (average, 29 years).

**Survivors have an increased risk of chronic health problems.** Study results show that, compared to siblings, survivors are more likely to have one or more chronic health conditions and are also more likely to have a severe or life-threatening condition. By 25 years after diagnosis, almost 70 percent of survivors had at least one chronic condition, compared to about 40 percent of siblings. The most common conditions were problems with balance or vertigo, underactive thyroid, problems with swallowing, and chronic cough or shortness of breath. *(Please see the table on this page for additional details.)*

Dr. Kevin Oeffinger of Memorial Sloan-Kettering Cancer Institute in New York City led the research team that conducted this study. Their report was recently published in the *New England Journal of Medicine*.

### Comment from Dr. Melissa Hudson

The findings of this study are important for both survivors and their health care providers. Adults treated for cancer and similar illnesses in childhood have a high rate of chronic health problems that may get worse as they get older. The study identifies groups whose diagnosis and specific treatment combinations increase their chances of developing problems. In their report, the study team emphasizes the importance of continued medical monitoring and outlines the steps that doctors should take to keep survivors well. Regular medical follow-up is important to monitor existing health problems, screen for new or hidden health problems, and begin corrective or preventive treatments. However, the recommended screening tests may not be done if the physician is not aware of key information about the survivor's medical history.



Dr. Hudson

**Often, survivors don't know their treatment details.**

A previous LTFU report (authored by Dr. Nina Kadan-Lottick and published in JAMA in 2002) showed that a significant number of survivors did not know the specific details of their diagnosis and treatment. Long-term survivors are not usually being cared for by the doctors who treated their childhood illness and their current doctors are not likely to be informed about the risks they face if the survivors themselves do not know their medical history.

**Did you have a blood transfusion?**

The results of another recent LTFU study stress this concern. An accurate test to screen for hepatitis C in blood donors was not available until 1992. Because of this, survivors of childhood cancer and similar illnesses who received blood transfusions before that time may have been infected with the hepatitis C virus.

Hepatitis C causes a slowly progressing liver disease that may not have symptoms in its early stages. Individuals with chronic hepatitis C can develop cirrhosis (liver scarring), liver failure and, in rare cases, liver cancer. Identifying survivors with chronic hepatitis C is important because some may be candidates for anti-viral therapy or liver transplantation. All patients with chronic hepatitis C infection should have their liver function tested on a regular basis and be advised about ways to keep their liver healthy and ways to prevent spread of the virus. They should be immunized against hepatitis A and B, and they should abstain from alcohol and maintain a healthy weight. Knowledge about transfusion history and hepatitis C screening is important so that the infection can be diagnosed promptly and so corrective or preventive measures can be taken to maintain liver health.

A team led by Dr. Meagan Lansdale and Dr. Neyssa Marina of Stanford University looked at the number of LTFU Study participants who reported receiving a blood transfusion and the number of those who reported having a screening test for hepatitis C. Almost 48 percent had received a blood transfusion, while 36 percent had not; 17 percent were not sure if they had received a transfusion. Of those who reported having a transfusion, only 39 percent had been tested for hepatitis C; 31 percent had not been tested and 30 percent were not sure if they had been tested.

**Knowledge is key.** This is a remarkable number of survivors who might be at risk for hepatitis C but have not been screened and are unaware of whether they are infected! It suggests that many survivors need education about their transfusion status and hepatitis C screening. Knowledge of other aspects of childhood cancer treatment is likewise important to assure understanding about potential health risks and screening.

The box at left outlines the key information a survivor needs to have available to fully understand health risks. With this information, you or your doctor can go to a resource like the Children's Oncology Group Long-Term Follow-Up Screening Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancer to find out about health screening recommendations associated with specific treatments. You can find these guidelines online at the following address:

[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

**To ASSESS YOUR RISK, KNOW THIS . . .**

**ABOUT YOUR ILLNESS:**

- Your original diagnosis
  - diagnosis date
  - type of cancer
  - the part of your body where it occurred
- If you had a re-occurrence or relapse
  - date of relapse
  - type of cancer
  - the part of your body where it occurred

**ABOUT YOUR TREATMENT:**

- Surgical procedures
- Radiation treatment - dates, doses, fields
- Chemotherapy - names of specific drugs
  - If you were treated with **ANTHRACYCLINES AND/OR ALKYLATING AGENTS**, find out the **CUMULATIVE DOSE** you received
  - If you received **METHOTREXATE**, find out the **"HIGH DOSE PARAMETERS"**
- Bone marrow or stem cell transplant - date

**Camp Mak-A-Dream 2007**

Camp Mak-A-Dream is pleased to announce its 2007 schedule. All camps are free of charge (travel is not included) and provide the opportunity to network with other cancer patients and survivors from across the country

The Fourth Annual Young Adult Survivors Conference, for survivors of cancer who are in their 20s and 30s and at least two years beyond therapy will be held May 16-21. This educational conference in a community setting is offered to provide tools and skills for people to become advocates in the cancer community. In the past, several LTFU Study participants and investigators (including Dr. Kevin Oeffinger, the author of the report featured in this newsletter) have attended this conference. For further information about the Young Adult Survivors Conference or other scheduled camping opportunities, please contact Shirley at (406) 549-5987 or [shirley@campdream.org](mailto:shirley@campdream.org). Or visit the camp's website:



[www.campdream.org](http://www.campdream.org)

## Notes from study participants

To lend perspective to the research results highlighted in this issue, we asked two LTFU Study participants to share their experiences with chronic health conditions. Both Nicole and Steve are living with very serious health problems as a result of being cured of childhood cancer. As you'll see below, however, they're not just surviving, both are passionately involved with life, and thriving. Thank you, Nicole and Steve, for your contributions!

### Nicole Kellogg



I am a 27 year old survivor of stage IV neuroblastoma. I was treated in southern California at Children's Hospitals of Orange County and Los Angeles starting in 1980. The treatments I received were harsh. I was not expected to survive. I did survive, though, and I have chronic conditions that go along with it, the worst being thyroid disease. I have had two surgeries on my neck since

remission, with a third surgery becoming likely. Along with thyroid disease I have chronic nerve pain in my right neck, face, ear, clavicle, shoulder, arm, and hand. . . . I had part of my right lung removed during treatment so breathing has been an issue off and on. Major dental problems have also been a big weight.

As an adult I have found that the mind is the most essential organ. In coping I have figured that, no matter if the pain level is high or low, my mind can make it better or worse. Every exam is a new fear factor, but I am here to win! I am strong enough to seek help when I feel warning signs.

### DID YOU KNOW?

*A commentary in the New England Journal of Medicine on the research report featured in this newsletter stated that the LTFU Study "is clearly the standard by which all future studies [of survivors] should be judged." Thanks to all of you for helping to make this important research possible!*

Lately my chronic conditions have been causing chaos in my body. So, I recruited a new general – I have been seeing a therapist. She helps me keep my pain and fear out of my daily life and off of my pillow!

I know that the problems I have now are because of the treatments I received. My oncologist has told me that the radiation to my neck and chest are the most concerning and that I am likely to have additional problems as my body ages. This will not bring me down!

I am involved with the Children's Neuroblastoma Cancer Foundation. I have a thread in one of their forums which makes it easy to be in contact with others who have been affected by neuroblastoma. I look forward to being a part of their 2007 conference. Their website is:

[cncf-childcancer.org](http://cncf-childcancer.org)

### Steve Rom

I was diagnosed with Ewings sacroma (bone cancer) in my upper spine when I was nine years old. I had emergency surgery, 75 weeks of chemotherapy and full-body irradiation. I never had any followup treatment and that was a mistake. I have severe scoliosis as a result.

As for my recent cancer, ALL (acute lymphoblastic leukemia), I have one more bone marrow biopsy left. Next May will be my fifth. My transplant, from an unrelated stem-cell donor from Germany was performed at the City of Hope in Duarte, California, on May 4, 2002. I still take about eight different medications a day, from Prednisone to Diflucan, Prograf, Acyclovir, magnesium, etc. I have checkups (bloods and sugar level) every three months or so. Because of the steroids I'm on (Prednisone) I have drug-induced diabetes. I'll take insulin till I'm off the meds in about a year or so. Other than that, I have very little graft versus host disease (GVHD) and have never felt better. I devote all my time to traveling and visiting patients, students, businesses, or anywhere a message of teamwork and inspiration is needed.



**Editor's note:** Together with his best friend Rod, a former professional football player, Steve has written a book about his battle with leukemia and Rod's role in helping him through it. The book's title is *Centered by a Miracle*. It is available at major booksellers. In an article on his website Steve comments, "This may sound strange because I sure didn't feel that way when I was going through it, but my illness was the best thing that's ever happened to me. It showed me that I wasn't alone in the world, that I had tremendous support from so many friends." Steve and Rod's website can be found at:

<http://www.centeredbyamiracle.com/>

### TO CONTACT THE LTFU STUDY . . .

**STARTING DECEMBER 1, 2006**

*Our new website address will be:*

**[www.stjude.org/ltfu](http://www.stjude.org/ltfu)**

*Our new email address will be:*

**[ltfu@stjude.org](mailto:ltfu@stjude.org)**

*Our toll-free phone number will remain:*

**1-800-775-2167**