



www.cancer.umn.edu/ltfu

- University of Minnesota
- The Denver Children's Hospital
- Children's Hospital of Pittsburgh
- Children's Hospital at Stanford
- Dana-Farber Cancer Institute
- Emory University
- 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 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

As the Long-Term Follow-Up Study enters its eighth year, we would like to take this opportunity to thank you for your support of the study. Thanks to your contributions, we have completed a great deal of research that has increased our understanding about the physical and emotional health of individuals treated for cancer, leukemia, tumor or a similar illness during their childhood or adolescence. (A complete list of our published results can be found on the back page of this newsletter.) These studies are important because they help doctors understand the characteristics of people who are at risk of developing health problems following treatment. They are also critical for the planning of future studies to prevent or correct these health problems.

Update on Follow-Up 2002 Survey. By now, most study participants have received the "Follow-Up 2" questionnaire, our third comprehensive survey. The goal of this survey is to gain insight into how treatment for serious illness affects the long-term survivor's quality of life, or sense of well-being. For some participants, treatment has had little or no impact on quality of life; others have experienced significant changes that affect their daily activities. Since the factors that determine quality of life are unique to every person, the questions in this survey are more personal and may take longer to complete than those we have asked before. Also, some of the questions deal with sensitive issues that may be painful to think about. We appreciate your time and patience in responding.

The "big picture". The plan of the LTFU study is to continue to survey all of our participants every two years. As our name indicates, we hope to be in contact with you for the long term! The next survey, which we will begin mailing out in the second half of 2004, will be much shorter than the current Follow-Up 2002 questionnaire. Some of you have commented on the frequency of the follow-up surveys. We are trying to make sure that no one is contacted too frequently. However, you may have received one or more questionnaires in addition to those we send to everyone every two years. This is because we occasionally need to survey small groups of participants to find out about specific health issues affecting people who received certain treatments or who are having particular health problems. We realize that these extra surveys take additional time and effort to complete. We appreciate your participation in these smaller studies. We will continue to try to keep them to a minimum to reduce the burden on individual participants.

If your brother or sister participates in the LTFU as a member of our sibling group, please let them know that they will be receiving the Follow-Up 2002 survey in the next few months. And please thank them for us. Their participation is crucial to the validity of the LTFU study results, just as your is.

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Study update: Obesity and leukemia

LTFU researchers have published results of a new study of obesity in adults who were treated for acute lymphoblastic leukemia as children. Dr. Kevin Oeffinger of the University of Texas Southwestern Medical Center in Dallas led the research team. The study compared 1765 leukemia survivors who are participants in the LTFU with 2565 siblings (brothers and sisters) of study participants.

The research team found that children who were treated with doses of more than 20 Gy of radiation to the brain had an increased chance of being overweight or obese in adulthood, compared to individuals in the sibling group. Girls diagnosed before age 4 who received this dosage were at the highest risk. More than half were overweight or obese as adults.

The researchers also found that the older a person was at diagnosis, the less likely he or she was to be obese in adulthood. In fact, leukemia survivors who were 15 years old or older when diagnosed did not have an increased chance of being overweight, no matter what treatment they received for their leukemia. Chemotherapy treatment did not increase the chances of obesity for any age or treatment group.

The research team used a tool called the Body Mass Index (BMI) to discover which participants in the study were overweight. The BMI is calculated from a person's height and weight. According to the U.S. National Heart, Lung, and Blood Institute, a BMI of 25 to 29.9 indicates that a person is overweight. A BMI of 30 or higher is the Institute's standard for obesity. If you would like to learn more about the Body Mass Index you can visit the Institute's website at the following location:

www.nhlbi.nih.gov/guidelines/obesity/ob_home.htm

This site has a link to a BMI calculator where you can calculate your own BMI. Obesity is becoming a serious problem for more and more people. Whether or not you were treated for leukemia, if you are overweight it is important to know that losing weight, and especially increasing your activity, can help reduce your risk of diabetes, high blood pressure, heart disease, and other life-threatening conditions. The website listed above has information to help you assess your risk of getting these types of diseases. It also provides useful information on achieving and maintaining a healthy body weight. On the next page, Dr. Melissa Hudson of St. Jude Children's Research Hospital offers advice for adjusting to physical changes such as weight gain after experiencing a serious illness.

The paper "Obesity in Adult Survivors of Childhood Acute Lymphoblastic Leukemia" can be found in the *Journal of Clinical Oncology*, Vol. 21, No. 7 (April 1), 2003, pages 1359-1365.

Brian Price, world champion

Study participant Brian Price is a member of the world champion Canadian National Rowing team. He writes below about how surviving cancer contributed to his accomplishment.

At the age of 7, I was diagnosed with acute lymphoblastic leukemia. At that young age, it is a difficult thing to understand and put into perspective. I just remember my mother telling me that I had to have these needles and take these drugs so



Brian (front row, left) and his teammates

that I could live. Going to the hospital, knowing when I would be sick, having no energy, keeping away from friends with a cold, all this became routine. Upon reaching age 12 I was officially in remission. My battle with cancer was over but it didn't go away without leaving a long-term influence on my life.

By having to endure all the chemotherapy and rounds of drugs, only 50 percent of my thyroid was functional. For a kid who

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Camp Mak-a-Dream

The first annual Young Adult Survivors Camping Conference was held at Camp Mak-A-Dream in Gold Creek, Montana this August. The conference was presented through a partnership with the Lance Armstrong Foundation. It was cost-free and open to cancer survivors age 20 to 39. Several of our participants attended the event, which was advertised in the Spring 2003 LTFU newsletter. Study investigators Dr. Brad Zebrack and Dr. Kevin Oeffinger led workshops at the camp.



The theme of the conference was advocacy. Participants learned to advocate for themselves, others, and society. The conference included sessions that focused on skills such as networking, becoming a mentor, public speaking, and establishing productive relationships between survivors and health care providers. Between

sessions there was plenty of time for more traditional camping activities like hiking, fishing, and relaxing in a hot tub.

A second camping conference is planned for Spring 2004. For more details, call the camp at 406-549-5987.

Physical changes after cancer and similar illnesses

by Dr. Melissa Hudson

Most people who have had cancer or a similar serious illness go through physical changes of some sort during therapy. Among the most common of these are weight changes, including weight loss associated with nutritional problems and weight gain associated with steroid medications like prednisone and dexamethasone. After completing therapy and going back to their regular physical activity, most people return to their usual weight. However, treatment may increase the risk of obesity in adulthood for some individuals. Survivors of bone and muscle tumors may have functional problems or chronic pain after surgery that limits their physical activity. Some survivors experience decreased stamina and chronic fatigue that reduce their desire to exercise regularly. Radiation effects on hormone-producing glands like the pituitary and thyroid may affect growth, metabolism, body fat distribution, and energy level. These treatment-related effects may be made worse by poor dietary habits and an inactive lifestyle. Usually, a combination of cancer-related factors and health habits is the most common explanation for obesity. Changing health habits can dramatically reduce the risk of obesity and obesity-related health problems.

Obesity has been linked to several common adult health problems, including diabetes mellitus, high blood pressure, high cholesterol, and heart disease. In addition, obesity has been associated with higher rates of uterine, breast, and colon cancer. Improved understanding about how cancer treatment causes obesity helps doctors plan therapies that avoid this problem in future childhood cancer patients and interventions to help long-term childhood cancer survivors stay healthy as they get older. The recent report by Dr. Oeffinger describing obesity in survivors of childhood acute lymphoblastic leukemia shows that treatment with higher radiation doses of (20 Gy or more) to the brain, especially in girls younger than 4 years, is associated with a greater chance of being obese as an adult. Radiation may cause obesity by affecting the hypothalamus, a gland in the brain that regulates the body's energy use and the "fullness" you typically feel after eating a meal. Radiation effects on the production of growth hormone by the pituitary gland in the brain may also play a role in obesity after childhood cancer. Early results from the LTFU "Scope" mouthwash study show a relationship between genetic factors and treatment in the risk of obesity in girls with ALL. Until the effects of cancer treatment on weight control are better understood, doctors are trying to prevent this problem in childhood cancer patients by using treatments other than brain radiation, if at all possible. Presently, practicing a healthy lifestyle is the best way for survivors who received obesity-promoting treatments to maintain a healthy weight.

Survivors of childhood cancer and similar illnesses should realize that they are not alone in their battle against obesity. Poor nutritional habits and changes in recreational activities have been linked to an alarming increase in the rate of obesity in the general population. More meals are eaten outside the home and include foods that are higher in calories and fat. Restaurants serve larger portions that promote over-eating. Soft drinks and snack foods that are high in sugar, salt, and fat make up an increasing portion of the average daily intake instead of fruits and vegetables. Unfortunately, this increased intake of dietary calories and fat has not been balanced by greater physical activity. Instead, more time is spent in sedentary recreational activities like watching television, playing video games, and surfing the Internet.

Making lifestyle changes to correct or prevent obesity is one of the most important steps a person can take to stay healthy. These efforts are more likely to be successful if the entire family commits to eating healthier and becoming more physically active. Specific health-promoting recommendations are listed below.

If you'd like to lose weight. . .

Set specific goals for diet and exercise

- Example, "Walk 30 minutes 5 days a week"

Keep a food and activity journal.

- This can be a great motivator.

Think "slow food"

- Practice eating slowly to allow time for your brain to get the message you've been fed
- Try to establish regular meal times
- Home-cooked food tastes great and is often more nutritious and less fattening than fast food

Make healthy substitutions

- Try sherbet – or watermelon! – instead of ice cream
- Serve pasta with veggies instead of cheese sauce

Read nutrition labels

- Become familiar with serving sizes and calories per serving as well as servings per container.
- Remember that some of the best food choices – fresh fruits and veggies -- don't always come with nutrition labels

Find some partners

- Exercise with a friend
- Check out weight loss programs such as Weight Watchers
- Use community resources - workplace facilities, community education programs, YMCA/YWCA
- Talk to your doctor

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wanted to be 6'4", the outlook was not good. Actually, this was the best thing that could have happened to me. I have been able to take this misfortune and turn it into an international rowing career.

No, I didn't suddenly become 6'4" tall, but I do get to tell guys that size what to do. At 5'4" tall, 120 pounds, I am the coxwain of the Canadian National Rowing team, with my crew being twice World Champion in men's eight-man competition. The coxwain (a.k.a., cox) is the guy who sits at the back of the boat to steer and makes calls to the rowers in front of him. My journey from cancer to cox has been many years evolving. I started rowing in 1995 with my first national team appearance being in 1998. By 2000 I was ranked number two coxwain in Canada and then secured the number one job in 2001, which I hold to this day.

To win the World championships two years in a row is certainly exciting, but winning my battle with cancer has always been the most important achievement of my life. My years rowing have not always been easy, but whenever I've hit a rough patch I have often reflected back to my childhood. I think about all the time, effort, and sacrifice that my parents, family, and friends went through, and I row for them. It's just the motivation that I need to get me back focusing on the opportunity to prove myself as a champion.

It may sound odd to hear, but without cancer my life would not be where it is today. I would never wish to turn back time and have it play out a different way. Cancer helped me become a two-time world champion, and I hope that it will help me become an Olympic champion next year in Athens.

Annual Investigators' Meeting

LTFU investigators held their annual meeting at the University of Minnesota Cancer Center in Minneapolis on May 17-18, 2003. Researchers from all 28 participating U.S. and Canadian institutions attended. They discussed the current state of research and presented proposals for several new research projects.



University of Minnesota Cancer Center

Dr. Les Robison, LTFU principal investigator, presented a proposal for expanding the study cohort to include individuals who were diagnosed with childhood cancer or a similar illness between 1987 and 1999. The LTFU study currently includes individuals who were diagnosed between 1970 and 1986.

A list of LTFU study publications is at right.

LTFU Published Research

Oeffinger KC, et al. Obesity in Adult Survivors of Childhood Acute Lymphoblastic Leukemia. *J Clin Oncol* 21:1359-65, 2003.

Mitby PA, et al. Utilization of Special Education Services and Educational Attainment among Long-Term Survivors of Childhood Cancer. *Cancer* 97:1115-26, 2003.

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Green DM, et al. Pregnancy Outcome of Partners of Male Survivors of Childhood Cancer. *J Clin Oncol* 21:716-21, 2003.

Emmons K, et al. Smoking Among Participants in the Childhood Cancer Survivors Cohort: The Partnership for Health Study. *J Clin Oncol* 21:189-96, 2003.

Zebrack BJ, et al. Psychological Outcomes in Long-Term Survivors of Childhood Leukemia, Hodgkin's Disease and non-Hodgkin's Lymphoma. *Pediatrics*, 110:42-52, 2002.

Sklar CA, et al. Risk of Disease Recurrence and Second Neoplasms in Survivors of Childhood Cancer Treated with Growth Hormone. *J Clin Endocrinol Metab* 87:3136-3141, 2002.

Robison LL, et al. Study Design and Cohort Characteristics of the Childhood Cancer Survivor Study: A Multi-Institutional Collaborative Project. *Med Pediatr Oncol* 38:229-39, 2002.

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Green DM, et al. Pregnancy Outcome of Female Survivors of Childhood Cancer. *Am J Obst Gynecol* 187:1070-1080, 2002.

Emmons K, et al. Predictors of Smoking Initiation and Cessation among Childhood Cancer Survivors. *J Clin Oncol* 20:1608-16, 2002.

Neglia JP, et al. Second Malignant Neoplasms in Five-Year Survivors of Childhood Cancer. *J Natl Cancer Inst* 93:618-29, 2001.

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Sklar C, et al. Abnormalities of the Thyroid in Survivors of Hodgkin's Disease. *J Clin Endocrinol Metab* 85:3227-32, 2000.

Rauk AM, et al. Marriage in the Survivors of Childhood Cancer. *Med Pediatr Oncol* 33:60-3, 1999.

LTFU study toll-free phone number:

1-800-775-2167