

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 Hospitals and Clinics of Minnesota
- 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

We are very pleased to be able to tell you that the Long-Term Follow-Up Study recently received renewed grant funding from the U.S. National Cancer Institute for the next five years - December 2005 through December 2010. The renewed funding is a testament to the value of the information our study participants have so generously shared with us over the last 12 years. We thank you.

We're growing! In the next five-year grant period the LTFU Study will go through some important changes. First, we will be enlarging the study to include individuals who were diagnosed with cancer or a similar illness between 1987 and 1999. Current study participants were diagnosed between 1970 and 1986. The new study participants will be enrolled from the same institutions as the original participants.

We're moving! The other important change to the study is that the Coordinating Center is preparing to move from the University of Minnesota in Minneapolis to St. Jude Children's Research Hospital in Memphis, Tennessee. Dr. Les Robison, the principal investigator of the LTFU Study has accepted a position at St. Jude. St. Jude has been a participating institution in the LTFU Study since the study began. Over the next year or two the activities of the Coordinating Center will gradually move from Minneapolis to Memphis.



Dr. Les Robison leads the study

The Coordinating Center is responsible for sending out study questionnaires, doing the telephone interviews, and answering the study's toll-free line - all the various types of contacts we have with study participants. The transition to St. Jude will take place gradually and most of you will likely not see many changes except for the addition of the St. Jude logo on newsletters and questionnaires. The University of Minnesota will remain active in the study, as will all of the other participating centers (see the complete list of LTFU institutions at left.) You can find additional information about St. Jude on page 4 of this newsletter.

Follow-Up 3. This Fall we are wrapping up "Follow-Up 3," the LTFU Study's third comprehensive follow-up survey. Thank you to everyone who has returned a questionnaire. Planning for "Follow-Up 4" is in the works. We expect to start mailing it in early 2007.

Best wishes for the upcoming holidays from the Coordinating Center staff.

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Study update: Physical limitations and daily life activities

Some survivors of serious childhood illnesses, such as cancer, have lifelong problems being physically active and can be limited in their ability to take part in everyday activities at home, school, and work. LTFU Study investigators looked at the experiences of study participants in this area. The research team, led by physical therapist Kirsten Ness, examined participants' responses to questions about physical activity from previous LTFU Study questionnaires. The team noted how many participants reported that health problems limited their ability to do things such as running, climbing stairs, bending, lifting, stooping, walking, eating, or dressing. They also looked at whether these problems restricted participants' ability to carry out everyday activities like taking care of themselves or going to school or work.

Overall, about 20 percent of the LTFU Study participants in this report said that they had trouble performing some physical activities. However, almost 40 percent of people who had bone tumors and 30 percent of those who had brain tumors reported having this type of trouble. Problems with physical activities occurred least often in Hodgkin's (23 percent) and leukemia (15 percent) survivors.

Survivors of brain tumors or bone tumors, more often than other survivors, reported that physical limitations prevented them from taking part in activities needed for daily living, such as grooming or getting dressed. People who received radiation or a combination of radiation and chemotherapy were more likely to have difficulty than those who were treated with surgery alone.

Medical problems involving glands, bones and muscles, the nervous system, the heart, or the lungs were linked with both reduced physical activity and restricted participation in daily activities. Participants who reported complications affecting the bones and soft tissues like muscles were most likely to have problems with physical activities. Survivors with chronic pain or poor balance, abnormal sensation in their trunk or legs, or weakness in their arms or legs were most likely to be limited in their ability to take part in activities of daily living. Similar findings were observed for survivors who had vision or hearing loss following treatment for childhood cancer. The results of this study emphasize how cancer therapy side effects on the muscles, bones, organs, and other parts of the body may limit activity and lead to difficulty completing daily tasks in the home or at school or work.

Comment from Dr. Melissa Hudson

Medical late effects that interfere with physical function are very common after treatment for childhood cancer. Adults who have survived childhood cancer are at risk for developing these health problems many years after treatment. For this reason, survivors should have regular check-ups throughout

life to identify problems that can be corrected and obtain referral to rehabilitation services that can help improve function. If you currently have physical problems that limit your ability to perform everyday activities, an important first step is to schedule a visit with your primary care doctor for a general check-up. Share details of your cancer history and treatment with your doctor and discuss if you should have further testing for medical late effects that could be limiting your physical activities. If your doctor is not familiar with health risks after childhood cancer therapy, contact medical staff at your cancer treatment center to request this information. The Children's Oncology Group Long-Term Follow-Up Screening Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers is another good resource for information about health issues related to common pediatric cancers. The guidelines are available on the Internet at this web address:

www.survivorsguidelines.org

After receiving the proper medical evaluation and treatment, if needed, ask your doctor for a referral to a rehabilitation specialist. These are health professionals such as physical therapists, occupational therapists, and physical medicine doctors who can offer advice about changes you can make at home, school, or work, to improve function and mobility. Regular exercise is important to maintaining physical activity, even when medical problems limit function. Rehabilitation specialists can help you develop a safe fitness program that takes the health restrictions identified by your doctor into account. These specialists are also well informed about community programs that can provide or donate adaptive devices to help you increase your physical activity.

A book for your doctor

An important new book about medical aspects of childhood cancer survivorship has recently been published. *Survivors of Childhood and Adolescent Cancer* is written for doctors who work with survivors. The book is organized by organ systems. Each chapter has information your doctor needs about the effects of cancer treatment on various body system (heart and lungs, thyroid gland, vision, hearing, etc.) We recommend that you let your doctor know about this resource. The book is available at most large bookstores and libraries. It is a great tool to help primary healthcare providers understand the impact of childhood cancer diagnosis and treatment on the health of adult survivors.

Wendy Hobbie and Kathy Ruccione, who helped edit this book, also worked on *Childhood Cancer Survivors: A Practical Guide to Your Future*, which was written for survivors themselves. It was featured in the Fall 2000 LTFU Study newsletter.

Living with limitations: Community resources

Many service and not-for-profit organizations and government agencies provide adaptive resources, some free of charge, for people living with physical (as well as mental or emotional) limitations. These resources range from assistive equipment, like bathroom grab bars, to job training to child and adult day care programs. In addition to the resources listed below, your primary care doctor or your cancer treatment center may be able to help you find local resources in your community.

Lions Clubs - offer services for blind and visually impaired people

- guide dog sponsorship and support for guide dog schools
- scholarships for blind students
- camps and recreational activities for the blind/visually impaired
- provision of devices such as white canes, braille, or computers

Contact the Lions website: www.lionsclubs.org
email: executiveservices@lionsclubs.org

Most services are provided through local clubs. To locate a Lions club in your area, use the club finder on their website.

Easter Seals - offers services for people with all types of disability

- medical rehabilitative services, including assistive technologies for home, school and workplace
- job training and employment
- child care and adult day centers
- camping and recreation

Contact Easter Seals address: 230 West Monroe Street, Suite 1800
Chicago, IL 60606
telephone: 800-221-6827 (toll-free)
website: www.easterseals.com (U.S.)
www.easterseals.org (Ontario)

Sertoma (Service to Mankind) Clubs - offer services for hearing impaired people

- hearing aid recycling program
- scholarship program for people with communicative disorders and the hearing impaired

Contact Sertoma mailing address for scholarship applications:
*Sertoma International
\$1,000 Hearing Impaired Scholarship Program
1912 E. Meyer Blvd.
Kansas City, MO 64132*
website: www.sertoma.org
email: infosertoma@sertoma.org

To locate a Sertoma club in your area, use the club finder on their website.

Goodwill - offers education, training, and career services for people with physical, mental, and emotional limitations

- free online computer classes
- job training and job placement
- website links to govbenefits.gov, a one-stop website where you can determine if you are eligible for U.S. government benefits

Contact Goodwill address: Goodwill Industries International, Inc.
15810 Indianola Drive
Rockville, MD 20855
telephone: (301) 530-6500
website: www.goodwill.org

Human Resources and Skills Development Canada (HRSDC): www.hrsdc.gc.ca

- comprehensive Canadian government website with information about jobs, disability issues, social insurance and more

Please let us know if you contact any of these organizations. Were they helpful? Did you find the services you were looking for? Call the study toll-free number or email us at ccss@epi.umn.edu. We will publish an update about people's experiences in a future newsletter.

Advocacy: You've got the power!

Advocacy: *The act of pleading or arguing in favor of something, such as a cause, idea, or policy; active support.*

“Advocacy skills may be a key in helping survivors overcome the challenges of their illness and achieve optimal quality of life,” says Dr. Brad Zebrack, LTFU Study investigator and childhood cancer survivor. Advocacy is defined as the act of representing, promoting, or providing support for an individual (including yourself!) or group. An important part of survivor advocacy is empowering the individual with skills and knowledge to influence others, especially health care providers. For a young adult becoming responsible for your own health and health care, advocacy starts with being informed about your cancer history, its potential health risks, and steps you can take to stay healthy. Survivors who learn advocacy skills can learn what questions to ask their doctors, demand new or improved services, and address their specific health issues.

Advocacy can occur on different levels. Survivors who are self-advocates learn to feel comfortable talking to their doctor about cancer and their specific health needs. Some gain experience in speaking on behalf of other cancer survivors and become mentor advocates. And other survivors become involved with community or national organizations and go on to be community advocates. Each level of advocacy is important to address health needs of the individual cancer survivor as well as the growing community of childhood cancer survivors.

A variety of programs are available to teach adolescent and young adult cancer survivors advocacy skills. These include internet web sites, chat rooms, listservs, oncology camps, outdoor adventure programs, and cancer survivor day celebrations. The following online resources can help you explore advocacy training opportunities that fit your style:

- **Planet Cancer** - a website written by and for young adult cancer survivors: www.planetcancer.org.
- **Livestrong** - the Lance Armstrong Foundation created this website to help people take control of their experience with cancer and survivorship: www.livestrong.org.
- **ACOR** (Association of Cancer Online Resources) - provides an online community for long-term survivors: <http://listserv.acor.org/archives/lt-survivors.html>.
- **Camp Mak-A-Dream** - cost-free, medically supervised camping experiences for cancer patients and survivors. Annually hosts the Young Adult Survivors Conference, which teaches advocacy skills. Information about the conference is available at: www.campdream.org.

St. Jude Children's Research Hospital

St. Jude Children's Research Hospital, located in Memphis, Tennessee, is one of the world's leading centers for research and treatment of serious diseases in children, especially pe-

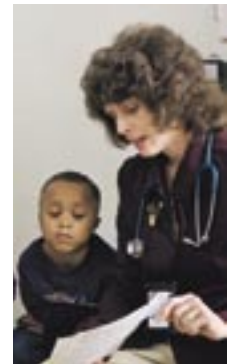


diatric cancers. It was founded by entertainer Danny Thomas and opened in 1962. It is supported primarily by funds from volunteer contributions raised by ALSAC, the national fund-raising organization established by Danny Thomas expressly for the purpose of funding St. Jude. St. Jude

also receives assistance from federal grants (mainly through the National Institutes of Health and the National Cancer Institute), insurance and investments.

St. Jude has treated children from across the United States and from more than 80 foreign countries. All were accepted by physician referral because the children had newly diagnosed diseases that were being researched at St. Jude. St. Jude is the only pediatric research center where families never pay for treatment not covered by insurance, and families without insurance are never asked to pay.

St. Jude has been a participating institution in the Long-Term Follow-Up Study since the study began in 1993. It enrolled one of the largest groups of study participants. Dr. Melissa Hudson is the LTFU Study investigator from St. Jude. She chairs the study's Education Committee and is a frequent contributor to this newsletter.



Dr. Hudson at St. Jude

Over the next year or two, the Coordinating Center of the Long-Term Follow-Up Study will be moving from the University of Minnesota to St. Jude. The University of Minnesota will continue to play an important role in the study but, eventually, most of the study's day-to-day operations will take place at St. Jude.

While moving the Coordinating Center to St. Jude will be a big change for study staff, we expect - and hope! - that study participants will not notice much of a difference in their routine contacts with the study. University of Minnesota Coordinating Center staff will work closely with St. Jude personnel as they begin to take on this new role in the Long-Term Follow-Up Study.

**LTFU study toll-free phone number:
1-800-775-2167**