

CCSS

*An NCI funded
Resource*

Education Committee Meeting

CCSS PI Meeting
June 14, 2017

Objectives

- To disseminate study findings to participants
- To educate study participants about
 - Cancer-related health risks
 - Health surveillance recommendations
 - Survivor advocacy/resources
- To promote survivor resiliency/self-advocacy
- To facilitate ongoing participation in research

Communication Content

- Study operations/progress
- Study results
- New research opportunities
- Educational content relevant to survivor health
- Survivor vignettes/notes
- Survivorship resources

Distribution 3 to 4 times per year

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA

Summer 1996

University of Minnesota

The Denver Children's Hospital

Children's Hospital of Pittsburgh

Children's Hospital at Stanford University

Dana-Farber Cancer Institute

Emory University School of Medicine

Children's National Medical Center

U.T.M.D. Anderson Cancer Center

Memorial Sloan Kettering Cancer Center

Texas Children's Hospital

About the Study

The Long-Term Follow-Up Study is designed to examine many different aspects of health care for people treated for cancer or similar illnesses. Questions that may interest you are:

- What will be the result of the treatment you receive?
- Are there any nonmedical effects associated with having cancer or similar illnesses?
- What long-term side effects might arise from one treatment compared to another?

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA
Summer 2001

From the editor

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

Here's to your health! As someone who has successfully overcome a serious illness, your perspective on health may be quite different from that of many people. We realize that you value your health and do not take it for granted. Reviewing and analyzing the information you have provided as part of the Long-Term Follow-Up Study has confirmed what we had hoped. The overall health of the participants is good and most participants want to know what steps they can take to stay active and healthy. In this issue you will find information we think can help you do just that. Everyone is "at risk" for some kind of health problem, whether it is heart disease, breast cancer, brittle bones, or something else. Medical research can help us determine if our individual risk is higher than that of others and, if so, what we can do to either bring that risk down or detect problems before they are too serious. Being "at risk" for a certain disease, or finding something about yourself in a

In 1975, not much was known about the long-term side effects of treatments for childhood cancer. And, of course, the first priority at the time was to save Mark's life. Researchers have since discovered that both daunorubicin and chest radiation can cause damage to the heart. Both chest radiotherapy and BCNU can damage the lungs.



Study participant Mark Miller: "Don't give up!" when facing possible long-term effects of treatment.

LTFU

Long-Term Follow-Up Study

www.cancer.umn.edu/ltfu

University of Minnesota
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 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
 Children's Hospital
 Roswell Park Cancer
 Mayo Clinic



"The medical staff in long-term follow-up clinics are familiar with potential late complications of treatment such as treatment-related malignancies and cardiovascular disease, which would not normally occur in individuals as young as many of our survivors are." —Dr. Daniel Green

UNIVERSITY OF MINNESOTA

Spring 2006



From the editor

It's always nice to see summer come back again (especially here in Minnesota.) We can put away the big coats and look forward to more time outdoors. It is a great time to look at our own health and take stock of our habits and experiences that could impact our health in the future. This issue of the newsletter reports on two pertinent studies of secondary cancers in LTFU Study participants. The details follow, but we all should be reminded of the need for proper diet, exercise, regular check-ups, and the avoidance of excess sun as part of our health care plan. Summer is a good time to begin these healthy habits (if you're not doing them already.) Preventive medicine begins with each of us.

Update on Coordinating Center transition. In the last edition of the newsletter we reported that the LTFU Study Coordinating Center will be moving to St. Jude Children's Research Hospital in Memphis where Dr. Les Robison, the Study's principal investigator, is now located. The move process is proceeding about as expected. It is scheduled to be

Moving on in Life After Childhood Cancer and an Amputation

Dave Michael inspires others to keep moving in his role as their personal trainer. It's a good job for someone who has never liked to stand still for very long.

As a kid Dave excelled in baseball and basketball. He enjoyed all types of rough-and-tumble sports, including football and snow-skiing. None of that stopped when doctors found that he had osteosarcoma, a bone tumor. When chemotherapy didn't shrink the tumor, Dave, then 12, opted for amputation rather than risk the cancer coming back in some other part of

Dave's experiences have given him an unexpected edge with other clients. "I take away their excuses," he says. When a client lags behind in his program, Dave tells him: "If I can do an exercise with just one leg, you should be able to do it with four good limbs!"



Notes from Survivors

Childhood Leukemia Survivor Manages Life, Family, Health

In January of this year, Blair Huddleston Collins of Richmond, Virginia, celebrated her 37th year as a survivor of childhood leukemia by running in her first marathon and helping to raise \$5 million dollars for leukemia research.

Keenly aware of the potential for adult health issues resulting from childhood treatment, Blair understood the importance of a regular health and fitness routine. To help achieve her fitness goals, she had already been working with a personal coach when she decided to train for the marathon. Her commitment to help raise money by running in marathons is just one way she "gives back" to those whose work saved her life more than 30 years ago.

Blair was just 3 years old when doctors diagnosed her disease as ALL (acute lymphoblastic leukemia). After a year of in-patient treatment, Blair received radiation therapy and chemotherapy as an out-patient until the fourth grade. Since then, she has never experienced a relapse (disease recurrence).

Before treatment began, doctors told Blair's mother that she would be infertile. Unlike some girls who received radiation and chemotherapy at early ages, Blair began having menstrual periods at about the normal age, and without taking hormones.



Encouraged by success with Tyler, Blair and Jeff adopted Kaitlyn in 2005.

of becoming pregnant again, Blair and Jeff began considering other options for starting a family.

A BRIEF UPDATE

From the Long-Term Follow-Up Study

January 2011

<http://ltfu.stjude.org>

Topic: DENTAL HEALTH

Why did we study participants' dental health?

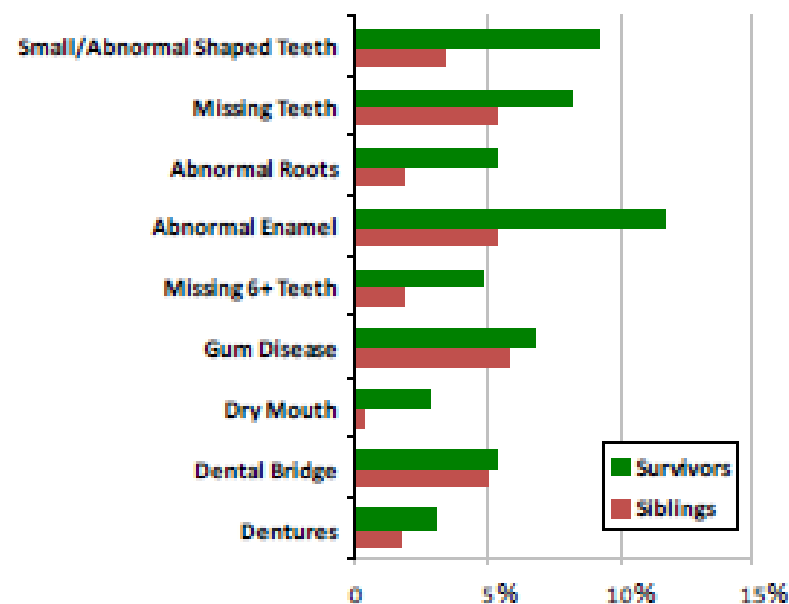
Treatments including radiation and chemotherapy in children can result in problems with oral health.

Who participated in this study?

11,353 Long-Term Follow-Up Study participants (8522 Survivors and 2831 Siblings)

- 50 percent females and 50 percent males
- 87 percent white non-Hispanic
- Between 15 and 34 years old

What we studied:



Percent of Survivors and Siblings with Dental Problems

A BRIEF UPDATE

From the Long-Term Follow-Up Study

January 2012

<http://ltfu.stjude.org>

LTFU Study Expansion - We're Growing!

Thanks to LTFU Study participants, we have learned a great deal about the effects of treatment among childhood cancer survivors. And, we are exploring ways to improve health outcomes for these individuals. Now, the study is expanding to include people diagnosed in the more recent treatment era.

Why is the LTFU Study expanding?

- The combined cohort will include more than 37,750 eligible survivors with detailed treatment information available for study. Of these, we expect that a total of 26,000 to 27,000 active survivor participants will contribute information about their health and well-being by completing the periodic Study surveys.

What do we study?

The LTFU Study has published more than 150 research papers since 2001 on a wide range of topics

New Study of Women's Health

The EMPOWER Study is an exciting new LTFU study focused on women's health. If you are a woman between the ages of 25 and 49 who was treated with chest radiation for a childhood cancer, you may be contacted for this study.



If you'd like additional information about the EMPOWER study, please call the LTFU Study toll-free telephone line: 1-800-775-2167.

What is a Gene, Anyway?

DNA, genes, and genetics are common topics in the news and in many everyday conversations. Many of us, however, might not have a clear understanding of what these terms mean. Following are brief definitions of some of the most important genetic terms.

HEREDITY. Heredity is the passing of physical and mental traits from parents to children. We pass on our traits by means of an amazing molecule called DNA.

DNA. DNA is a chemical that is found in all the cells of the body. The DNA molecule is in the shape of a twisted ladder. Each rung of the ladder is made of a pair of chemical building blocks called bases, or nucleotides. There are only 4 bases in the DNA molecule. They are symbolized by the letters G, A, T, and C. The order of the base pairs is a code the body uses to make proteins .



GENES. Genes are segments of the DNA code that contain the instructions to make a particular protein. Genes are the basic units of heredity. We inherit our genes from our parents and pass them on to our children.

PROTEINS. Proteins are large biological molecules that are used in the body in many ways. Our muscles, bones, blood, and organs all contain proteins that our bodies make by using the instructions

GINA: The Genetic Information Non-Discrimination Act

GINA was passed by the US Congress in 2008 to prohibit discrimination in insurance or employment based on genetic information. GINA put the following safeguards in place:

- Health insurance companies and group health plans may not request your “research only” gene test results.
- Health insurance companies and group health plans may not use your genetic information from your medical record when making decisions about your eligibility or premiums.
- Employers with 15 or more employees may not use your gene test results to decide to hire, promote, or fire you or when setting the terms of your employment.

Additional information about GINA is available at:

www.ginahelp.org

www.ginahelp.org/GINA_you.pdf

Fall 2014

LTFU

Long-Term Follow-Up Study

Stay linked to the LTFU Study:

email: ltfu@stjude.org

phone: 1.800.775.2167

Update your contact information at:

<http://ltfu.stjude.org>

The LTFU Study is 20 years old! It is the world's longest-running study of survivors of serious childhood illnesses like cancer. Thank you survivors, siblings, and families, for your continuing support. We appreciate your partnership in this historic research effort.

The study has collected information from over 24,000 survivors and over 5,000 of their siblings to find out about the long-term effects of treatments for serious childhood illnesses. In addition, it has helped survivors understand the health challenges they may face and has informed them about ways to stay on top of their health. Many participants have been in the study since the very beginning, and we are still enrolling new participants so we can learn about late effects of newer treatments.

New leadership. After leading the study since its beginning, Dr. Leslie Robison is handing off the leadership to Dr. Gregory Armstrong. They have worked closely together since 2006, when the study headquarters moved to St. Jude Children's Research Hospital. Dr. Armstrong has been in charge of the study's daily operations while Dr. Robison has been responsible for overall planning and direction.



Dr. Robison (left) and Dr. Armstrong

Dr. Robison notes that after 20 years it's a good time for new leadership at the top. And he says, "Greg is the right person for the job." They'll continue to work closely together and both expect that the leadership change will be seamless. Dr. Robison will continue to take an active role in the LTFU Study. The study staff join in thanking him for his great leadership over the past two decades! He and Dr. Armstrong discuss the leadership change and share some upcoming plans for the study on page 3.

Study Updates

Healthy Habits Are Especially Important for Survivors

The importance of healthy habits for survivors has been underlined by findings from two recent studies done by LTFU Study researchers. The studies looked at *modifiable* risk factors that can increase the chances of serious heart disease or stroke for childhood cancer survivors.

What are modifiable risk factors? A *risk factor* is something that raises your chance of developing a disease. Risk factors can be personal traits like age or sex. Certain treatments you received may also be risk factors for disease.

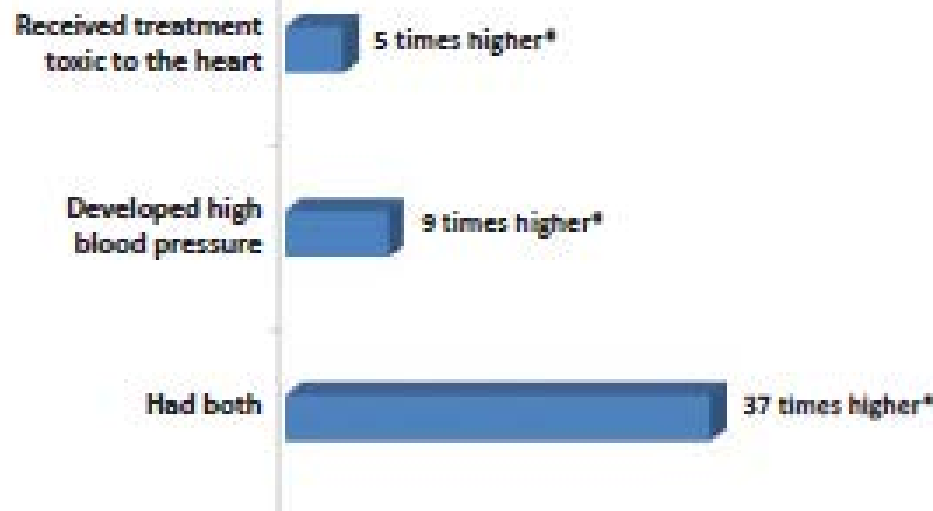
For example, radiation therapy and anthracycline chemotherapy drugs like doxorubicin or daunorubicin are risk factors for heart

of the vessels. Coronary artery disease is a major cause of heart attacks.

Heart failure: *Damage to the heart muscle that makes the heart unable to pump adequately.*

Heart valve disease: *Damage to the valves in the heart that causes them to leak or to become stiff and narrow so that blood backs up in the heart.*

RISK FOR CORONARY ARTERY DISEASE



*Compared to those who did not receive cancer therapy toxic to the heart and did not develop high blood pressure

Conditions that Are Modifiable Risk Factors for Serious Heart Disease or Stroke

- ➔ High blood pressure
- ➔ Diabetes
- ➔ Obesity
- ➔ High levels of cholesterol and other fats in the blood

LOOKING FORWARD

(Don't Look Back. You're Not Going That Way!)

INTRODUCING A NEW LTFU STUDY NEWSLETTER



Billy is holding a southern stingray.

Unstoppable Billy Rivard

he recalls. In 2012, Billy found out that he would need a kidney transplant, too. "My uncle donated a kidney for me. No one in my immediate family was a match for the transplant because my blood type had changed from A to O as a result of the BMT!"

Billy's mom Linda is a nurse who is also a cancer survivor. She manages a survivorship clinic at Advocate Health Care in the Chicago area. She says that despite having so many issues Billy takes great ownership of his follow-up care: "He has been a great teacher for me in how to handle life after cancer."

or researcher and figure out a way that nobody ever again will have to go through what I did.

Billy's favorite hobby is fishing. "And because of that I have a huge passion for the environment. I also think that being sick has made me realize how important a healthy environment is for everyone's health."

To pursue both interests, Billy is involved with an organization called the Coastal Marine Education Research Academy (CMEERA), in Clearwater, Florida.

"We go out and tag sharks and sting rays as well as studying other marine life such as sea turtles."



Julia with her daughters Mila (left) and Grace.

Community Partners:

Julia Stepenske & SurvivorVision®

Julia Stepenske is a childhood cancer survivor whose experience helped decide her career path. She was diagnosed with non-Hodgkin lymphoma in 1989 at age 15. She was treated on a clinical trial at Children's Memorial Hospital in Chicago and her cancer went into remission.

SurvivorVision partners with participating hospitals to provide gift packs to bone marrow transplant patients to acknowledge their 100th day after transplant. The 100th day is a major milestone for BMT recipients. The packs include gifts such as a t-shirt, a waterbottle, a notepad for journaling, and a commemorative bead from the children's charity "Beads of

For more information,
please contact us at:

1-800-775-2167

On the web: LTFU.stjude.org

Email: LTFU@stjude.org



things for the kids on that day," Julia says. "Also, I was blessed to have a textbook scholarship in college and figured why not start one, so we did."

While pregnant with her second child Grace, Julia's cancer unexpectedly returned 19 years after it went into remission. Fortunately, she was diagnosed and treated quickly thanks to advances in cancer treatment and to being cared for at a childhood cancer program that helped her navigate life after cancer. "Being connected to a specialized survivorship

Update

A NOTE FROM US

On behalf of our entire study team, thank you for your dedication to the Long-Term Follow-Up Study (LTFU). You are a vital partner in this research.

The LTFU Study is the world's longest-running study of survivors of childhood cancer. Together we're helping to improve the health of survivors everywhere and for generations to come.

Our goal is to keep you engaged and informed. That's why we're launching a redesigned newsletter that we think is as exciting and future-oriented as the LTFU Study itself. In addition to the articles you've enjoyed in the past, you'll read about what's been happening, what's upcoming, and how your participation is making a difference.

The National Cancer Institute (NCI) recently renewed its support for the study through 2022. In announcing the award, NCI described the Long-Term Follow-Up Study as: "One of the most powerful NCI-supported research efforts for tracking the needs and health of survivors."

NCI's ongoing support affirms the importance of the advances we are making, thanks to your dedication. We are proud to have their support and grateful to our 24,363 participants.

We are always glad to hear from you. We welcome your suggestions and feedback and invite you to call us toll-free at 800-775-2167 or email LTFU@stjude.org.

With thanks,

Gregory Armstrong, MD
Principal investigator



Shorter survey coming

We are in the process of finalizing our next survey, Follow-Up 2017. New questions in this survey will help us learn more about the important financial

issues that survivors may face as a result of their childhood illness.

Much shorter! Follow-Up 2017 will be short. The last survey was 36 pages, and some of you reported that it was a challenge to find the time to complete it. We value your time and recognize that you have busy lives, so we designed a much shorter survey this time.

When to expect it? We plan to start sending our Follow-Up 2017 this summer. It takes several months to actually process and send more than 20,000 surveys.

For this reason, some participants will receive their surveys in 2017, others will receive them in 2018.

We will send you an announcement a few weeks in advance so you can be on the lookout for your survey in the mail.

We need your response! When your survey arrives, please take a few minutes to fill it out. We need everyone's responses to ensure the accuracy of our results. As always, we welcome your feedback or questions on any aspect of the new survey.

Thank you for participating!

Thank you to everyone who completed the study's most recent follow-up survey. A majority of participants completed it, and their commitment is helping to improve treatments for children newly diagnosed with cancer, and to identify ways of protecting people's health for years beyond their cancer.

The data is currently being prepared for analysis and will allow researchers to study the impact of childhood cancer in new ways, including:

- What survivors experience as they get older
- How the effects of treatment might influence the aging process

24,363 PEOPLE CURRENTLY PARTICIPATE IN THE LONG-TERM FOLLOW-UP STUDY



The LTFU Study community

Study size

Treatments for childhood cancer have changed over time, in part because of what has been learned from the Long-Term Follow-Up Study. When the study began in 1994, we enrolled participants who were diagnosed between 1970 and 1986. More recently, we have added a new "generation" of participants diagnosed between 1987 and 1999.

Three decades of data

Now the study includes participants who were diagnosed and treated over the span of 30 years! This allows researchers to show how

advances in treatment have improved the lives of survivors. They can also identify areas where more progress is needed to help kids diagnosed with cancer in the future.

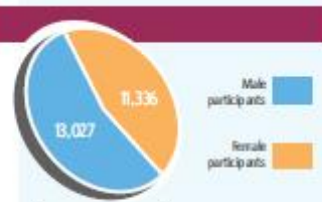
NUMBER OF PARTICIPANTS BY TREATMENT DECADE



Total study size: 24,363

Gender balance

Because men and women may experience some different issues related to their childhood cancer, it is important to have good representation of both males and females.



Total study size: 24,363

Founder receives ACS medal of honor

Dr. Leslie L. Robison, who founded the LTFU Study in 1994, was recently awarded the American Cancer Society (ACS) Medal of Honor Award "in recognition of his lifetime contributions and dedication to research on the long-term outcomes of pediatric cancer survivors."



Dr. Robison (far right) was one of three individuals receiving the ACS award (he's photographed here with the two other recipients, Joan Brugge, PhD, left, and Charles Sawyers, MD, middle). Past recipients of the Society's Medal of Honor include former US President George H.W. Bush and former First Lady Barbara Bush, and former US Surgeon General C. Everett Koop, MD.

Good Morning America gives "Surprise Salute"

Dr. Gregory Armstrong, the LTFU Study's principal investigator, got a "surprise salute" from Good Morning America's hosts on September 9, 2016. You can watch the video here: <http://abcnews/21Q3IE6>



2016 achievements

You can be proud of what you helped achieve in the past year:

- 22 publications in scientific journals
- 15 presentations at major conferences
- 9 open ancillary studies
- Funding support renewed through 2022 by the National Cancer Institute

EMPOWERed by research

We conducted the EMPOWER study to increase breast cancer screening rates among women who were treated with chest radiation. Guidelines recommend an annual mammogram

and breast MRI starting at age 25, or eight years after radiation, for these survivors. "Screening is important because women who develop treatment-related breast cancer do very well if it's detected early," said Dr. Kevin Oeffinger, who led the study.

Rebekah Hughes, a participant in the LTFU study, took part in the EMPOWER study. Rebekah was diagnosed with a fast-growing sarcoma in 1979, while visiting family in England. Doctors

relieved to get the good news. "Participating in the study showed me the importance of having these tests," she says. "I hadn't been sure that for me, personally, they were important because if I did develop breast cancer I didn't think I would be able to go

and more likely to have a breast MRI. A follow-up study, or EMPOWER II, is being planned to increase physicians' awareness of the importance of recommending MRI screening for women treated with chest radiation.



"The side effects of treatment have been lifelong and challenging, and I needed to understand what I was going through."

— Rebekah Hughes,
Participant, LTFU Study

Thanks for asking...

I used to be in the study but I haven't completed the last few surveys. Am I still in the study?

Yes! If you were ever part of the study in the past, you will continue to be a study participant. Even if you skipped some of the surveys, we need and value you! Please get in touch so we can reconnect with you.

We hope you will contact us (call our toll-free number at 800-775-2167 or email us at LTFU@stjude.org) to make sure we have your correct contact information and find out when you might expect to receive your next survey. You can also update your contact info online: ltfustjude.org

Help us keep in touch

Stay connected with the Long-Term Follow-Up Study! If you have moved, changed your email address, or have a new phone number, it's easy to update your contact information:

- Call us toll-free at 800-775-2167
- Send us an email at LTFU@stjude.org
- Visit ltfu.stjude.org. Click on "Update Your Info." You can also choose to receive the LTFU newsletter by email instead of the print version by selecting that option.

"I found it helpful and informative."

Future Communications

- Newsletters in collaboration with Harvard Health Communications
- ? *Looking Forward* insert
- Multimedia distribution of content
 - Website
 - Phone app
- Enhanced dissemination through linkages with other survivor advocacy or professional oncology websites

Acknowledgements

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Jenny Lanctot

Diana Merino

Linda Rivard

Les Robison

Chris Vukadinovich

The Education Committee needs new/young investigators to bring fresh perspective!



Your thoughts/suggestions?

- Survivors to feature
- Newsletter topics?