

LTFU

Long-Term Follow-Up Study

Spring 2017

# 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.

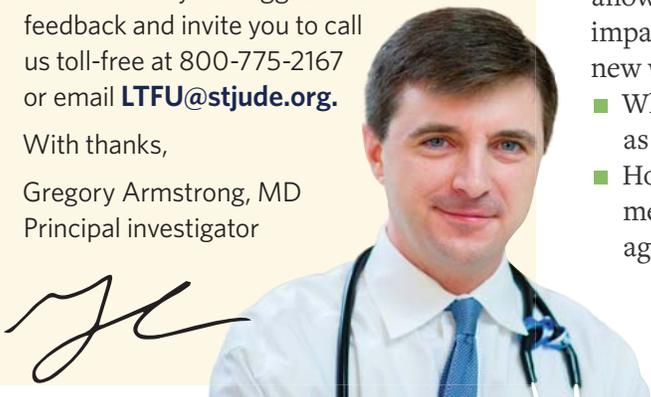
The National Cancer Institute (NCI) recently renewed its support for the study through 2022. In announcing the award, NCI described the Long-Term Follow-Up Study as **"One of the most powerful NCI-supported research efforts for tracking the needs and health of survivors."**

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](mailto: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 out 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.

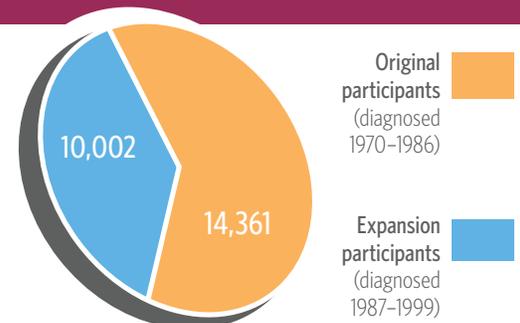
## Thank you for participating!

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

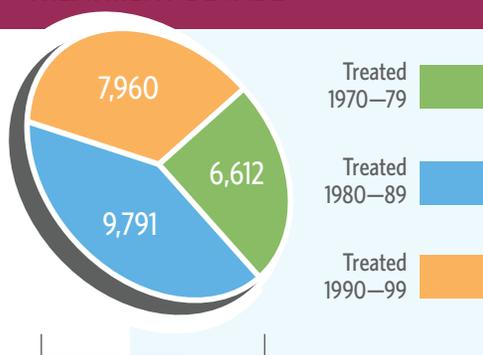
Treatments for childhood cancer have changed over time, in part because of what has been learned from the Long-Term Follow-Up Study. When the study began in 1994, we enrolled participants who were diagnosed between 1970 and 1986. More recently, we have added a new “generation” of participants diagnosed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

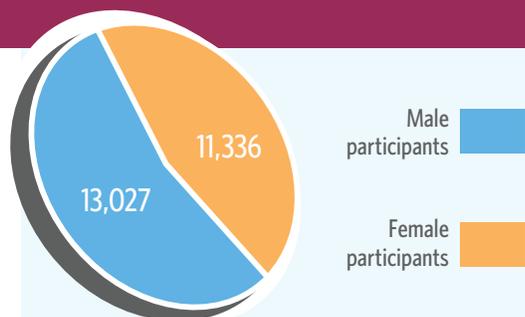
NUMBER OF PARTICIPANTS BY TREATMENT DECADE



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://abcn.ws/2iQ3iE6>



# 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 there discovered the tumor near her right lung. The month she turned three, Rebekah’s parents rushed her home to Toronto, where she was aggressively treated with surgery, chemotherapy, and chest radiation.

When Rebekah was asked to join the EMPOWER study, she says, “The timing was right. The side effects of treatment have been lifelong and challenging, and I needed to understand what I was going through. I was also glad to be able to provide information to help other patients and survivors.”

## Recognizing the importance of early detection

During the study, Rebekah had a breast MRI and a mammogram. Both tests were negative. She was

## 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](mailto: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: [lifu.stjude.org](http://lifu.stjude.org)

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 through another surgery and more treatment. My doctor convinced me—he reinforced the study message about the importance of finding any cancer early when it’s small so treatment is less difficult and invasive.”

Rebekah had a repeat MRI and mammogram this past summer and again got good news—both tests were negative.

## Next step

The EMPOWER study showed that participants who received printed information and phone counseling were almost twice as likely to get a mammogram compared to others who did not, but they were no more likely to have a breast MRI. A follow-up study, 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

## 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](mailto:LTFU@stjude.org)
- Visit [lifu.stjude.org](http://lifu.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.