

Update



LTFU participants, now partners for life

Lindsey Wilkerson and Joel Alsup were children when they met in 1993, while they both were being treated for cancer at St. Jude Children's Research Hospital. Eventually, they both became participants in the Long-Term Follow-Up Study.

Leslie and Joel became reacquainted as adults after each returned to St.

Jude to work—she in the event and patient liaison department, and he in creative media services.

On September 1, 2018 they got married, after decades of friendship. The story of their romance was covered in the New York Times. Read about it here:

<https://nyti.ms/2QkCKMK>.

Call to participants: We need your input!

The LTFU study team is committed to making participants' study experience as rewarding as possible, and we sometimes find ourselves wishing we could ask you, "What do you think?"

Participants who are willing to share their opinions and ideas are invited to become part of a new **LTFU Study Participant Advisory Council (PAC)**. Any participant can volunteer

to be available for possible contact when questions arise that would benefit from your perspective. We hope PAC volunteers will also proactively share their feedback with us.

Volunteering for the Participant Advisory Council doesn't require a time commitment. We'll reach out, on an as-needed basis, to people who have signed up. If we contact you and you

First mobile study launches

A new app makes it easier to contribute to survivor research.

Phones that let us see the person we're talking to. Wristbands that can track everything from our location to our heart rate.

Until recently, these only existed in science fiction novels and James Bond films. But nearly 80% of people in the US owns a smartphone, and the popularity of wearable devices like smartwatches is skyrocketing.

Innovative technologies are opening up new research opportunities by making it possible to collect detailed, real-time data from study participants no matter where they live, as long as they have access to the internet. To benefit from the exciting potential offered by emerging technologies, LTFU established its mHealth Technology Resource Center in 2017, funded by the National Cancer Institute.

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have a lot going on, you can say, "Sorry, next time."

To volunteer, please email your interest to ltfu@stjude.org.

EASE: A new mobile study

We are excited to announce the launch of the first app-based LTFU study, bringing together the power of our participants and the convenience of smartphone technology. Our first mobile study, EASE (Exploring Aspects of Survivors' Experience of Pain), was highlighted at a recent conference on "Emerging Technologies in Childhood Cancer Survivorship." You can learn more in the cover article.

Inside this issue, you'll read about some of the past year's achievements and research results. Thank you for all you do to make this possible.

Greg Armstrong, MD, Principal Investigator

The difference you make

In 2018, LTFU Study researchers published 30 new articles in scientific journals. This chart illustrates the number of publications since the study began. View a list of all 335 publications at ltfu.stjude.org.

LTFU PUBLICATIONS 1999-2018



Why publications matter

Publications in scientific journals share new discoveries with other researchers and help clinicians stay up to date with recent advances so they can provide patients with the best care. Research findings may also be summarized in "abstracts" that are presented at scientific conferences. LTFU researchers presented 29 abstracts in 2018.

What this means for you

Over the past 30 years, LTFU research has resulted in better understanding of health problems that may develop years after cancer treatment. The **Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers**, which are based on what has been learned from the LTFU Study and similar studies, are an important resource for


Long-Term Follow-Up Guidelines
for Survivors of Childhood, Adolescent,
and Young Adult Cancers
Version 5.0 - October 2018

physicians who provide follow-up care to childhood cancer survivors. The Guidelines are online at: www.survivorshipguidelines.org. (If you choose to review them, you are encouraged to do so with the assistance of your physician. Be sure to bring your treatment summary with you). A series of **Health Links** have also been developed to provide patients with useful information, available at the same URL.

Mobile study launches

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EASE: Our first mHealth study

LTFU's first mobile study uses smartphones to learn about survivors' experience of pain. Nicole Alberts, PhD, St. Jude Children's Research Hospital,

leads the EASE (Exploring Aspects of Survivors' Experience of Pain) Study team. They are inviting a group of LTFU participants to join the new study. Some EASE participants will be asked to wear a sensor, attached to their clothing, that can help them control their breathing patterns. This may help them reduce stress levels and pain.



"EASE is the first study of its kind," says Dr. Alberts. "We're recruiting participants who may or may not have chronic pain. After downloading the app onto their smartphones, they will be able to quickly and easily send us information that will help us understand survivors' experience of pain."

Dr. Alberts recently spoke about the EASE Study at a conference on "Emerging Technologies in Cancer Survivorship Research," at Baylor College of Medicine in Houston, TX. The conference also highlighted another LTFU study, ASK, which used dermoscopic cameras attached to smartphones to aid in the early detection of skin cancer.

(Read about the ASK Study in the Autumn 2017 newsletter, available at ltfu.stjude.org.)

LTFU researchers are developing more app-based studies. While not everyone will be able to access them right away, over time these app-based studies will make it easier than ever to contribute to life-changing research. We will keep you updated as new studies are launched.



Nicole Alberts, PhD, St. Jude Children's Research Hospital

Most survivors highly satisfied with life

New LTFU research suggests that the difficult and challenging experience of being treated for cancer as a child may lead to surprisingly positive outcomes.

A research team led by Aurelie Weinstein, MD, Georgia State University, analyzed survey responses from more than 2,000 participants and their parents. The study examined overall life satisfaction and posttraumatic growth in adolescence, and their effect on survivors' future emotional and physical health in young adulthood. (Posttraumatic growth means that an individual experiences personal growth in response to difficult life challenges such as cancer diagnosis and treatment.)

On average, the survivors rated their satisfaction with their lives as higher than 7 on a scale of 1 to 10. Those who were highly satisfied with their lives reported fewer emotional problems and were more optimistic about their future health. They also reported lower levels of perceived pain.

The study also found that adolescent survivors who got along well with their family and peers had

greater life satisfaction during young adulthood; as adults, they had a more positive outlook on their health and fewer emotional problems.

Read the full summary at ltfu.stjude.org.

We're glad you asked...

I haven't completed my follow-up survey yet. Is it too late?

It's not too late, and your response is as important as ever. The study's success depends on the information we receive from you and other participants.

No time? It won't take much. The survey is much shorter than in the past. Use your smartphone or computer to respond—if you're interrupted, you can come back and finish later. Contact us (see below) and we'll send your login information.

Prefer to complete it verbally? Our trained interviewers can help you take the survey during a phone call. We hope you'll give it a try.

Didn't receive a survey? Let us know (see below) and we'll send it right away.

Can't find it? Mail piles up, things get lost—it happens! Contact us and we'll resend.

Wondering if you're still in the study? If you were a participant in the past, you are still important to us. Even if you skipped some surveys, we need and value you! Please get in touch so we can reconnect (see contact info below).



Citation: Weinstein AG, Henrich CC, Armstrong GT, et al. Roles of Positive Psychological Outcomes in Future Health Perception and Mental Health Problems: A Report from the Childhood Cancer Survivor Study. *Psycho-oncology*, September 6, 2018

2018 achievements

In addition to the launch of our first mobile study and an impressive number of new publications, here are some additional achievements our participants can take pride in.

■ The follow-up survey has been mailed to all LTFU Study participants. **More than 70% of survivor-participants and 58% of their siblings have completed their surveys to date.** Thank you to all of you!

If you haven't responded, we still need you! Please read the information in the next column for more info. We continue to actively follow-up with participants who have not yet returned their surveys, in hopes of increasing the response rate. It's not too late, and we hope to hear from you soon.

■ **Six new ancillary studies received funding in 2018.** Ancillary studies either collect new data from LTFU participants, or analyze existing LTFU data in a new way. The EASE Study featured in this issue is an example of an ancillary study.

Unlike your contact information,

Take a minute to confirm your contact information!

our appreciation of you never changes.

- Visit ltfu.stjude.org and click on "Update Your Info"
- Call us toll-free at **800-775-2167**
- Email us at LTFU@stjude.org