

LTFU

Long-Term Follow-Up Study

Winter 2018

# Update

## Survivorship and financial stress

Despite tremendous advances in the treatment and cure of children with cancer, many adult survivors experience health problems that need ongoing medical care.

LTFU Study researchers recently published a study that looked at survivors' experience of financial stress due to the cost of medical care. They conducted a survey of a group of LTFU Study participants that included 580 survivors and 173 siblings.

The research team found that one in 10 survivors in the study spent 10% or more of their annual income on out-of-pocket medical costs (medications, co-payments, and insurance deductibles) compared to 3% of the siblings.

Survivors who spent a high percentage of income on medical costs were more than eight times as likely as their siblings to report having problems paying medical bills. They were also more likely to limit or forgo medical care because of their financial concerns.

### What does this mean for you?

This study is a first step in understanding the impact of the financial burden of medical costs for adult survivors of childhood cancer. "It is important to appreciate that the survivors in the study were, on average, more than 30 years from their cancer diagnosis, and yet many still struggle with



"Many survivors struggle with high out-of-pocket costs and the resulting financial burden."  
—Dr. Ryan Nipp

high out-of-pocket medical costs and the resulting financial burden," noted Dr. Ryan Nipp, an oncologist at Massachusetts General Hospital in Boston, who led the study.

The study's authors urged health systems and

providers to make it a priority to develop programs that include financial services, social work services, and patient navigators for survivors who are experiencing hardship because of high medical costs.

View a complete list of published research on our website: [ltfu.stjude.org](http://ltfu.stjude.org)

"Financial Burden in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study" was published in the *Journal of Clinical Oncology* in August 2017.

JOURNAL OF CLINICAL ONCOLOGY

## A NOTE FROM US

We are excited to announce the new **LTFU research app!** The app will make it easier than ever to contribute to life-changing research. Our first app-based study is currently being launched. Not everyone will be able to access the app right away, but ultimately every participant with a smartphone will benefit from it. We'll keep you updated as new studies are launched.

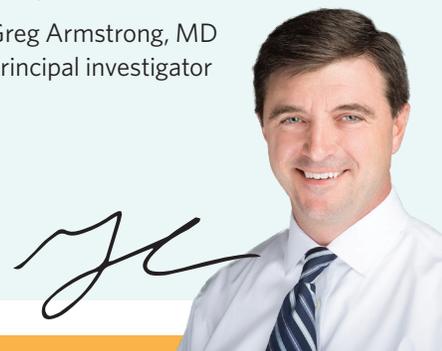
Have you seen the LTFU **website redesign?** New expanded content includes a list of all of our publications from 1999 to the present. Visit [ltfu.stjude.org](http://ltfu.stjude.org) to take a look at the research results you have contributed to!

More than 10,000 **follow-up surveys** have been mailed out, and we are on target to complete the send-out in 2018. Many thanks to all of you who responded so far. Feedback is positive about the shorter questionnaire and online/mobile formats. If you misplaced your survey, let us know, and we'll send another. If you didn't receive yours yet, you'll get a "heads up" card a few weeks in advance to let you know it's coming.

I recently presented at the **International Pediatric Neuro-Oncology Conference**, sharing some of the important scientific advances resulting from the LTFU Study with colleagues from around the world. The difference you make, through your dedicated participation, has global impact.

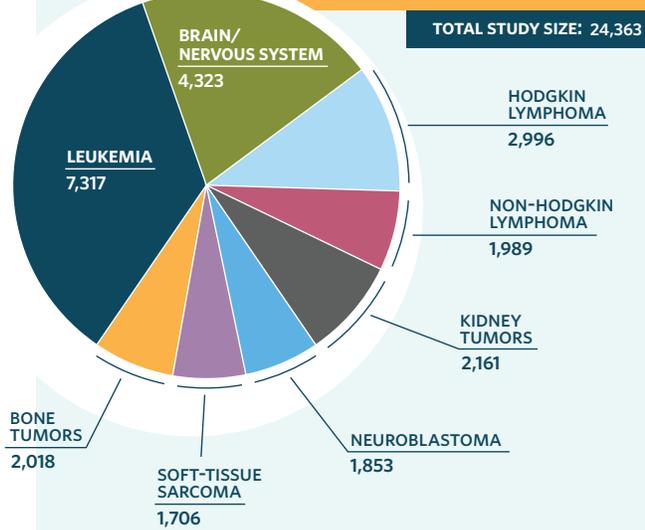
Many thanks, from all of us.

Greg Armstrong, MD  
Principal investigator

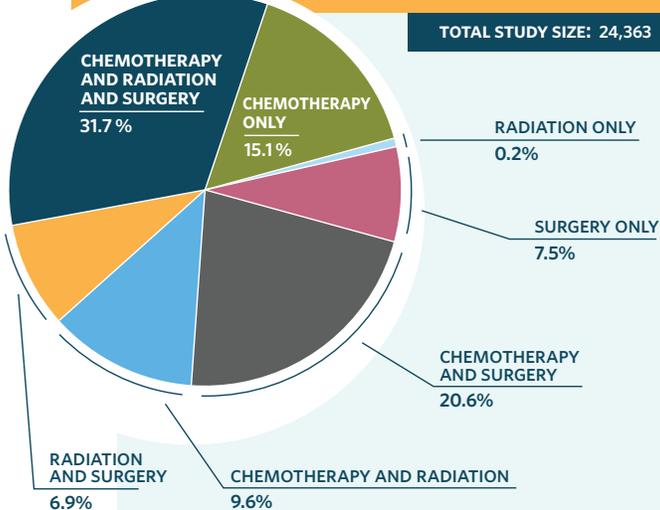


# The LTFU Study community

## NUMBER OF PARTICIPANTS BY ORIGINAL DIAGNOSIS



## NUMBER OF PARTICIPANTS BY TREATMENT EXPOSURE



### Three decades of treatment data

The LTFU Study includes participants who were diagnosed and treated over the span of 30 years (1970-1999). This allows researchers to show how advances in treatment have improved the lives of survivors (see “In the news” for examples of these important advances).

### Learn more

Visit the “Participant demographics” page of our website (in the ABOUT section) for more detail about LTFU Study participants, including the decade in which they were treated for childhood cancer: [ltfu.stjude.org](http://ltfu.stjude.org)

# In the news

The LTFU Study received widespread media attention for recent studies that confirmed that survivors of childhood cancer are living longer, and better, after treatment.

The rate of second cancers in survivors of childhood cancer has declined 38% over the past three decades, analysis of LTFU Study data revealed.

Patients treated in more recent years now face fewer long-term health issues than in the past. A separate study showed that during the same period of time, the rate of severe long-term side effects that occurred in the first 15 years after childhood cancer diagnosis decreased from 12.7% to 8.8%.

These successes are largely due to important advances in childhood cancer treatment, including a reduction in the use of radiation and chemotherapy. In the 1970s, 77% of pediatric cancer patients were treated with radiation therapy; in the 1990s, that number dropped to 33%.

the guardian

The Washington Post



REUTERS

### The difference you make

These publications are yet more evidence that your participation in the Long-Term Follow-Up Study is helping to improve the lives and health of survivors everywhere and for generations to come.

You can read more about what the study is achieving at: [ltfu.stjude.org](http://ltfu.stjude.org)

# 2017 achievements

Thanks to the dedication of our participants, the LTFU Study continued to make significant progress during the past year, including:

- 20 publications
- 20 presentations at national conferences
- 13 new studies launched
- Funding renewal by the National Cancer Institute (NCI)
- Investigator meeting in June 2017 in Atlanta, Georgia, attended by 140 researchers, clinicians, and survivorship experts from around world
- Establishment of an mHealth Technology Center supporting innovative app-based studies

# Exercise and Quality Diet After Leukemia: The EQUAL Study

Adults who had leukemia when they were kids often struggle to maintain a healthy weight. Being overweight can lead to many health problems, including diabetes, high cholesterol, high blood pressure, arthritis, and heart disease.

The goal of the EQUAL Study is to find the best way to help leukemia survivors lose weight.

EQUAL

Dr. Emily Tonorezos, of Memorial Sloan Kettering Cancer Center in New York City, leads the study. She says, “In the EQUAL Study we’re testing whether a weight-loss program that works for people who are not cancer survivors will work for childhood leukemia survivors. If we can learn an effective way to help them lose weight, it may help them avoid serious health problems in the future.”

“We don’t really know why many leukemia survivors become overweight or obese, and the results of this study might also give us insights into what is causing leukemia survivors to gain weight.”



“We’re extremely grateful to the participants in the LTFU Study for their willingness to engage in studies like EQUAL. If it weren’t for them, we wouldn’t be able to do the study.”  
—Dr. Emily Tonorezos

The study uses written materials about living a healthy lifestyle, as well as email and telephone counseling with a health coach. Participants fill out three questionnaires and agree to have a small blood sample drawn in their homes three times over the two-year study period.

The EQUAL study is ongoing but is not taking any new participants. Thank you to the 358 participants who are part of this important study! We will keep you updated as the results become available.

## We’re glad you asked...

### Why do publications about LTFU Study results refer to the Childhood Cancer Survivor Study (CCSS)?

Long-Term Follow-Up Study (LTFU) is the name we use when communicating about the study with participants, while Childhood Cancer Survivor Study (CCSS) is the scientific name used by researchers and the medical community.

“Long-Term Follow-Up Study” emphasizes what the study is about without disclosing that some participants may be survivors of childhood cancer, thus protecting their personal health information.

You may hear about the Childhood Cancer Survivor Study or CCSS when mass media publicizes important new findings from our research. We want you to take pride in the attention the study receives, because your dedication contributes to every advance we make in protecting the health of survivors.

A complete list of the study’s publications is available in the RESOURCES section of our website: [ltfu.stjude.org](http://ltfu.stjude.org)

People **move.**

Email addresses **change.**

Cell phones **replace** landlines.

Take a minute to confirm your contact information!

But we can’t replace **you!**

- Visit [ltfu.stjude.org](http://ltfu.stjude.org) and click on “Update Your Info”
- Call us toll-free at 800-775-2167
- Email us at [LTFU@stjude.org](mailto:LTFU@stjude.org)