

Education Committee Update

CCSS

Childhood Cancer
Survivor Study

Education Committee Objectives

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- Encourage → Inspiring survivorship stories
- Educate → Cancer-related health risks
- Empower → Resources to optimize health
- Engage → Survivorship research

LTFU Study Communications

CCSS



Autumn 2017

Update

LTFU
Long-Term Follow-Up Study

Looking Forward

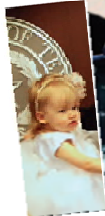
Encourage

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LTFU Long-Term Follow-Up Study Looking Forward

A family founded on hope

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**LTFU participants,
now partners for life**

Lindsey Wilkerson and Joel Alsop Jude to work—she in the event

LTFU Long-Term Follow-Up Study Looking Forward

AC Walton: Living life on his own terms

A rare diagnosis

A vocation to help survivors preserve fertility

AT AGE 29, JOYCE REINECKE WAS DIAGNOSED with leiomyosarcoma, a type of tumor that develops in soft tissue. She was on a business trip for her law firm when she became ill. She was hospitalized and, during emergency surgery, doctors found and removed four tumors from her abdomen. As a young married woman, Joyce was shocked to learn that some of the options for treating the cancer might leave her unable to bear children.

"Nobody talks to me about fertility preservation," she recalls. "It was only mentioned by a medical fellow the day before I left the hospital." She discovered that her experience was not unusual. Research has shown that many survivors do not recall discussing fertility preservation with their oncologist or are not routinely referred for fertility preservation services.

Joyce, a New York state native, was living in Seattle when she was diagnosed. She chose to undergo in vitro



Joyce Reinecke, JD, with her husband and twin daughters

Community partner: The Alliance for Fertility Preservation

The goal of the Alliance for Fertility Preservation

fertilization and freeze embryos for the future. She and her husband travelled to Cornell University for the procedure, and they are now the parents of twin girls. As a result of her experiences, Joyce found a passion for informing survivors about their options for preserving fertility and helping them connect

LATEST RESULTS

Risk of breast cancer after radiation to the chest: Early menopause and hormone replacement therapy

Some female survivors who were treated for childhood cancer stop having menstrual periods, often decades before the usual age of menopause.

What does this mean for you?

HRT in survivors who experienced early menopause slightly increased breast cancer risk but not to the extent as the naturally produced hormones in women who continued to menstruate naturally. This radiation may help discuss the risks and with their provider consider placement for some of the benefits through the national breast

Exercise improves long-term mental functioning

By Emily Tonorezos, MD

This is the first study to look at the long-term effects of exercise on survivors' depression, anxiety, memory, and concentration. When we compared data from LTFU participants' baseline surveys with



Emily Tonorezos, MD



LATEST RESULTS

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.

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



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

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

Meeting survivors' health-related needs

Adult survivors of childhood cancer have many health-related needs that go beyond medical treatment, but their needs may not be met because of poor communication with their health care

CCSS Cardiovascular Risk Calculator

This risk assessment tool predicts risk of heart failure, ischemic heart disease, and stroke by age 50 among survivors of childhood cancer. It uses information from the CCSS papers, "Individual prediction of heart failure among childhood cancer survivors" (Chow et al., ...) and "Prediction of ischemic heart disease and stroke among childhood cancer survivors" (Chow et al., ...). These models were designed for use in recently completed cancer treatment studies and have been validated in cancer survivors from the Erasmus Children's Cancer Center (Amsterdam, the Netherlands), the National Wilms Tumor Study, and the National Wilms Tumor Study.

To determine one's risk of cancer, information below (All fields are required)

Gender?

☐ Male

☐ Female

Patient's age at diagnosis?

☐ < 5

☐ 5 - 9

☐ 10 - 14

☐ ≥ 15

Were any anthracyclines used?

A tool for you and your provider

The new Cardiovascular Risk Calculator can help you and your health care provider assess your risk of heart disease or stroke.

ccss.stjude.org/cvcalc

Lead author Cheryl Cox, MD (left), with Melissa Hudson, MD, one of the study's co-authors



Protecting survivors' heart health

LTFU Study researchers have developed an important new tool that can help survivors of childhood cancer, and their health care providers, be more

Let's get moving! By Kiri Ness, PT, PhD

Physical activity can improve survivors' physical and mental health. I encourage my patients to add activity to their daily routines in easy, realistic ways. You don't need to make big changes!

Tips to try

- ☐ Park a few spaces further away than you normally park.
- ☐ Instead of the elevator, take the stairs for one or more flights, then take the elevator the rest of the way.
- ☐ When you're sitting at home or at work, get up once in a while and walk around for 2-3 minutes. Set a timer to remind yourself it's time to move!

Explore what's available on YouTube, or search for some of my favorites:

- ☐ Five(ish) Minute Dance Lesson: African Dance (Kennedy Center Education Digital Learning)



Kiri Ness, PT, PhD, is a physical therapist

Engage

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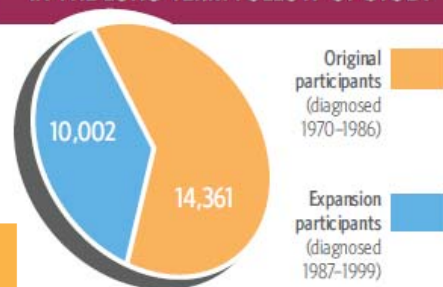
Thank you for participating!

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

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



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.

New survey rolling out

Great early response!

In August, we began mailing out about 500 surveys a week. We will continue to mail surveys weekly according to a pre-set schedule—so some participants will receive their surveys in 2017, others will receive them in 2018.

Wondering if your survey is coming? We'll mail you a heads-up announcement a few weeks beforehand, so you can be on the lookout.

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

The LTFU Study community

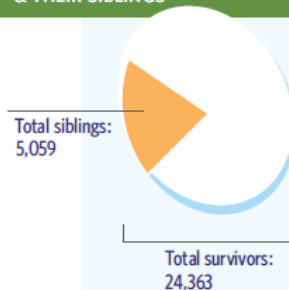
Siblings

More than 5,000 brothers and sisters of Study participants are part of the study as a comparison group. The sibling

study are siblings of survivors but they did not have treatment for similar childhood cancer.

The LTFU study follows the survivors and their siblings over time to see how they have different issues when their brothers

NUMBER OF SURVIVORS & THEIR SIBLINGS



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

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.

Advancing Survivors' Knowledge (ASK) About Skin Cancer

Skin cancer is the most common subsequent malignancy among childhood cancer survivors. It's also the most treatable if it's diagnosed early.



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 breast cancer in 2010.

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



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.

Dr. Emily Tonorez, 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."

EQUAL

"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."



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Participant Advisory Council (PAC)

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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

A NOTE FROM US

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

LTFU PAC update

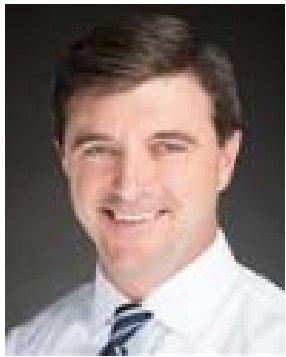
More than 100 participants volunteered for the LTFU Participant Advisory Council (PAC) after reading about it in the last newsletter (Winter 2019, online at ltfu.stjude.org).

PAC members are already helping to shape the study by sharing their suggestions on how to improve communication about the LTFU follow-up surveys. We are grateful for their insights!

Study participants who are willing to share their ideas and opinions can still join the LTFU PAC. We will reach out on an as-needed basis to people who signed up. There's no time commitment. To volunteer, please email your interest to ltfu@stjude.org.

Thanks to the Education Committee

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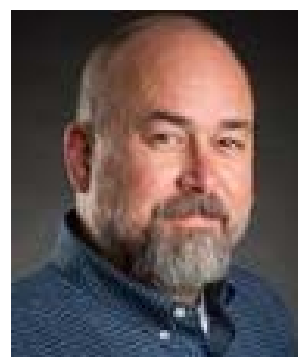
Greg Armstrong



Todd Gibson



Aaron McDonald



Chris Vukadinovich



Diana Merino



Linda Rivard



Catherine Coleman



Julia Stepenske



Kathy Ruccione