

LTFU

Long-Term Follow-Up Study

Spring 2023

Update

Every day our hearts beat more than 100,000 times, pumping about 2,000 gallons of blood throughout our bodies. Keeping our hearts healthy and strong is one of the most important things we can do to take care of ourselves and prevent heart disease, which is the leading cause of death in the US.

This issue features two LTFU studies with excellent names—CHIIP and SALSA—that are exploring how to promote the heart health of childhood cancer survivors. This research aims to discover how communication and support can help survivors become warriors for their own health. Inside,

A NOTE FROM US

you'll also find resources and tools that can help you be that warrior.

Our Fall 2022 issue focused on colorectal cancer (CRC) and survivorship, another timely and important health topic. While it was being printed, Hollywood celebrity Ryan Reynolds shared his CRC screening experience in a YouTube video that has been viewed more than one million times. During his colonoscopy, his doctor detected and removed a precancerous growth. "This was potentially lifesaving for you," his doctor told him.



The video is part of a public awareness campaign promoting colorectal cancer screening. If you missed the LTFU newsletter or haven't seen the video, here are the links:

- **LTFU newsletter:** Through the myLTFU portal or online at ltfu.stjude.org
- **Youtube:** bit.ly/3Q6Cnof

We always welcome your feedback. Let us know what topics you'd like us to focus on in future issues of the LTFU Update by calling 1-800-775-2167 (8 a.m. to 5 p.m. CST) or emailing ltfu@stjude.org.

Greg Armstrong, MD
Principal Investigator



The goal of these two studies is to help childhood cancer survivors become more aware of how their treatment may have affected their heart, and what they can do to stay healthy, says Eric Chow, MD, a researcher and pediatric oncologist at Fred Hutch Cancer Center in Seattle, Washington.

Survivorship and heart health

LTFU research is exploring new ways to increase awareness of survivors' unique risks for heart disease and discover how best to protect their heart health.

"More than 85% of children with cancer are now surviving beyond five years and they are living longer, healthier lives," says Eric Chow, MD, Co-Chair of the LTFU Study Chronic Disease Working Group. "However, some radiation and/or chemotherapy treatments can increase their risk of developing heart disease earlier than the general population.

"Survivors who received these treatments are more likely, at a younger age, to develop high blood pressure, diabetes, or high cholesterol—conditions that can lead to heart disease. The good news is that, once detected, they can be treated. The goal of our research is to help survivors become more aware of how their treatment may have affected their heart, and what they can do to stay healthy."

CHIIP: An intervention for survivors and their PCPs

The CHIIP (Communicating Health Information and Improving Coordination with Primary Care) Study was launched five years ago. "Many of today's survivors were treated a long time ago, and they may have forgotten, or perhaps they never received, important details about the types and doses of chemotherapy or radiation treatment they received," says Dr. Chow.

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Survivorship and heart health

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“We’ve also found that primary care physicians may not be aware of their patient’s cancer history or the heart health risks associated with some childhood cancer treatments,” he says.



“The CHIIP Study created a ‘virtual’ survivorship clinic,” says Dr. Chow. “We enrolled nearly 700 LTFU participants and their primary care physicians into the study. The physicians received information about their patient’s treatment history, current health, and recommendations for ongoing care, just as they would in an actual survivorship care setting.”

The LTFU participants in the study received video consultations with a survivorship-trained health practitioner. “If a patient says, ‘I’m on blood pressure medicine but I don’t take it consistently,’ they can work with the study practitioner to create strategies that will help them take it more reliably,” says Dr. Chow. “Or, if someone is overweight, we talk about what they can do to be a little more active or what tweaks could be made to their diet.”

After one year, the CHIIP study team again collected participants’ health data. Analysis will show whether the intervention group had better-managed risk factors, more knowledge about their own health, and stronger confidence about managing their own health.

SALSA: Making meaningful changes

Dr. Chow launched a second study with LTFU participants to build on prior research results. “Most research focuses on either physical activity or diet,” he says.

“It’s hard to make meaningful changes affecting your heart health if you only do one or the other. The SALSA Study (Study of Active Lifestyle Activation), which is in its first year, explores whether we can address both at the same time, and compares several different strategies to find out which is more effective.”

Some SALSA participants meet with a study counselor for a one-on-one telehealth session every two months and receive personalized feedback and support.

The other group tracks its activity with a fitness watch and an electronic diet log. At-home weight and blood pressure equipment sends measurements to the study team. Participants receive feedback via text messages based on their reports, like, “Last week you took 4,000 steps. Let’s see if you can hit 4,500 this week.”

Fun, and full of potential impact

After three months, if participants don’t improve sufficiently, they are reassigned to a different intervention strategy and have the chance to try something new.

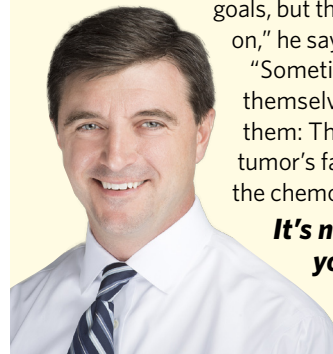
“We’re trying to make this study as enjoyable and easy as possible for participants,” says Dr. Chow. “For

example, the group that’s doing digital tracking has a Facebook page. We share articles with them, and they give each other support and community.”

“If we can demonstrate which of the strategies we’ve developed work better, they can be offered to more survivors.”

Responding to risk, changing what we can

Greg Armstrong, MD, Principal Investigator of the Long-Term Follow-up Study, often sees patients who struggle to manage their weight or their blood pressure. “Keeping these levels within healthy ranges are important lifestyle goals, but they can be hard to improve on,” he says.



“Sometimes my patients blame themselves or feel shame. I tell them: This is not your fault! It’s the tumor’s fault, the radiation’s fault, the chemo’s fault.

It’s not your fault, but it is your battle now, and we will help you fight it.

For Diana Vega, a 20-year childhood cancer survivor and member of the LTFU Study Education Committee, trying to stay as healthy as possible produces ongoing stress.

“I struggle with anxiety when my weight goes up,” she says. “I feel afraid that if I don’t exercise and sweat at least five times a week, or if I give into my sweet-tooth cravings, I am going to get sick and die young. The guilt I put on myself and the lies I start to believe can really be an issue.

“But then I remind myself: Yes, some damage was done by the therapies that helped me survive my cancer, but I’m glad I had those treatments. They are why I’m here today. So I give myself a break and stop being so hard on myself. I do my best to eat healthy and be active, one day at a time, and I reassure myself that, if that isn’t enough, there are good medications that can help and it’s OK to take them.

I can’t change what happened to me, so I focus on the things I can do now.

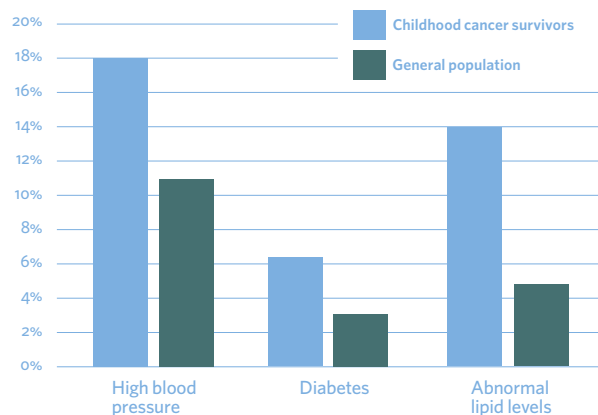


New results highlight survivors' heart risks

LTFU researchers recently compared data from 571 childhood cancer survivors without any diagnosed heart disease, and data from similar adults who had no cancer history.

“We were surprised to find that many survivors were not being diagnosed and treated for conditions that can lead to heart disease,” says Melissa Hudson, MD, Director of the Cancer Survivorship Division at St. Jude Children’s Research Hospital and Chair of the LTFU Study’s Education Committee.

“We want patients and their providers to know that, although some treatments for childhood cancer can make survivors more likely to develop heart disease, there are things they can work on together, like getting regular screenings, changing lifestyle habits, or starting a new medication to help manage their risk factors.”



LTFU Study research found that childhood cancer survivors were more likely to have conditions that can lead to heart disease, like diabetes, high blood pressure, and high cholesterol, than similar adults who had not had cancer. This chart shows the percentage differences between both groups for high blood pressure (18% vs 11%), diabetes (6.5% versus 3.2%), and abnormal lipid levels (14% versus 4.9%)

Protecting your heart health *What you and your provider can do*

Make blood pressure a priority

Nearly half of the general US adult population has high blood pressure, according to current guidelines that identify 130/80 as high blood pressure. “This is an especially important concern for survivors,” says Dr. Hudson. “Our research shows that it significantly increases risk for kidney failure and other health issues. Blood pressure treatment may need to begin earlier among this group than in the general population. Physicians should be aware of this, and patients should consider lifestyle changes that can help keep blood pressure in a healthy range.”

Check out the new heart health checklist

The American Heart Association has issued a new checklist for maintaining heart health, called Life’s Essential 8. The checklist can help guide decisions about diet, physical activity, and tobacco and alcohol use. Sleep has been added as a new contributor to heart health; research shows that people who get the recommended 7-9 hours of sleep per night tend to manage other health factors more effectively. Learn more about the Essential 8 on the American Heart Association website: heart.org/en/healthy-living/healthy-lifestyle/lifes-essential-8

Free, easy, online tools for providers

A set of tools to help guide follow-up care for childhood cancer survivors has been developed by LTFU Study researchers. The latest addition is a risk calculator for kidney failure, for which survivors of childhood cancer may be at increased risk because of their treatment. Like the other tools, the kidney failure calculator uses an individual’s specific treatment data, as well as information like age at cancer diagnosis and sex, to provide a rapid, precise assessment (see link below).

“We encourage childhood cancer survivors to share these tools with their health care providers,” says Melissa Hudson, MD.

The tools were created using data from LTFU participants and are a powerful example of how your contributions to the study have improved survivorship care. These resources are freely available online for health care providers’ use.

In addition to the kidney failure tool, calculators are available to predict risk of:

- Acute ovarian failure
- Breast cancer
- Cardiovascular disease
- Thyroid cancer

All of the risk calculators can be accessed from the study’s research website: ccss.stjude.org/tools-documents/calculators-other-tools.html