

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

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Insurance anxiety: Where do I start...or go from here?

Jeanette Lavecchia, LCSW, LICSW, Social Work Team Leader in the After Completion of Therapy (ACT) Clinic at St. Jude Children's Research Hospital, has supported hundreds of survivors dealing with health and insurance issues. "Many survivors recognize that they face increased health risks, and that insurance is important for getting the care they need. But it is often overwhelming for them," she says.

"I tell them, 'You've already taken the first step: Acknowledging the importance of insurance. Now, start educating yourself. Take it in small pieces, and don't try to do everything at one time. Consider enlisting an ally to help, like a friend or family member. Some local cancer organizations have volunteer patient navigators.'"

Here are some of the resources she frequently recommends:

- **TriageCancer:** Useful, understandable information about insurance, a database of resources by location or topic, great videos and materials. trriagecancer.org. Especially useful is their Quick Guide to Health Insurance Options: trriagecancer.org/QuickGuide-HealthInsuranceOptions
 - **St. Jude Together:** Information on insurance basics, assistance programs, public health insurance, and COBRA. together.stjude.org/en-us/for-families/navigating-health-care/finances.html
 - **Finding and Paying for Health Care (Children's Oncology Group):** Guidance on finding providers, working with a medical team, defining your needs, and laws about insurance benefits. In English, Spanish, French, and Chinese. www.survivorshipguidelines.org/pdf/2021/COVID-19_Health_Link_English.pdf
 - **Essential Hospitals:** Database of hospitals with programs serving uninsured/vulnerable patients. essentialhospitals.org/about/listing-of-american-essential-hospitals-members-2/
 - **HRSA-funded health center clinics:** Searchable (by location) list of clinics serving at-risk individuals. findahealthcenter.hrsa.gov/
 - **NeedyMeds:** Prescription assistance and prescription discount cards, links to free/low-cost/sliding scale clinics. www.needymeds.org
- Drug manufacturers often have need-based patient assistance programs. Some pharmacies like CVS and Walgreens have their own discount cards; their "cash price" is sometimes lower than an insurance copay.

'I want to be a healthy grandparent'

Four years ago, Billy Carson knew his life needed to change.

During checkups, both his primary care physician and his survivorship clinic doctor told him the same thing – he was about to develop type 2 diabetes. His blood sugar levels were high. He was overweight and did not get much exercise.



Billy and his wife, Kim, love to walk at a park near their home.

"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.



Don't let these "myths" get in the way of your recommended screenings

If you need motivation to schedule your CRC screening, remind yourself that delaying could put your health at serious risk. Here are some common misconceptions and concerns.

1. **My health care provider says I'm too young for screening.** Many providers are not aware of some survivors' increased risk and guidelines for CRC screening. Share your treatment history with your provider, as well as the Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers ([http://www.survivorshipguidelines.org/pdf/2018/English%20Health%20Links/10_colorectal_cancer%20\(secured\).pdf](http://www.survivorshipguidelines.org/pdf/2018/English%20Health%20Links/10_colorectal_cancer%20(secured).pdf)).

What you need to know about... Colorectal cancer

Colorectal cancer (CRC) is the second leading cause of cancer death in the US. When diagnosed early by screening tests, CRC is more likely to be cured than cancer diagnosed after symptoms have developed during later stages of the disease.

CRC is a type of cancer that develops in the colon (large intestine) or the rectum (the section of the large intestine closest to the anus). Among the general population, screening recommendations have been adjusted because of an increase in CRC rates among younger adults. Factors like family history and lifestyle affect everyone's cancer risk. While we can't change our family history, healthy changes to diet and activity levels can decrease our risk. (See page 2 to learn more.)

Abdominal or pelvic radiation increases risk

Everyone is at risk for colorectal cancer, but the risk is more than ten times higher for childhood cancer survivors who were treated with abdominal or pelvic radiation. [continued on page 2](#)

Explore your CRC screening options

This chart summarizes information about the most common CRC screening tests. Be sure your primary care physician is aware of your specific screening recommendations, and discuss any questions or concerns you may have.

RESEARCH RESULTS

How health insurance affects your health

Drs. Elyse Park and Anne Kirchoff, along with other LTFU researchers, have been documenting survivors' health insurance concerns since 2005.

"Health insurance coverage is a real stressor for long-term survivors," says Elyse Park, PhD, an LTFU Study researcher at Massachusetts General Hospital and Harvard Medical School in Boston. "I saw in my clinical work that they are more likely to be uninsured, have trouble getting insurance, or have inadequate coverage."



Elyse Park, PhD, who has researched the effects of insurance concerns on survivor health since 2005, leads the new HINT (Health Insurance Navigation Tools) Study.

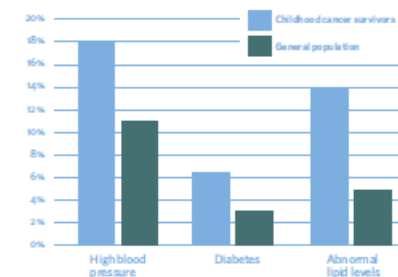
RESEARCH RESULTS

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

Primary care providers and survivors are a team for life

"I am your physician, but I'm your partner too. You and I work together."

That is Dr. Purvi Patel's belief as a physician. Patel, MD, an internal medicine doctor, cares for many childhood cancer survivors at Advocate Medical Group in Orland Park, Ill. It is near Advocate Children's Hospital in Oakland.

As a childhood cancer survivor, you may face unique health care challenges. A primary care physician can help you manage them. If you don't have a provider, ask your cancer care team to help you find one. It is important to tell your doctor what you need and what is most important, Dr. Patel said.

Share your survivorship care plan so your doctor knows your health care needs. The plan includes a summary of your cancer treatment, possible treatment-related health problems, and needed screenings.

"The survivorship care plan is my bible," Dr. Patel said. "When I'm talking with patients, I have their chart open. And I have the survivorship guidelines next to it, so I know the whole picture."



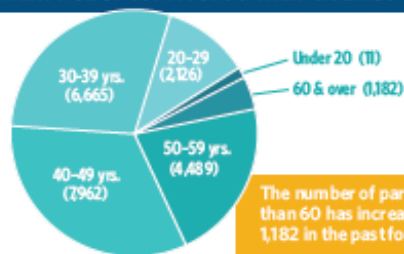
Dr. Purvi Patel treats long-term survivors of childhood cancer at her internal medicine practice in Orland Park, Ill..

Why this matters

More children than ever are surviving cancer, and survivors are living longer. You can give yourself a pat on the back here, because you're part of the largest, longest-running cohort of childhood cancer survivors. Your data has helped to improve cancer treatments and survivor care.

When LTFU launched in 1994, the oldest participating survivor in the study was 43 years old; today, the oldest is 71. Understanding the health of survivors as they age is important to developing ways to keep them healthy.

CURRENT AGE OF SURVIVORS & THEIR SIBLINGS



The number of participants older than 60 has increased from 160 to 1,182 in the past four years.

What you can do to... Reduce your risk of colorectal cancer

- Exercise**: Represented by an icon of a person running on a treadmill.
- Maintain a healthy weight**: Represented by an icon of a scale.
- Eat well**: Represented by an icon of a carrot and other vegetables.
- AVOID:**
 - Smoking**: Represented by a cigarette with a red prohibition sign.
 - Excessive alcohol**: Represented by a glass of wine and a beer.
 - Processed meats**: Represented by a hot dog and a slice of ham.

Explore your CRC screening options

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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 Hutchinson Cancer Center in Seattle, Washington.



Communicating
Health
Information &
Improving Coordination with
Primary Care

Survivorship and heart health

HINT Study: Navigating health insurance



Allyson Foor, the navigator for the HINT Study, was diagnosed with cancer when she was 16 and understands the challenges survivors face.

The health insurance landscape is complex and constantly changing. A new LTFU study helps childhood cancer survivors find their way through the challenges.

LTFU's new HINT (Health Insurance Navigation Tools) Study is exploring innovative ways to help survivors understand, obtain, and make the most of their health insurance.

“Regular check-ups and screenings are critical for childhood cancer survivors,” says Elyse R. Park, PhD, Professor of Psychiatry and Medicine at Massachusetts General Hospital and Harvard Medical School. She is the study's lead researcher. “Three-quarters of survivors develop at least one chronic health condition in the decades after their treatment. The medical costs can be immense. We learned from our prior LTFU research that financial issues often prevent survivors from getting the

medical care they need.” (See Research Results on page 3)

Personal teaching provided online

HINT recruited 80 LTFU participants for an initial pilot that was conducted from September 2020-August 2021. Half of the participants engaged with a health insurance “navigator”—someone trained to deliver education about health insurance coverage—in virtual sessions via Zoom. All participants received a health insurance educational booklet developed by the HINT team.

Participants in the study, like most childhood cancer survivors, had health insurance but nevertheless faced significant financial obstacles like co-pays, deductibles, and

[continued on page 7](#)



health
insurance
navigation
tools

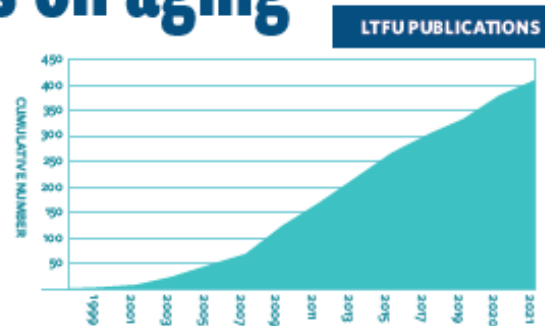
New survey, new focus on aging

The LTFU Study team has launched the next follow-up survey. We are using the myLTFU platform for the initial rollout. If you have not yet received your email invitation to the survey, you can expect it soon.

You won't just see the same old questions in this one (though questions that repeat over the years are essential for monitoring long-term effects). Aging is an important new focus of this survey. You can expect interesting topics and questions that you've never been asked before.

Why this matters

More children than ever are surviving cancer, and survivors are living longer. You can give yourself a pat on the back here, because you're part of the largest, longest-running cohort of childhood cancer survivors. Your data has helped to improve cancer treatments and survivor care.



You're more important than ever

In 2022, we passed the milestone of more than 400 articles published in scientific publications. The volume is increasing...

ASPIRES: Increasing CRC screening

A majority of childhood cancer survivors who are at high risk for CRC are not receiving recommended screenings.



Tara Henderson, MD, Chief of Hematology, Oncology and Director of the Childhood, Adolescent and Young Adult Survivor Center, University of Chicago.

Follow-up care guidelines state that childhood cancer survivors treated with abdominal or pelvic radiation should begin screening at age 30 or five years following the radiation treatment, whichever occurs last.

“Only 37% of survivors at higher risk follow these screening recommendations,” says Tara Henderson, MD. “From previous research, we know that many survivors and their primary care providers are not aware of the increased risk and screening recommendations for survivors treated with abdominal or pelvic radiation.”

Incorporating mobile health apps

Dr. Henderson and Karen Kim, MD, University of Chicago, lead the ASPIRES Study, which aims to find new ways to increase the number of childhood cancer survivors who get recommended CRC screenings. ASPIRES is recruiting 315 LTFU Study participants and

...about colorectal cancer

[continued from page 1](#)

What's my CRC risk?

Your colorectal cancer risk as a childhood cancer survivor depends on your treatment. Abdominal or pelvic radiation increases your risk of developing CRC, so you may benefit from earlier CRC screening than the general population. Your treatment records should indicate if you received abdominal or pelvic radiation treatment and when it was given.

What are my screening recommendations?

Received abdominal or pelvic radiation: Start screening at age 30 or five years after the final radiation treatment, which



Dennis, front center, as a child with his family

Helping with the impact of cancer on families

According to Dr. Tillery, research suggests ways to help families experiencing cancer:

- Give siblings opportunities to process this experience with someone
- Provide appropriate medical information to siblings throughout the cancer experience that's understandable and age appropriate to help with their coping and adjustment
- Consider family therapy, especially as you're trying to go back to a new normal and establish new routines
- Help siblings rebuild their relationships with their parents and sibling with cancer, remembering that sometimes we need outside support to help that happen
- Help children learn to identify their emotions

Perspectives from psychology research: *Cancer and families*

“The dynamics in the family change quite a bit when a child is diagnosed with cancer,” says Rachel Tillery, PhD, pediatric psychologist.



“Primary caregivers spend a lot more time with the sick child, and that’s really difficult for the sibling. If they don’t know what’s happening, it can create uncertainty.” She says that even with a good prognosis, with limited information, siblings may imagine

For Dr. David Buchbinder, volunteering at the SIBS (Special and Important Brothers and Sisters) session at Camp Okizu during medical school led to a long-standing interest in understanding the psychosocial impact of cancer on families.

Dr. Buchbinder, a pediatric hematologist-oncologist at the Children’s Hospital of Orange County, acknowledges that despite the best intentions of pediatric cancer care teams, time and resources are often limited to address the needs of siblings of cancer patients.

LTFU Study siblings

Siblings participating in the LTFU study have been important partners in Dr. Buchbinder’s research that has helped us understand how the family cancer experience affects

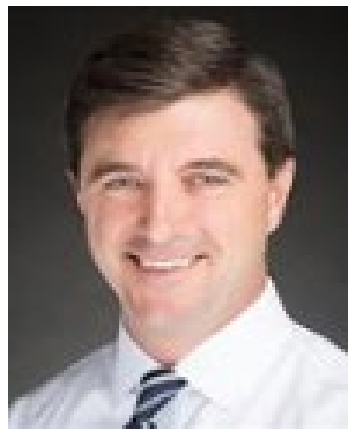
Addressing sibling needs

Addressing sibling needs is a passion Dr. Buchbinder shares with members of Sibling Partnership for Advocacy, Research, and Care in Childhood Cancer (SPARCCC), a collaboration involving the pediatric cancer community. SPARCCC has highlighted the importance of anticipating and meeting siblings’ needs. Despite having a published standard of psychosocial care for children with cancer and their families, this standard is often not met in day-to-day care of siblings. As a result, SPARCCC recently teamed up with Mattie Miracle Cancer Foundation to focus on overcoming barriers to meeting the supportive care needs of siblings.



Thanks to the Education Committee

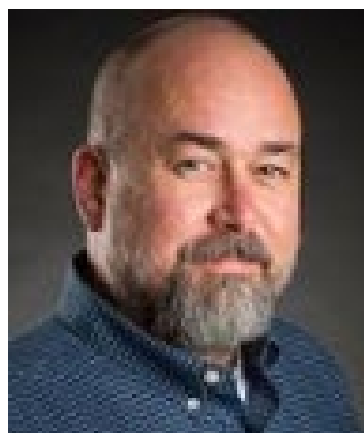
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Greg Armstrong



Aaron McDonald



Chris Vukadinovich



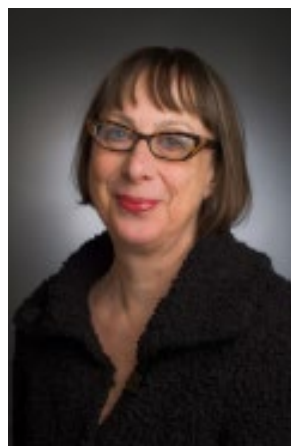
Diana Merino



Linda Rivard



Kayla Foster



Catherine Coleman



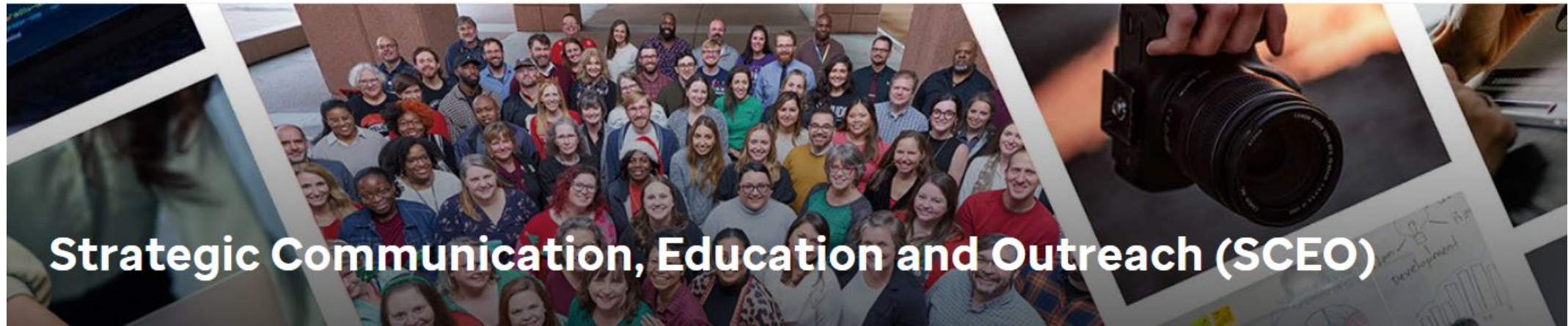
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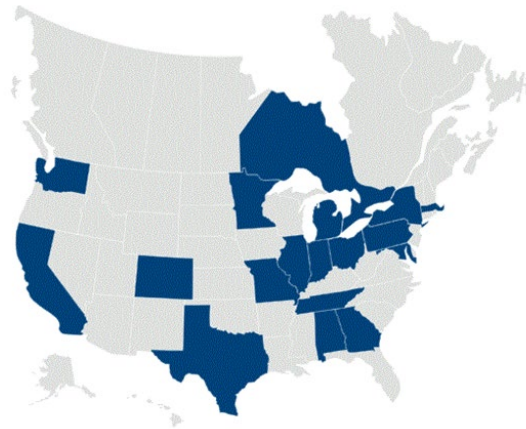
Elizabeth Walker



Beth Bartholomew



Anna Acerra



Join the education committee.

We would love more institutions to be represented.

Help Us Communicate with Survivors

CCSS

- **Suggest story/ topic ideas**
- **Share resources to help survivors**
- **Join the education committee**

Share your ideas and information here.

