

LTFU

Long-Term Follow-Up Study

Summer 2022

Update

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

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More than 500 researchers and clinicians from 51 countries participated in the annual LTFU Study Investigator Meeting, which took place virtually on May 27, 2022. Several investigators

A NOTE FROM US

presented their recent findings, including Elyse Park, PhD, who leads the innovative new HINT (Health Insurance Navigation Tools) Study that's highlighted in this issue of the LTFU Update. Dr. Park and other LTFU researchers have studied survivors' health insurance challenges for more than a decade. The HINT Study is a great example of how your data is helping to identify

critical needs and guide efforts to develop solutions to these challenges.

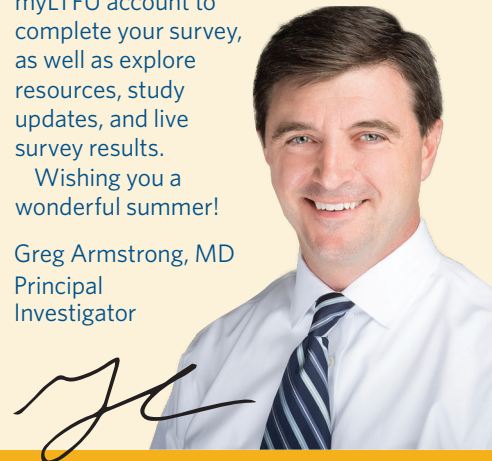
The Investigator Meeting is one of the ways that knowledge gained through your contributions to the study is freely shared to support efforts promoting the health of survivors across the globe. Another way is through publications. We recently passed the landmark of more than 400 articles published in well-respected scientific journals. Thank you for your dedication!

We're excited to be receiving early responses to the latest follow-up survey, which includes an important new focus on aging. You can read more about this, and how the survey is being rolled out, on page 2. We're eager to learn from you how

survivorship can be enhanced throughout people's lives. You can log into your myLTFU account to complete your survey, as well as explore resources, study updates, and live survey results.

Wishing you a wonderful summer!

Greg Armstrong, MD
Principal Investigator



HINT Study continued from page 1

denied claims. They were diverse in terms of their financial status, medical needs, and familiarity with insurance topics.

From terminology to policies

Allyson Foor, the survivorship navigator who conducted the online sessions, is a childhood cancer survivor herself. “I had cancer at 16,” she says. “I’ve been a survivorship navigator for nearly 10 years and, even for me, it can feel intimidating to look at what’s available and pick the best option. I understand that for many survivors, it might feel easier just to do what you did last year, but that might not be best.”

Allyson and each participant began by talking about the importance of survivorship care. If someone wasn’t sure about his or her recommended follow-up care, they learned how to get that information.

“Then we tackled insurance terminology and policies like the ACA, ADA, and FMLA,” Allyson explains. [These refer to the Affordable Care Act, Americans with Disabilities Act, and Family and Medical Leave Act]. “We looked at their current insurance to identify any coverage gaps, and we talked about the challenges they face.”

The importance of self-advocacy

A key part of the program is developing self-advocacy skills to help survivors communicate their concerns and work with their clinicians to address them.



“We looked at real-life situations,” she says. “Maybe your oncologist recommends long-term monitoring of your heart health, but your new primary care provider says you don’t need it. How can you self-advocate?”

“We also talked about how to be strategic about deductibles and co-pays. Can you bundle together several appointments? Explore alternatives to expensive medications? What if a medical claim is denied?”

Appealing is your medical right. Self-advocacy skills help participants feel more comfortable talking with their insurance companies.”

Less worry, better decisions

The results of the HINT Study pilot have been analyzed and were presented at the LTFU Annual Investigator Meeting on May 27, 2022.

“Knowledge is power,” says Dr. Park. “It’s normal to want to avoid learning about health insurance. This intervention proved that if you take a little time to improve your understanding, you can increase your comfort in seeking medical care. We also reduced worry about financial burden—an important quality of life issue.”

The next phase of the study, HINT2, which will launch in 2023, will compare the helpfulness of online interactive sessions to prerecorded videos. It will be conducted through the myLTFU portal. More information will be available in upcoming newsletters.

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.

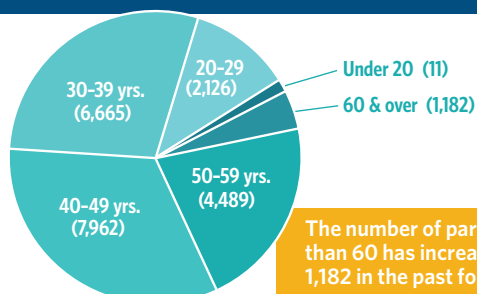
You won’t just see the same old questions in this one (though questions that repeat over the years are essential for monitoring long-term effects). Aging is an important new focus of this survey. You can expect interesting topics and questions that you’ve never been asked before.

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.

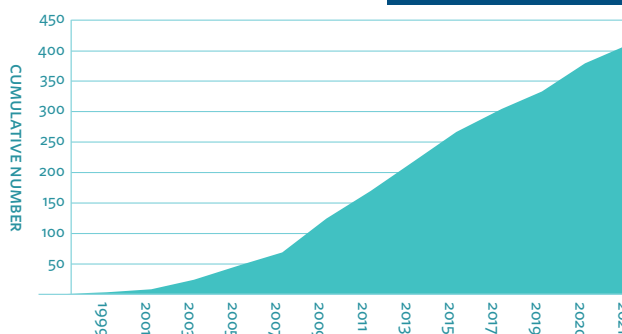
When LTFU launched in 1994, the oldest participating survivor in the study was 43 years old; today, the oldest is 71. Understanding the health of survivors as they age is important to developing ways to keep them healthy.

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.

LTFU PUBLICATIONS



You’re more important than ever

In 2022, we passed the milestone of more than 400 articles published in scientific publications. The advances in knowledge and ground-breaking insights they bring to researchers and clinicians has improved survivorship care around the globe.

With each year of participation, your data becomes more important. To show our thanks, we’ll continue to offer a gift card, as well as the option to donate the amount of your card back to the study if you prefer.

We will also continue to provide paper and phone-based surveys, but hope you will consider completing your survey online. More than 11,000 participants are using the myLTFU portal to complete surveys and stay updated on the study.

Please call our toll-free number at 1-800-775-2167 or email us at LTFU@stjude.org if you have any questions or concerns. We are always happy to hear from you.

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."

Material, Behavioral, and Psychological Financial Hardship Among Survivors of Childhood Cancer in the Childhood Cancer Survivor Study, recently published by Dr. Park and her research team, is the latest in this important line of study. It analyzes data provided by 700 LTFU participants and 210 siblings who completed a detailed health insurance survey.

The study found a high level of financial hardship resulting from medical care costs, even decades after cancer treatment ended. The study team categorized this hardship into three areas.

- **Behavioral (a person's actions and decisions):** More than 50% reported skipping or delaying medical tests, treatments, or follow-up care because of the cost.
- **Material (access to necessary financial resources):** About 40% reported being unable to pay for food, heat, or rent, needing to borrow money, or considering filing for bankruptcy.
- **Psychological (mental and emotional effects):** Half of the participants reported worrying about paying for insurance or staying employed.

Siblings and survivors did not differ significantly in their levels of behavioral or psychological hardship. However, compared to siblings, survivors were much more likely to experience material hardship.

"We were able to show that many survivors were underinsured and avoided seeking health care because of their fear of costs. They also lacked knowledge of health care reform, like the Affordable Care Act and Medicaid expansion (in some states)," says Dr. Park. "This highlights the need for programs that help survivors access health care and affordable health care coverage. That's why we created the HINT Study." Dr. Park leads the HINT Study (see page 1), which explores ways of addressing issues facing survivors.



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.

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. [triagecancer.org](https://www.triagecancer.org). Especially useful is their Quick Guide to Health Insurance Options: [triagecancer.org/QuickGuide-HealthInsuranceOptions](https://www.triagecancer.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.