

## RESEARCH RESULTS

# SLEEPWELL Study

## An ehealth intervention for late effects of childhood cancer

Apps and wearable technologies explore the potential benefits of a good night's sleep on cognitive function.

About 40%-50% of survivors live with impaired brain function that was caused by their cancer and/or treatment. "We know we can't go back in time and undo treatment-related brain injury," says Kevin Krull, PhD, Endowed Chair in Cancer Survivorship at St. Jude Children's Research Hospital and Chair of the LTFU Study's Psychology Committee.

"But other factors, like sleep, also affect cognitive function, including attention, learning, and memory. Sleep is often overlooked as a health behavior, compared to things like exercise and eating well. The SLEEPWELL Study is exploring whether better sleep might help survivors' brains to function better."

SLEEPWELL grew out of an earlier study, led by Tara Brinkman, PhD, also a survivorship researcher at St. Jude

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Kevin Krull, PhD, and Tara Brinkman, PhD, are leading new research on the relationship between sleep and survivors' brain function.

### *I'm a childhood cancer survivor... I have questions about the COVID-19 vaccine*

As COVID-19 vaccines continue to become more available, many childhood cancer survivors may have concerns and questions. Here is guidance for you from the LTFU Study Education Committee.

#### **Should I get the COVID-19 vaccine?**

Yes! We encourage you to get the vaccine as soon as it is offered to you. If you have a weakened immune system, talk with your provider to identify the best time for you to get the vaccine.

#### **Which vaccine should I get?**

All of the approved vaccines are safe and highly effective in preventing severe illness, hospitalization, or death from COVID-19. The "best" vaccine is the one that is readily available. "Get the vaccine that is offered to you, as soon as you can," says Melissa Hudson, MD, Director, Cancer Survivorship, St. Jude Children's Research Hospital.

#### **Caution for leukemia survivors**

Leukemia survivors should talk to their pediatric cancer care teams about precautions to take if, during treatment, they had a severe reaction to PEG-asparaginase. This is usually *not* a reason to avoid the COVID vaccine.

When you arrive to receive your vaccine, let your vaccine provider know about any allergies, and stay for the full observation period. Vaccine sites are prepared to respond to any adverse reactions quickly and

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### **More information about COVID-19 vaccines**

Experts at St. Jude Children's Research Hospital have compiled detailed, up-to-date information about COVID-19 and survivorship in response to the many inquiries they've received from survivors. You can find more information here: <https://together.stjude.org/en-us/life-after-cancer/survivors-covid-19-vaccine.html>

# LTFU Study is the model for a national childhood cancer cohort



Greg Armstrong, MD, Principal Investigator of the LTFU Study, is co chair of the National Childhood Cancer Cohort working group.

An exciting new national initiative aims to gather data from every child diagnosed with cancer in the US. The National Cancer Institute (NCI) has awarded \$50 million in funding annually for the next 10 years to establish the Childhood Cancer Data Initiative (CCDI), which will track childhood cancer patients and follow them long-term. NCI describes learning from the experiences of the LTFU

Study as “essential to the success of this effort to create a truly national resource.”

Greg Armstrong, Principal Investigator of the LTFU Study, has been named co-chair of the CCDI’s National Childhood Cancer Cohort working group. “NCI is tapping our expertise in order to take the LTFU Study’s efforts into the

future,” says Dr. Armstrong. “Thanks to dedicated participants like you, the LTFU Study has become the biggest survivorship resource in the country. This is impressive testimony to the difference you make.”

## A NOTE FROM US

### Your voice is making a difference

In this issue, you’ll read about a new, unprecedented national initiative that is being modeled on the LTFU Study. You’ll also read about innovative research exploring how improved sleep may enhance survivors’ brain function, and our current expansion of the study’s collection of biospecimens.

The old proverb, “Mighty oaks from tiny acorns grow,” comes to mind. None of this would exist without you. Your dedication to the first large-scale scientific community of childhood cancer survivors has led to life-changing advances. I hope you share my enormous excitement at this evidence of our study’s success.

### Completing the current follow-up survey is vitally important

We need your voice because there is still so much to learn about childhood cancer survivorship.

Each participant’s survey response is vitally important. Please take the time to return your current survey so we can continue to make a difference.

### It’s not too late to be heard

You can complete your survey online, through the myLTFU portal, or on paper. Contact us with any questions about your survey: [ltfu@stjude.org](mailto:ltfu@stjude.org) or 1-800-775-2167.

Greg Armstrong, MD  
Principal investigator

A handwritten signature in black ink, appearing to be 'JA' or similar, written over a light blue background.

## Mobile phlebotomy expands research

Without leaving their homes, more than 1,350 LTFU Study participants across the country are helping to expand our biological sample collection. This new effort significantly enhances resources for molecular and genetic research on survivorship.

“Recruitment response for this study has been strong,” says Aaron McDonald, PhD, Project Director. “As part of our planning, we emailed a sample of study participants to explore how they felt about having a mobile phlebotomy technician come to their homes to draw a blood sample. They were overwhelmingly enthusiastic, even with the COVID-19 pandemic.”

After participants provide consent, study staff arrange for technicians to come to their homes and draw a small amount of blood, following strict COVID-19 safety guidelines. Samples are stored in a central biobank with ultra-low temperature freezers that are secure and protected. A participant’s name is not attached to the sample at any time.

“Large numbers of high-quality samples are essential to research,” says Dr. McDonald. “As ever, we are grateful to everyone for their contributions.”



Biological samples contributed by LTFU participants from across the country are stored in freezers like these that protect this important research resource.



# SLEEPWELL Study

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Children's Research Hospital. She found that participants whose sleep improved over the course of six months showed improved cognitive functioning.

"We realized that if we could improve sleep, we might be able to improve survivors' functioning," says Dr. Brinkman. That scientific insight paved the way for SLEEPWELL's five-year effort, which is supported by \$4.3 million in funding from the National Cancer Institute. Drs. Brinkman and Krull are the study's lead researchers.

## Sleepless in survivorship

Insomnia (difficulty falling or staying asleep) has been around for centuries—it's described in the earliest written records—and causes significant problems. In the general population, research has shown the extent to which poor sleep affects work productivity and relationships. Exhausted employees have more trouble concentrating, learning, communicating, and remembering. They have more accidents and often feel unhappy.

Generally, the "gold standard" of insomnia treatment is Cognitive Behavioral Therapy (CBT). CBT helps people identify and explore the ways their emotions and thoughts can affect their sleep. The SLEEPWELL Study is testing the effect of this approach on the cognitive function of survivors with insomnia. "There's a lot of evidence showing that the CBT insomnia program we're using is effective," says Dr. Krull. "We're confident that it will improve participants' sleep. The big question is: Will it also improve cognitive function?"

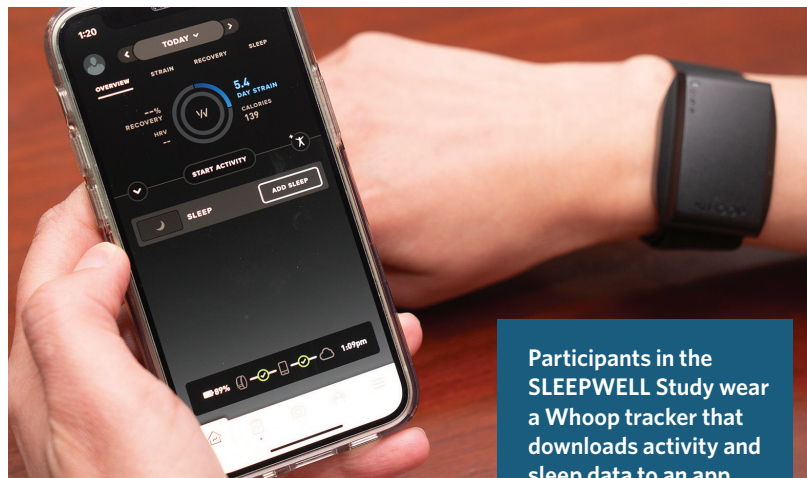
## How the study works

The research team is recruiting a group of 400 LTFU participants who have trouble falling asleep or staying asleep, and have problems with thinking and learning.

People who join will be randomly assigned to one of two study arms: "Active" or "Educational." All participants will complete online sleep diaries and computerized training modules designed to improve their sleep habits. The "Active" arm will receive recommendations based on their specific difficulties; the "Educational" arm will receive more generalized guidance.

## Whoop, SHUTi, and CNS Vital Signs

New technologies are key to this intervention. Participants will wear a fitness tracker, called Whoop, for one week at three time points: the beginning and end of the intervention, and six months after



Participants in the SLEEPWELL Study wear a Whoop tracker that downloads activity and sleep data to an app.

completing the intervention. Whoop will measure their sleep and provide information about their heart health.

Another of the study's innovations is SHUTi, a scientifically validated program of internet-based CBT for insomnia. "SHUTi's recommendations include targeted and straightforward behavioral changes that people can easily make," says Dr. Brinkman.

Participants will also complete brief tests of attention, memory, and thinking skills through CNS Vital Signs, which they can link to from home via their laptops or desktop computers. The tests take a total of 15 minutes and will be done three times, at the same times as when they wear the Whoop device.

## How this study will help survivors

"Sleep is an extremely important behavior," says Dr. Krull. "We spend one-third of our lives in bed sleeping (or trying to sleep), but we know very little about it. This study will help address some of the issues experienced by survivors who have sleep difficulties, including how sleep affects their short- and long-term brain and body health."

## Questions about the vaccine

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safely, and can advise you about which vaccine is the safest and what precautions to take after vaccination.

### "Don't be afraid!"

Julia Stepenske, RN, a childhood cancer survivor, encourages other survivors to embrace this opportunity to protect themselves. "Don't be afraid of the COVID-19 vaccine," she says. "If you have concerns, discuss them with your health care provider. When you arrive at your vaccination site, make sure your vaccine provider is aware of any allergies or other possible issues, and be sure to remain for the full observation period recommended for you (usually 15-30 minutes)."