

**SJLife**

St. Jude Lifetime Cohort Study FALL 2022

# LIFELINE

## from the study team

This has been a banner year for St. Jude Children's Research Hospital. Sixty years ago, the hospital opened its doors. Its mission was simple: To save the lives of children with life-threatening diseases through research and treatment.

Thanks to St. Jude researchers, care teams, patients, and families, we have made astounding progress since 1962.

More children with cancer are surviving their disease.

We are reducing the side effects of cancer treatment. And our research is helping long-term survivors live better

lives. All of these

milestones are possible because of you and your

willingness to partner with us.

We want to make even more meaningful connections with you.

That's why we are launching an online version of LIFELINE. The updated newsletter will give you links to helpful resources for your survivorship journey.

Please visit [stjude.org/lifeline](https://stjude.org/lifeline) and fill out a form to get the newsletter by email. As always, if you have feedback or suggestions, give us a call at 800-775-2167 or email [sjlifeline@stjude.org](mailto:sjlifeline@stjude.org).

Scan this QR code with your phone to sign up for LIFELINE.



Kiri Ness, PT, PhD  
Co-Principal Investigator,  
SJLife Study



## St. Jude survivor aims for the stars

When Hayley Arceneaux was 10 years old, she found out she had bone cancer. Any dreams she had—whether for that year or in the future—were set aside. Instead, limb-sparing surgery, chemo, and long-term side effects loomed on the horizon.

After cancer treatment, she yearned to work for St. Jude, the hospital that had saved her life. So, she studied hard and became a physician assistant. Now she gives other children a chance to survive cancer, too.

"Cancer has made me tough, taught me to expect the unexpected, and made me brave. And I see that same bravery and resilience in the kids I work with every day," she said.

Last fall, she accepted a new challenge—to raise funds for St. Jude as part of the world's first all-civilian space mission. She became the youngest American to orbit Earth, and the first person to do so with a prosthesis.

As part of the Inspiration4 crew, Arceneaux helped raise more than \$243 million for St. Jude. To honor this mission, St. Jude named its newest building the Inspiration4 Advanced Research Center.

Arceneaux encourages other childhood cancer survivors to say "yes" to new challenges. Read her blog post: [stjude.org/hayley-arceneaux-together](https://stjude.org/hayley-arceneaux-together)

# Two studies address survivor symptoms

Do you have health problems related to your childhood cancer treatment? If so, you're not alone.

Most childhood cancer survivors have symptoms related to their cancer or its treatment. Your health care providers want to help. But they can't truly understand what you're going through.

Two new studies will create tools to help providers better assess your symptoms. St. Jude researcher I-Chan Huang, PhD, leads the PROSYM and HEALTH SHARE studies. St. Jude and the National Institutes of Health sponsor both studies.

## PROSYM

As part of PROSYM, 1,800 childhood cancer survivors will answer questions about their symptoms. People who have never had cancer will also answer questions. Researchers want to find out which symptoms occur most often in childhood cancer survivors. The answers will help scientists improve the screening tools that providers now use.

## HEALTH SHARE

You may visit the doctor 1 or 2 times a year. But what happens if new symptoms arise between checkups? The HEALTH SHARE study uses technology to collect this data from the home setting.

If you take part in HEALTH SHARE, you will visit the St. Jude campus for exams. At home, you will wear an activity tracker on your wrist. A special blood pressure cuff will connect via Bluetooth to your smartphone or tablet. You will also answer symptom questions through a mobile app.

Tools created through PROSYM and HEALTH SHARE will help providers give better care and find health problems earlier. If you are asked to take part in one of these studies, please consider doing so.



## Relax in the Family Commons

Childhood cancer can be stressful and isolating. The hospital's new Family Commons provides a treatment-free floor where patients and families can relax, snack, make travel plans, and handle basic needs. Located on the Patient Care Center's second floor, the Family Commons will be open only to patients, families, and Family Commons staff. Be sure to drop by during St. Jude LIFE visits beginning in early 2023.

## 5 TIPS FOR SYMPTOM MANAGEMENT

I-Chan Huang, PhD, studies the symptoms of childhood cancer survivors. He offers 5 tips based on his years of research:

1. Get regular checkups.
2. Listen to your body. No one knows your body as well as you do.
3. Tell your health care provider as soon as possible if any symptoms appear, are long lasting, or get worse.
4. Share your St. Jude survivorship care plan with your providers. Discuss your health risk and how to reduce it.
5. Take part in St. Jude survivor studies. You will learn more about your health while helping other childhood cancer survivors.

# Connect with St. Jude through 2 apps

St. Jude has launched a new tool to help you more easily navigate your care. It's a new electronic health record called Epic. Many other hospitals and health care organizations also use this system. You can access your medical information through Epic's patient portal, **St. Jude MyChart**.

The **St. Jude MyChart** and the **Our St. Jude** patient apps work together for you.



**MyChart**

## With St. Jude MyChart, you can:

- Access your health record and schedule
- Find patient education
- Connect with your care team
- Refill prescriptions
- View test results, and more

## With Our St. Jude, you can:

- Get help with travel and housing
- Get directions around campus
- Meet care team members
- Learn about social events and things to do in Memphis
- Get notifications about important news on campus

## How to sign up:

1. Sign up for MyChart: Call 901-595-4636 or visit [mychart.stjude.org/mychart/signup](https://mychart.stjude.org/mychart/signup) (for patients over 18) or [stjude.org/mychartrequest](https://stjude.org/mychartrequest) (for caregivers).
2. Download MyChart from the Google or Apple App store or log in online at [stjude.org/mychart](https://stjude.org/mychart)
3. Download the Our St. Jude app from the Google or Apple App stores.

Once you complete these steps, use your MyChart username and password to access both St. Jude MyChart and the Our St. Jude patient apps.

## Learn more about St. Jude MyChart:

[stjude.org/mychart](https://stjude.org/mychart).

## Learn more about Our St. Jude:

[stjude.org/treatment/patient-resources/before-arrival/our-st-jude-help-and-support.html](https://stjude.org/treatment/patient-resources/before-arrival/our-st-jude-help-and-support.html)



## STAY IN TOUCH

Call us: 800-775-2167

Email us: [sjlife@stjude.org](mailto:sjlife@stjude.org)

Go online: [stjude.org/sjlife-participate](https://stjude.org/sjlife-participate)

## Building for the future

If you come to campus for a St. Jude LIFE visit, you'll see exciting changes. The Kmart St. Jude LIFE Center has been torn down to make room for two 15-story towers.

The new buildings will house the hospital's outpatient clinic and clinical offices. In the meantime, your St. Jude LIFE visit will take place in the Patient Care Center.

# Take steps to manage pain

Pain is a common symptom in childhood cancer survivors. But there are tools to manage it. Studies show that cognitive behavior therapy (CBT) is one of the most effective treatments for chronic pain.

## What is cognitive-behavioral therapy?

CBT focuses on how our thoughts, feelings, and behaviors affect our well-being. It is natural to have negative thoughts about pain. CBT teaches you how to think differently. It is the “gold standard” behavioral treatment for chronic pain.

Pain may happen in many ways, including headaches, muscle aches, or joint pain. The key is to seek treatment when symptoms begin, said Rachel Tillery-Webster, PhD, St. Jude psychologist. “If we can introduce CBT earlier, it’s more likely to be effective and helpful,” she said.

If you wait, you can fall into a negative “pain cycle.” You avoid physical activity because it may hurt. That can lead to muscle weakness and loss of function. You may also feel sad or depressed when you avoid doing things you enjoy.

CBT teaches you to break that cycle, said Tara Brinkman, PhD, St. Jude psychologist. You learn to focus on what you can do. Start with small steps and build up. “What’s something that you feel good about today? Focus on what you can accomplish instead of negative beliefs about pain,” Brinkman said. Mental health therapists such as psychologists can provide CBT. Ask your primary care provider for a referral.

## Other pain treatments:

CBT can be used along with other treatments. Medicine may be an option. But it is not a long-term solution. Other treatments may include massage, meditation, yoga, and acupuncture. But they are not as well-studied as CBT.

Focusing on your overall health can also help. Studies show unhealthy habits increase the risk of symptoms such as pain, Tillery-Webster said. It is important to be physically active, eat a healthful diet, avoid smoking, and manage stress.

It is also vital to visit your local health care provider regularly. Tell your provider about any symptoms you have. Make sure to have a copy of your St. Jude survivorship care plan.

It is important to have regular checkups and screening tests recommended for your specific cancer treatment.

For more tips to manage pain, visit [together.stjude.org](https://together.stjude.org) and search **Managing Pain Without Medicine**.



## VIP treatment at the airport

You’ll feel like a VIP when you visit the new St. Jude Lounge in the Memphis International Airport. The space is open only to St. Jude patients and families traveling for St. Jude appointments. You and your family can enjoy beverages, snacks, toys, books, games, and TVs. Located in the airport’s main concourse, near Starbucks, the lounge is open Tuesday–Friday, 7 a.m.–6 p.m.

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