

Update

A note from us

STEVEN, A STUDY PARTICIPANT who lives in Illinois, found himself here at St. Jude Children's Research Hospital on business. He stopped by the LTFU Study center, where I and several other Study researchers were delighted to meet him.

As we talked, he mentioned having had a second cancer and heart disease. He wanted to know if these were common experiences among other survivors.

We pulled out two of our recent articles in medical journals and walked him through some of the Study's results about late effects of childhood cancer. It was a privilege to tell him in person, **"We've learned this thanks to you and your willingness to participate in the study. You are part of this knowledge, which teaches the medical community how they can help survivors around the world."** I think he was overwhelmed when he saw the significance of his contributions to the study.

I'm sharing this story as we begin mailing out our new survey, to illustrate the value of each participant's response. Even if you're healthy or you skipped a few in the past, your updated information allows us to continue improving survivors' health.

Meeting this individual was such a pleasure for us. If other participants find themselves in or near Memphis, we hope you will stop by and say hello!

With thanks,

Greg Armstrong, MD,
Principal investigator




Advancing Survivors' Knowledge (ASK) About Skin Cancer

Skin cancer is the most common subsequent malignancy among childhood cancer survivors. It's also the most treatable if it's diagnosed early.

The goal of the Advancing Survivors' Knowledge (ASK) About Skin Cancer Study is to increase early detection of skin cancer in survivors who were treated with radiation. More than 700 LTFU Study participants are part of the ASK Study.

"Skin cancer is the only cancer you can actually see," says Alan Geller, an investigator at the Harvard T.H. Chan School of Public Health, who leads the ASK Study. "Detection is as

(cont. on pg 3)

Hot tips to save your skin

MOST PEOPLE LOVE to soak up the sun. But nobody wants a sunburn. And tanning can lead to premature aging of the skin and, sometimes, to skin cancer.

For childhood cancer survivors, "handle with care" is the best approach to sun exposure. You may be at increased risk of developing skin cancer, especially if you were treated with radiation. While skin cancer is highly

treatable and survivable, prevention and early detection are key.

Stay skin-cancer-free year-round by following these tips from the American Academy of Dermatology:

- The sun's rays are strongest between 10 a.m. and 2 p.m. If your shadow is shorter than you, seek shade.
- Wear protective clothing outdoors, such as a long-sleeved shirt, pants, wide-brimmed hat, and sunglasses.

(cont. on pg 3)



The LTFU Study community

Siblings

More than 5,000 brothers and sisters of LTFU Study participants are part of the study, serving as a comparison group. The siblings in the

study are similar to the survivors in many ways, but they did not receive treatment for cancer or a similar childhood illness.

The LTFU Study follows the health of survivors and their siblings over time. If survivors in the study have different health issues when compared to their brothers and sisters,

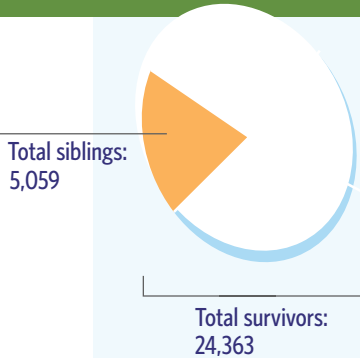
these results provide strong evidence about how cancer treatments affect long-term health. Continued sibling participation is essential to the study's success.

Current age

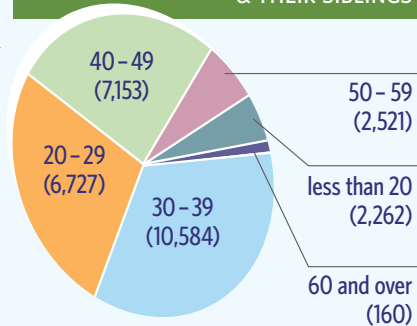
LTFU Study participants were diagnosed with cancer between 1970 and 1999, before reaching the age of 21. To be eligible to be part of the study, participants must have survived at least five years from their initial diagnosis with cancer.

Thanks to the dedication of everyone who is part of the study, our research can look at the health conditions found over time among a large group of survivors of childhood cancers.

NUMBER OF SURVIVORS & THEIR SIBLINGS



CURRENT AGE OF SURVIVORS & THEIR SIBLINGS



Stay connected!

If you have moved, changed your email address, or have a new phone number, it's easy to update your contact information:

- Call us toll-free at **800-775-2167**
- Send us an email at **LTFU@stjude.org**
- Visit **ltfu.stjude.org**. Click on "Update Your Info."

The difference you make

Childhood cancer survivors are living longer, and leading healthier lives, based on an analysis of LTFU Study data.

Results of the analysis made national headlines and were presented to the American Society of Clinical

Oncology (ASCO) in June. "Our analysis is the first of its kind to study changes in

the rates of health issues over time in a large group of cancer survivors," said Todd Gibson, PhD, a lead investigator. Read more about our research results at ltfu.stjude.org.



New survey rolling out

Great early response!

In August, we began mailing out about 500 surveys a week. We will continue to mail surveys weekly according to a pre-set schedule—so some participants will receive their surveys in 2017, others will receive them in 2018.

Wondering if your survey is coming? We'll mail you a heads-up announcement a few weeks beforehand, so you can be on the lookout.

Why an incentive?

A few people have asked why we are attaching a \$10 bill to the front of their surveys.

- **We value your time.** We respect your busy life, and this is our way of saying "thanks."
- **Maximizing participation is a priority.** The rapid return of completed surveys makes it possible for us to more quickly analyze data that can help improve care, and providing a small, up-front incentive has been demonstrated to increase response rates.
- **Your response is important.** The future success of the Long-Term Follow-Up Study depends on the information we receive from you and other participants, and we are committed to doing everything possible to maximize participation.

Meeting survivors' health-related needs

Adult survivors of childhood cancer have many health-related needs that go beyond medical treatment, but their needs may not be met because of poor communication with their health care

providers. A team led by Dr. Cheryl Cox of St. Jude Children's Research Hospital recently studied the health-related needs reported by survivors who responded to the LTFU Study needs assessment questionnaire.

What we learned

Survivors in the study reported that they needed help with a range of issues: from coping with worry, depression, or uncertainty about the future to interacting with the health care system. They also reported that they need more information—for example, about cancer and side effects, and what health screenings they should have.

Dr. Cox says, "Evidence suggests that patients want their providers to ask about their health-related needs but may hesitate to bring them up," but providers often focus on current, specific health conditions and may not be trained or encouraged to discuss other needs.

What does this mean for you?

Survivors can take the initiative to get help with health-related needs by bringing them up with their providers. The researchers also suggest that a needs assessment form similar to the one used for the study could be added to survivorship care plans to help providers and survivors better communicate.

Read more about the results of this and other LTFU Study research at ltfu.stjude.org.

"The unmet emotional, care/support, and informational needs of adult survivors of pediatric malignancies" (Cox CL, Zhu L, Ojha RP, et al.) was published in the Journal of Cancer Survivorship. 10:743-758.

We're glad you asked...

I've been healthy since I had cancer. Should I still complete my survey?

Yes! Everyone who is part of the study is important for its success. Participants enrolled in the study represent a sample of all the survivors of childhood cancer and their siblings. The results of the study will not be accurate if only those survivors and siblings who have problems continue to participate.

Lead author Cheryl Cox, MD (left), with Melissa Hudson, MD, one of the study's co-authors



ASK ABOUT SKIN CANCER (cont. from pg 1)

simple as doing a thorough skin self-exam once a month and scheduling a full-body examination with your doctor at least once a year."

Tools for survivors and their providers

The ASK Study developed a website, videos, and print materials to inform survivors and their primary care providers about the importance of early detection and help them become confident in performing skin exams. Participants also received text message reminders and prevention information.

A randomly selected sub-group of participants also received dermoscopic lenses for their cell phones, in order to photograph marks on their skin that they were concerned about. Images were then uploaded to a secure repository and reviewed by the study dermatologist.

The study is no longer enrolling new participants but is still collecting data. We will update you about the results when they are available.

TIPS TO SAVE YOUR SKIN (cont. from pg 1)

- Generously apply a broad-spectrum, water-resistant sunscreen with a Sun Protection Factor (SPF) of 30 or more to all exposed skin. "Broad spectrum" provides protection from both ultraviolet A (UVA) and ultraviolet B (UVB) rays. Reapply every two hours, even on cloudy days, and after swimming or sweating.
- Use extra caution near water, snow, and sand. They reflect and intensify the damaging rays of the sun, and can increase the chance of sunburn.
- Do not use tanning beds—the ultraviolet light can cause skin cancer and wrinkling.
- Use a self-tanning product or spray if you want to look tan, but be sure to use sunscreen with it.

A family founded on hope

CAMMIE JARVIS OF ARLINGTON, TEXAS, WAS diagnosed with embryonal rhabdomyosarcoma at 21 months of age. She and her family were living in Africa, where her parents worked as Bible translators and helped deliver humanitarian aid in Sudan, which was experiencing a civil war.

Cammie's mom worried because her toddler seemed to be sickly much of the time. When her



Cancer survivor Cammie Jarvis is adoptive mother to four girls.

health worsened, the family urgently sought medical help in neighboring Kenya, then flew back to Houston, Texas, where Cammie's grandparents lived.

Cammie was treated at the University of Texas M.D. Anderson Cancer Center in Houston, where doctors found a tumor in her reproductive organs. They had to remove a portion of her reproductive system, sparing as much as possible in the hope that she would eventually be able to have children.

After treatment, Cammie underwent several painful reconstructive surgeries. They were ultimately successful, and at age 17 she looked forward to a future that included marrying her high school sweetheart, Jeremy, and starting a family.

Love, marriage, and a recurrence

"At age 16 I met my best friend, Jeremy, and married him on my 28th birthday," she recalls. The couple met

at a church youth group. Jeremy wasn't daunted by Cammie's health problems, and he knew she might not be able to have children. "I'll just be your best friend," he told her, though he hoped for more.

In November 2001, when she was 22 years old, Cammie's cancer unexpectedly came back. Her doctors removed a grapefruit-sized tumor, and she received radiation and six months of chemo. She also had a hysterectomy, ending her hopes of bearing children. Cammie put her energy into finishing college, but two years later the cancer recurred again, this time in her lung. "Tumors kept showing up in one of my lungs," she says. "In 2004 I had surgery to remove two-thirds of my right lung, as well as some ribs. Thankfully, they were able to save one lobe of the lung."

Her doctors fought for her survival, even though they had never seen a patient survive rhabdo a third time. "I'm so grateful I was treated at M.D. Anderson," Cammie says. "It was hard to have all the surgeries, but it's been 13 years since I had my lung removed, and I'm forever grateful for the amazing care I received."

Through all the surgeries, treatments, disappointments, and uncertainties, Jeremy kept his promise to be Cammie's best friend. When she was finally well, the couple were married. Cammie earned her college degree and now works part-time as a special education teacher.

"We love them all so!"

Despite the fact that Cammie could not bear children, the couple could not give up on the idea of having a family.

(cont. on back)

Adoption links

If you're considering the possibility of adoption, check out the following links:

- Child Welfare Information Gateway of the US Department of Health & Human Services: www.childwelfare.gov/topics/adoption
- Adopt US Kids, a project of the Children's Bureau of the US Department of Health & Human Services: www.adoptuskids.org
- Oncofertility Consortium, hosted by Northwestern University: www.oncofertility.northwestern.edu
- Dave Thomas Foundation for Adoption, established by Dave Thomas, founder of Wendy's fast-food restaurants: <https://davethomasfoundation.org>

The following sites offer grants to help pay adoption expenses:

- Help Us Adopt: www.helpusadopt.org
- Gift of Adoption Fund: www.giftofadoption.org

A vocation to help survivors preserve fertility

AT AGE 29, JOYCE REINECKE WAS DIAGNOSED with leiomyosarcoma, a type of tumor that develops in soft tissue. She was on a business trip for her law firm when she became ill. She was hospitalized and, during emergency surgery, doctors found and removed four tumors from her abdomen. As a young married woman, Joyce was shocked to learn that some of the options for treating the cancer might leave her unable to bear children.

“Nobody talked to me about fertility preservation,” she recalls. “It was only mentioned by a medical fellow the day before I left the hospital.” She discovered that her experience was not unusual. Research has shown that many survivors do not recall discussing fertility preservation with their oncologist or are not routinely referred for fertility preservation services.

Joyce, a New York state native, was living in Seattle when she was diagnosed. She chose to undergo in vitro



Joyce Reinecke, JD, with her husband and twin daughters

Community partner: The Alliance for Fertility Preservation

The goal of the Alliance for Fertility Preservation is “to help alleviate one of the most distressing life-altering consequences of cancer treatment—infertility.” Since it was founded in 2012, the organization’s exclusive focus has been on fertility preservation for cancer patients.

The Alliance’s website (www.allianceforfertilitypreservation.org) offers information on reproductive health and choices, including fertility risk from cancer treatment, fertility testing after treatment, and pretreatment fertility preservation options for women and men. The site also includes patient stories, research publications, and resources for professional education and advocacy.

The site’s Fertility Scout™ is a free tool that survivors can use to find fertility preservation services by geographic area. According to the site, all of the listed providers “understand the urgent timeline facing . . . [recently-diagnosed] patients.” The providers have agreed to designate one “fertility preservation contact” to handle referrals for their clinic and to get in touch with patients directly within 48 hours to schedule an appointment. The Fertility Scout tool is one of Joyce’s proudest accomplishments as Director of the Alliance.

fertilization and freeze embryos for the future. She and her husband travelled to Cornell University for the procedure, and they are now the parents of twin girls.

As a result of her experiences, Joyce found a passion for informing survivors about their options for preserving fertility and helping them connect with services. Since 2014 she has been the Executive Director of the Alliance for Fertility Preservation (AFP), a charitable foundation created by professionals with expertise in all aspects of fertility preservation for cancer survivors (see sidebar). Before joining the AFP as its Director, she was a cancer and fertility adviser for the LIVESTRONG Foundation and served as the Vice President of Programs for Fertile Hope.

A FAMILY FOUNDED ON HOPE (cont. from front)

“We decided to look into becoming foster parents and adopting a child if things worked out,” Cammie says. “I was worried that my being a three-time cancer survivor would disqualify me from being accepted as a foster or adoptive mom and was so relieved to find that was not so.”

The first children the couple fostered were twin baby girls. “When they became adoptable, so did their half sisters, who were in another home. We were granted permission from the judge to adopt all four!” The twins are now five years old and their older sisters are 16 and 18—the oldest recently graduated from high school with honors.

Like all families, the Jarvis’s have had some struggles along the way, but being parents to four girls is a dream come true for Cammie and Jeremy. “We love them all so!” says Cammie. “Being their parents has been one of the best experiences of our lives.”