

LIFELINE

St. Jude for Life



Summer 2016

Research MATTERS: St. Jude LIFE Study Opens to All 5-Year Survivors

Dear St. Jude Alumni,



Since it was founded, St. Jude has been a leader in childhood cancer research. As you know, many of the treatment advances that have led to today's high cure rates were pioneered here.

St. Jude has also led the way in survivorship research. With the St. Jude LIFE study we were the first institution in the world to commit to providing our adult survivors with lifelong medical evaluations at no cost. Now we're proud to announce that we have opened this historic study to all of our 5-year survivors, regardless of age.

Thanks, participants, for making this research possible. We look forward to seeing you next time you return to St. Jude!

Melissa M. Hudson, MD
Principal Investigator,
St. Jude Lifetime Cohort Study

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In the St. Jude LIFE study childhood cancer survivors periodically return to St. Jude for two or three days of complete health testing throughout their lives. As a participant in St. Jude LIFE, you have the opportunity to learn more about your own health and to benefit from early detection of any potential health problems. Your participation also helps us learn about the the long-term health issues related to cancer therapy and this helps survivors everywhere.

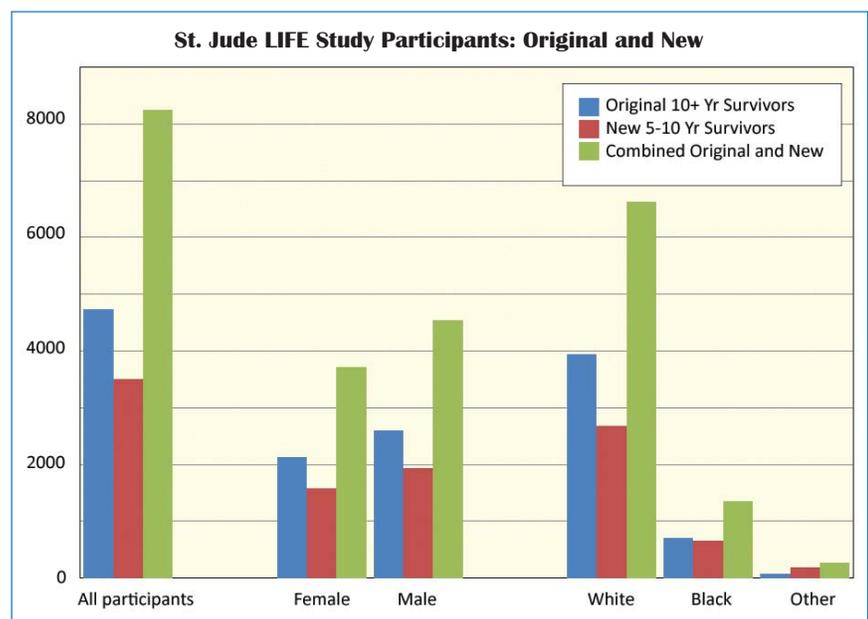
St. Jude LIFE began in 2007. Since then many participants have returned several times to take part in the study evaluations. Recently, the LIFE study was expanded to include all St. Jude survivors who are 5 years past diagnosis.

WHO is eligible to participate in St. Jude LIFE?

- Originally St. Jude LIFE was open to our patients who were age 18 years old or older and 10 years from diagnosis. More than 4700 people met these qualifications and most have joined the study.
- Over time, the expanded study will add about 3500 additional participants who reach 5 years from diagnosis. There is no longer an age limit for participants. Children as young as 5 are now eligible to join the study.

WHAT other changes have been made as a result of the expansion?

- In the original study the medical evaluations were "risk-based," tailored to the specific risks a survivor faced as a result of the treatment he or she received. For example, only those who received heart-toxic treatments like chest radiation or anthracycline chemotherapy were tested for heart problems.
- Now, each participant is screened for every type of health condition. For example, all patients are tested for heart problems whether or not they received treatments that are toxic to the heart.



WHY did we expand the study to all survivors?

By including survivors who are younger and closer to the end of treatment, we expect to learn more about how and when treatment-related problems start to develop. And testing every participant for every condition will help in the early detection of health problems that might be related to personal characteristics (genetics) or lifestyle and behavior. We hope to use the knowledge we gain to find new ways to promote good health and to help survivors lead long, satisfying lives.

Now all 5-year survivors can reap the benefits of lifelong health screening



Dr. Krull

St. Jude researcher Dr. Kevin Krull says that the expansion of the St. Jude LIFE study will have many benefits for both scientists and survivors. Dr. Krull is a psychologist and neuroscientist who oversees the neurocognitive testing done as part of the LIFE study evaluations. (These tests focus on thinking, memory, and other brain functions.) "The expansion greatly increases the number of study participants," he says, "and more participants make it possible for us to detect and better understand problems that might only affect a small number of survivors. Funding for the expansion also allows us to design new ways to help our survivors maintain their health and cope with any late effects of treatment," Dr. Krull observes. "In the neurocognitive area, for example, we've been able to set up a pilot program that offers web-based skill training to help survivors improve their memory, attention, and organization skills."

Dr. Krull notes that "Over the years a lot of effort has been directed toward developing therapies for childhood cancer patients that are less toxic to the brain and other organs. One of the greatest benefits the expansion offers is the ability to look at the experiences of younger survivors, earlier in follow-up, who were treated with therapies specifically designed to reduce late effects." See below for stories of two survivors, both diagnosed with acute lymphoblastic leukemia (ALL), but treated decades apart.

Journey Crutcher: first person to join the expanded study

Journey Crutcher, of Memphis, Tennessee, is the first person to join St. Jude LIFE under the new eligibility requirements. Journey was diagnosed with ALL at age 2½. She's now 13 years old and will be starting high school in the Fall. Journey and her parents returned to St. Jude in February, 2016, for her first LIFE study evaluation. The ability to contribute information that may help other cancer patients and long-term survivors is the reason she participates in research. She plans to take part in additional studies that she's eligible for in the future.

Journey says she enjoyed the tests. Her favorite was the flexibility testing done in the Human Performance Lab. Dr. Kiri Ness, the director of the lab, says that opening the study to younger people like Journey "will give us the ability to learn if the health problems we see in those farther out from treatment emerge in younger survivors (at earlier ages) but are less severe. This may help us understand the best time to intervene to prevent serious problems."

No problems showed up during Journey's study evaluation except for a slight hearing loss. Her mom Phyllis says the hearing loss was not linked to Journey's cancer treatment, though. "They thought it was caused by her using the headphones for her iPod, and recommended ways to prevent further hearing loss," Phyllis explains.



Journey with nurse practitioner Teresa Sweeney



Cherie with nurse practitioner Daniel Smith

Cherie Bault: a lifetime commitment

Cherie Bault has participated in three LIFE study evaluations since the study began. "I've gotten a clean bill of health and been reassured every time," she says. Cherie, 35, was diagnosed with ALL in 1983 when she was two years old and went into remission at age seven. Today she's a child care teacher at a day care in Jackson, Tennessee. She's been married for 13 years and has three sons, ages 10, seven and six.

In addition to taking part in the regular study evaluations, Cherie volunteered to participate in a study of frailty and early aging in childhood cancer survivors. (Frailty is defined by loss of muscle mass, strength, and overall staying power.)

"I learned that I weighed more than ideal. As a result I've cut back on certain foods, and I try to drink more water. I should try to exercise more but between my job and taking care of my three boys I'm already pretty active!" she says.

Cherie says, "I plan to participate in St. Jude LIFE forever. It's a way for me to give back that not everyone can do, and to me it's special. I just cheer up when I come back to St. Jude and look at those kids who are benefitting from the improved treatments since I was there."

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Melissa M. Hudson, MD, Medical Editor
melissa.hudson@stjude.org

Dept. of Oncology and Epidemiology & Cancer Control
St. Jude Children's Research Hospital
Memphis, Tennessee

E-Mail: sjlife@stjude.org

www.stjude.org/sjlife

1.800.775.2167