

LIFELINE

St. Jude for Life



Winter 2014-2015

St. Jude LIFE Study: Latest Numbers

- 4,845 survivors are eligible to participate—2676 men and 2169 women.
- 3,044 have agreed to come for the initial evaluation and 2899 have completed at least one visit.
- 996 participants in this lifetime study have returned to St. Jude for a second visit, 131 for a third visit and 7 for a fourth visit.
- Participants range in age from 18 to 64 years old. The average age is 32.
- Participants were originally diagnosed with cancer from birth up to 28 years of age. The average age at diagnosis was 8 years old.
- Study participants have taken part in 30 research projects and 30 articles have been written about the results of these projects.
- We expect our 3000th participant to complete their first visit in January 2015!

St. Jude Life Study
Toll-Free Number:
1-800-775-2167

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Dear St. Jude Alumni,

The St. Jude LIFE Study is beginning an exciting new era. In the future we are planning to expand the study in several ways so that we can learn even more about the long-term health of survivors.



First, we plan to include younger St. Jude survivors in the study. Currently, a person must be 10 years past cancer diagnosis and 18 years old to enroll in the study. We'll soon be expanding eligibility to include people who are 5 years past diagnosis, regardless of their age.

Second, we plan to include additional tests for all participants. Right now, the study evaluation is tailored to each survivor based on the health risks they face because of the specific treatments they received. We will be moving to a plan where the evaluations are more comprehensive. So, for example, all participants will be evaluated for heart health, whether they received heart-toxic therapy or not. This will help in the early detection of health problems that might be related to personal characteristics (genetics) or lifestyle and behavior.

Finally, we plan to increase our use of websites and mobile communication tools such as text messaging and mobile phone applications (“apps”). These tools will supplement the in-person study evaluations and help inform survivors about health issues, resources, and opportunities to participate in additional research. See the box on page 3 for more information about this topic.

Also in this issue of the LIFELINE we profile some of the people, both researchers and study participants, who make up this landmark study. I hope you enjoy reading about them.

As always, thank you for your ongoing participation in the St. Jude LIFE Study and your commitment to St. Jude.

Sincerely,

A handwritten signature in black ink that reads "Melissa M. Hudson, MD".

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

Some of the People Who Make Up the St. Jude LIFE Study

It takes all kinds to run a world-class study: doctors, nurses, physical therapists, exercise specialists, study coordinators, lab researchers, and many, many more. Most importantly, it takes patients and volunteers! We'd like to introduce you to just a few of the important people who make up the study.

More than Patients: Nurse Debbie Crom

Explaining her role in the St. Jude LIFE Study Debbie Crom says, "It's my privilege to see participants, review their treatment history, counsel with them, educate them, cheer for them, and remind them of their strengths." Debbie has been with the study since it began. She's a Family Nurse Practitioner and has specialized in Survivorship since 1984. She also has a PhD in Nursing, and is especially interested in the health of brain tumor survivors. Debbie is originally from Rochester, New York, but moved to Memphis as a child. She's married and has two grown children.

Debbie is a runner and a triathlon athlete. In addition, she practices yoga and commutes to work by bicycle. "I love anything physical," she says, "but I confess that my greatest interest is my work!"



Family Nurse Practitioner Debbie Crom consults with a participant (photo courtesy of St. Jude Children's Research Hospital Staff)

"It's inspiring to me to observe the strength of spirit of our patients, in spite of challenges they may face," she continues. "Survivorship has come such a long way. When the first childhood cancer patients began to be long-term survivors we just hoped they would be here in 10 years. Now increasing numbers are surviving well beyond 20 years from diagnosis and we need to continue to build solid knowledge to help survivors live a life of vitality as they age."

Debbie believes her job is to "recruit the patients to themselves,"—to equip them to become self-advocates and to see themselves not just as patients but as active participants both in their own care and in all areas of their lives.

Building Relationships: Exercise Specialist Robyn Karlage

Senior Exercise Specialist Robyn Karlage is the director of the Human Performance Lab, where St. Jude LIFE Study participants are seen for a two-hour head-to-toe functional assessment. This assessment checks heart rate, blood pressure, balance, flexibility, muscle strength and cardiovascular fitness, as well as many other physical measurements.

Robyn has been with the study for 5 years. She's originally from northern Kentucky and moved to Memphis for graduate school. She says she loves working with study participants.

"One of the first brain tumor survivors I assessed was a woman who had to deal with some long-term side effects of cancer treatment, but she was one of the happiest people I had ever met," Robyn recalls. "It turns out she was a swimmer and competed in the special Olympics. I'm a triathlete so I also

swim, and we ended up talking about swimming the entire time. At the end of her functional assessment she gave me a hug and said "I love you!" and then quickly walked out of the lab to go to her next appointment. At that moment I realized I had found my dream job and couldn't be happier working with the patients of St. Jude LIFE! Now, many patients are coming back for their second and third study visits and I've started to build relationships with them. It's very rewarding to know the patients remember me, even after several years."

Seeing Miracles: Visit Coordinator Michelle Fite-Weatherford

Michelle Fite-Weatherford is one of the visit coordinators for the St. Jude LIFE Study. Officially, she's a nurse-coordinator and manager of clinical research operations. Michelle is usually the first person to greet study participants when they come to St.



Robyn Karlage (right), senior exercise specialist and director of St. Jude's Human Performance Laboratory works with a study participant (photo courtesy of St. Jude Children's Research Hospital Staff)

Jude. She orients them to the hospital's campus, arranges for their compensation, schedules return visits, and makes sure everything goes smoothly for both participants and members of the study team. Michelle is a native of Memphis who is married and has two teenaged sons. She originally trained as a neonatal intensive care nurse. She has been with the St. Jude LIFE Study since the second patient was enrolled. "I had wanted to work with kids," she says, "but I was also interested in research and I fell in love with the survivors who had been treated from the 60s through the 80s. Our survivors have overcome sickness and side effects and many of them face big health challenges. In spite of all that, they are coming back to make a contribution to research and to future patients."

Michelle has also seen people receive direct benefit from their participation in the study. She recalls a patient who was having some memory issues during her evaluation and had temporarily forgotten how to use her cell phone. "Dr. Kaye Cash immediately sent her for an MRI and discovered she had a large brain tumor, which was treatable. That's why I love coming to work—we have such a dedicated team and I get to see miracles."



Michelle Fite-Weatherford is often the first person participants see when they come to St. Jude. (photo courtesy of St. Jude Children's Research Hospital Staff)

A Family Affair: Study Participants Tiffany and Jimmy Seaton

Tiffany and Jimmy Seaton were high school sweethearts. They met shortly after Tiffany celebrated her first year of remission from Hodgkin lymphoma and they have been married for seven years. They recently came to St. Jude to participate in the study evaluation, Tiffany as a returning patient and Jimmy as a volunteer.



Jimmy and Tiffany Seaton with their son Parker (photo courtesy of Tiffany Seaton)

Tiffany was 15 years old the first time she came to St. Jude to be treated for lymphoma. She was living with her family in Bossier City, Louisiana, when she was diagnosed. She received chemotherapy in her hometown but came to St. Jude for radiation treatment. She remembers that a highlight of each visit was comparing shoes with her doctor, Melissa Hudson. "We wore the same size and liked the same styles," she says. When she and Jimmy returned for the study evaluation, Tiffany had another chance to check out Dr. Hudson's shoes.

Of course, it's not ALL about shoes. "The study is really a great opportunity to go back and help other people," Tiffany says. "It's good to see that St. Jude is still concerned for their patients more than a decade after they were treated." She's proud that Jimmy decided to participate. "We need more volunteers for the study!" she states. As a volunteer Jimmy is less familiar than Tiffany with St. Jude but he is impressed by what he's seen. "I love the cafeteria," he says enthusiastically, "and it's great to see how happy the kids seem and the smiles on everyone's faces."

The Seaton family are parents of a two-year-old son, Parker. He gives them an additional reason to participate in research. "I wasn't sure it would be easy for me to have a baby after having cancer," says Tiffany. "We wouldn't have Parker if not for Dr. Hudson and St. Jude!"

St. Jude for LIFE: eHealth and mHealth Programs

eHealth and **mHealth** are names for programs that deliver healthcare, education, and resources through websites (eHealth) and text messaging and mobile phone applications (mHealth). eHealth and mHealth programs are becoming common as computers and mobile phones get more sophisticated and are used by more and more people.

According to the US National Institutes of Health (NIH), eHealth and mHealth programs have the potential to **empower and encourage** patients and are designed to be **easy-to-use, entertaining, and exciting, as well as educational**. (For more information, please see the "10 e's in 'e-health'" at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1761894/>)

In the coming year St. Jude will begin creating an eHealth website for St. Jude LIFE study participants that will match all those descriptions. The site will take time to develop but will eventually include text, images, video files, audio files, quizzes, questionnaires, and interactive features. It will be supplemented by mobile phone apps and will be a primary source of communication between survivors and the study between study visits. Watch for additional information about this exciting new development!

Highlights of Recent Research

Thanks to our participants, the St. Jude LIFE Study is continuing to help us learn more about the health of adults treated for cancer during childhood. Below are findings from two recent studies.

Managing chronic symptoms

Participants in the St. Jude LIFE Study complete a detailed health questionnaire as part of their study evaluation. St. Jude researchers recently analyzed the questionnaire responses and health history of 1,667 participants.

The researchers learned that most survivors experience a number of serious symptoms that can affect their quality of life and sense of wellbeing. They stressed that survivors should discuss their chronic symptoms with their doctors to discover ways to successfully manage their health.

The researchers found that:

- ⇒ More than 3 out of 4 individuals reported having more than one serious symptom.
- ⇒ More than half of the participants reported problems with physical pain and problems with personal appearance. These were the most commonly reported symptoms.
- ⇒ Survivors reported many other symptoms, including fatigue, sleep disturbance, problems with emotional health or with thinking and memory, or symptoms of physical illnesses such as heart or lung disease, etc.

What this means for survivors: Because the majority of survivors experience a number of serious symptoms, the study team stressed that health care providers should work with survivors to tailor individual approaches to coping with their specific symptoms. Such approaches might include counseling for pain, depression, and fatigue, physical exercise for fatigue and some physical symptoms, and meditation and relaxation techniques to help cope with chronic pain.

Reference: Huang IC, Brinkman TM, Kenzik K, et al: Association between the prevalence of symptoms and health-related quality of life in adult survivors of childhood cancer: a report from the St. Jude Lifetime Cohort study. *J Clin Oncol* 31:4242-51, 2013.

If you'd like more information about participating in research, please contact us! The St. Jude LIFE Study toll-free number is:

1-800-775-2167

Our email address is: sjlife@stjude.org

The study website is: www.stjude.org/sjlife

Thank you for participating in survivor research!

Adapting to adult life after cancer and treatment

Findings from a study of retinoblastoma may offer hope for many childhood cancer patients. Retinoblastoma is a rare tumor of a part of the eye called the retina. Most cases are diagnosed in very young children. More than 95 percent of children who develop retinoblastoma become long-term survivors, but not much is known about how well they are doing in adulthood.

St. Jude LIFE Study investigators studied the results of health surveys and cognitive (thinking skills) tests completed by 69 adult survivors of retinoblastoma. These survivors are now in their 30s and have survived an average of 33 years since diagnosis.

Results showed that even though they experienced cancer that affected their eyesight at an early age when their brains and senses were still developing, and even though some of them were treated with whole brain radiation, young adult survivors of retinoblastoma are doing well. Overall, these survivors are leading successful adult lives, similar to adults their age in the US population. They are finishing school, living independently, forming relationships, and joining the workforce.

Survivors who were diagnosed at less than one year of age performed better on tests of verbal reasoning and memory than those diagnosed later.

The results of this study suggest that brains, especially those of very young children, may have the ability to adapt their functioning in response to damage resulting from cancer and treatment.

Reference: Brinkman TM, Merchant TE, Zhenghong L, et al: Cognitive function and social attainment in adult survivors of Retinoblastoma: A report from the St. Jude Lifetime Cohort Study. *Cancer*:in press, 2014.

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