

Coordinating Center Report

CCSS Investigator Meeting

May 27, 2022

- Provide a staffing overview
- Discuss the core activities of the CCSS Coordinating Center
- Update regarding the myLTFU participant portal
- Review priorities for the next 5 years

Overview and Staffing

CCSS

Primary role: coordinate the daily activities of the study

3 main teams within the Coordinating Center:

- Project coordination, recruitment, survey administration, biologic specimen and medical record collection, coding
 - Led by Shani Alston, CCSS Project Coordinator
- Phone-based recruitment and data collection, participant tracing
 - Led by Dayton Rinehart, Call Center Coordinator
- Survey creation, database design, data cleaning, myLTFU portal development
 - Led by Chris Vukadinovich, Director of Data and Systems

Serve as the central liaison for all support facilities, committees, working groups, collaborating sites, and external investigators

Coordinate Follow-Up Surveys

- Administer questionnaires to 22,000+ active participants every 2 – 3 years
- Paper, online, and phone survey completion options
- Format, mail, process, code, transcribe, scan
- Reminders (lots of reminders!)
 - Email, text messages, phone calls, mailings

Follow-Up 7 Survey Status

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Participants Invited

Survivors (N = 17,552)

	n	% of Invited	% of Completed
Total Completed	11,745	66.9%	
Completed Online	8,008	45.6%	68.1%
Completed by Mail/Paper	3,028	17.3%	25.8%
Completed by Phone	709	4.0%	6.0%
Non-Responder	5,500	31.3%	
Refused Survey	92	0.5%	
Refused Further Contact	215	1.2%	
Survey Period: 8/19 – 12/21			

External investigator-initiated studies (ancillary studies)

- Project coordination
- Recruitment
- Data collection
- Regulatory requirements

Subsequent neoplasm confirmation

- Obtain pathology reports/records to histologically confirm reported conditions

Biologic specimen collection

- Oragene (saliva) kits
- Blood sample for participants with a subsequent malignant neoplasm
- Somatic tumor tissue for subsequent malignant neoplasms
- Blood sample for participants with a chronic health condition/matched controls

Collection of DNA: Oragene

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- Completed kits go to CCSS Molecular Biology Support Center in Cincinnati
- Front-end \$25 Target gift card

Kits Sent	Overall Survivors (n = 19,199)		Overall Siblings (n = 4,002)	
	<i>N</i>	<i>% of Sent</i>	<i>N</i>	<i>% of Sent</i>
Returned	10,409	54%	1,643	41%
Refused	1,486	7%	325	8%
Pending	5,165	27%	1,408	35%
In Tracing	1,636	9%	581	14%
Deceased	503	3%	45	1%

Core Activities

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Participant tracing

Data checks and quality control for survey data

Maintain participant and researcher websites

Participant communication and education in coordination with the CCSS Education Committee (M. Hudson, Chair)

- Newsletters 3 – 4 times per year
- Study results
- Respond to requests and questions
- Liaison with Participant Advisory Committee

Sample Participant Newsletter

ccss

LTFU

Long-Term Follow-Up Study

Winter 2021

Update

A NOTE FROM US

As 2021 begins with the roll out of an effective vaccine against COVID-19, we can finally see a glimmer of light at the end of the tunnel. The pandemic has impacted our lives, work, relationships, and mental health. As a childhood cancer survivor, you may have been challenged by worries about becoming sick, difficulties in seeing health care providers, and isolation from your usual support systems.

During this stressful period, completing your LTFU survey may not feel like a pressing priority. But your survey response, amidst a global health crisis, is critically important to help us learn how the pandemic is affecting the health and wellbeing of childhood cancer survivors.

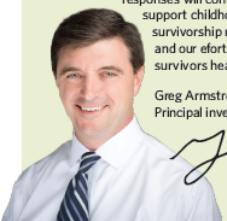
The information you provide will advance clinicians' and researchers' understanding of the pandemic's effect on all aspects of your health, including your physical, emotional, and social wellbeing.

This is a unique opportunity to "give back" to the survivorship community and help others at a time when we have all, at times, felt helpless.

Please complete your survey, if you have not done so. If you didn't receive the survey or need another copy, please contact us at 1-800-775-2167 or ltfu@stjude.org.

For those of you who have already completed it, know that we are grateful. Your responses will continue to support childhood cancer survivorship research and our efforts to keep survivors healthy.

Greg Armstrong, MD
Principal investigator



RESEARCH RESULTS

Pain and survivorship

Nearly one-third of LTFU Study participants reported moderate to severe pain more than 10 years after completing treatment. For many, pain significantly affects their daily life.

Pain is a serious medical concern that can affect relationships, work, and everyday experiences. Many options are available to help manage pain, but often survivors are not aware of them. "We conducted this study because, up until now, we lacked data on pain among survivors," says Cynthia W. Karlson, PhD, University of Mississippi Medical Center, who led the research team.

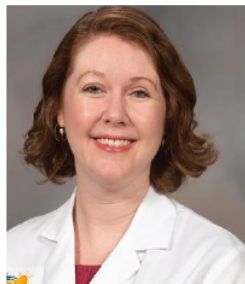
Comparing responses from 10,012 survivors and 3,173 of their siblings from the 2002 and 2007 LTFU Study surveys, researchers found that more than 10 years after treatment:

- 29% of survivors reported moderate to severe pain
- 20% of survivors reported that pain significantly interferes with their daily activities
- The study also identified factors that were associated with pain in daily life, such as:
 - Demographic: Female sex, minority race/ethnicity, older age at diagnosis
 - Cancer-related: Sarcomas/bone tumors, platinum-based chemotherapy, amputation surgery
 - Medical: Chronic conditions
 - Psychological: Depression, anxiety, fatigue

Predictors of pain

"Although some of these predictors, like a survivor's sex or cancer diagnosis, can't be changed, the study highlights lifestyle factors that are very effective for reducing and managing pain," Dr. Karlson says. "We can manage pain by decreasing stress and anxiety, and getting good sleep. When we're more stressed or not sleeping well, our pain is worse."

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"This is the first longitudinal study of pain among childhood cancer survivors. Thanks to the LTFU Study, researchers can keep moving the field forward."

Cynthia Karlson, PhD, is a pediatric psychologist at University of Mississippi and a childhood cancer survivor.

LTFU

Long-Term Follow-Up Study

Winter 2022

Update

LTFU Study siblings

While cancer research usually focuses on the patient, a cancer diagnosis affects the entire family. This is especially true for siblings.

Having a sibling treated for cancer during childhood is stressful. Family and school routines can change when parents must focus time and attention on the child with cancer. Parents' ability to work may also be affected, resulting in further hardships for some families. This upheaval may cause a range of emotions in siblings, such as worry, sadness, guilt, and even anger.

But how are siblings doing many years after this experience? Do these feelings persist? And how do they affect siblings' health? We asked LTFU Study siblings to share their experiences.

The siblings

Jack. Jack was in the fourth grade when his sister was diagnosed with cancer in 1975. His parents traveled from northeastern Massachusetts to Boston for his sister's treatment. "I remember getting bounced around a lot when my parents were at the hospital, going to neighbors or relatives," he says. "It was difficult at times. Childhood cancer is a completely different ballgame now—my sister is one of the first ones who lived."

Dennis. Dennis' brother was diagnosed with cancer in 1985 at four years old; Dennis was five and the fifth of seven siblings.



Dennis, front center, as a child with his family

They lived in Wyoming, which lacked a pediatric cancer treatment center, so his mom took his brother to Denver for treatment. "She would spend months there; sometimes we went, other times our grandmother came out to support us," Dennis says. "Then when my brother was five, he had a stroke that left him with severe permanent disabilities. He and I were really close, so in a way, I lost my best friend."

Kelly. Kelly's sister had cancer in 1977 when Kelly was three and her sister five, and she had a relapse in 1984. Kelly remembers her friend's mother telling her that her sister was in the hospital. "Those moments you never forget—coming off the bus happy, laughing with my best friend, happy to see my friend's mom, and then the crushing feeling. I remember the exact spot in the yard where I was told."

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A NOTE FROM US

Your health information is influencing childhood cancer survivorship care around the world! The LTFU Study's annual investigator Meeting was held virtually in June 2021 because of COVID-19. While I missed seeing colleagues in person, it provided the opportunity for 600 researchers from 167 hospitals in 35 countries to attend and learn about the latest advances in survivorship care after childhood cancer.

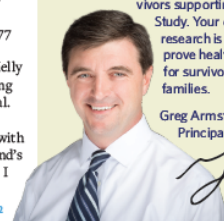
These advances are based on data you have provided. Thank you for completing the most recent survey during the last two years.

Beginning in 2022, you will receive the next LTFU Study survey. It will be a little shorter than the previous survey and, for the first time, will ask about your experiences accessing health care, the quality of the care you receive, and the impact of the cost of your care. Look for your survey soon!

This issue of the LTFU Update focuses on siblings of childhood cancer survivors. Siblings in the study share their experiences, reminding us that childhood cancer can have lasting effects on the whole family. You'll also learn about LTFU research on sibling health and find resources that support families that are affected by childhood cancer.

Thank you to all of the siblings and survivors supporting the LTFU Study. Your dedication to research is helping improve health outcomes for survivors and their families.

Greg Armstrong, MD
Principal investigator



Childhood Cancer
Survivor Study

An NCI-funded
resource

Goals:

- Implement a flexible, mobile participant portal that can remotely collect self-report and sensor-based data
- Scalable and adaptable system architecture to reliably curate large quantities of data
- Automate study processes
- Dynamic coordinator interface/dashboard for the study team
- Foster participant engagement and communication
- Establish a pool of participants available for mHealth and intervention studies

Utilize the DatStat Connect platform to create a mobile-friendly web portal accessible by smartphone, tablet, or PC

- Participants can bookmark site and save shortcut/icon to mobile device
- Administer online consents, forms, and surveys
- Upload files to the study team
- Schedule messaging (emails and texts) and data collection activities
- Provide participant resources
 - Recommended websites; newsletters; brief study results/updates; live survey results
- Coordinator portal

myLTFU Sample Screenshots

CCSS

10:50 sj-ltfu.datstat.com

myLTFU

Email Address *

Password *

☐ Login on this browser using a PIN from now on

Login

[Forgot Password](#)

Disclaimer/Privacy Notice: The myLTFU Portal is designed for educational purposes only and is not engaged in rendering medical advice or professional services. The information provided through this site should not be used for diagnosing or treating a health problem or a disease. is not a substitute for professional care. If you have or suspect you may have a health

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Follow-Up Survey

Not Started

COVID-19 Resources

The COVID-19 pandemic has presented new challenges and worries for all of us. Although we do not yet know how cancer survivors may be affected by this virus in comparison with the general population, please know that we are working to provide you with up-to-date resources to help you stay informed. To this end, we have created the [COVID-19 Resources](#) tab.

Communication


The myLTFU system will send emails and texts

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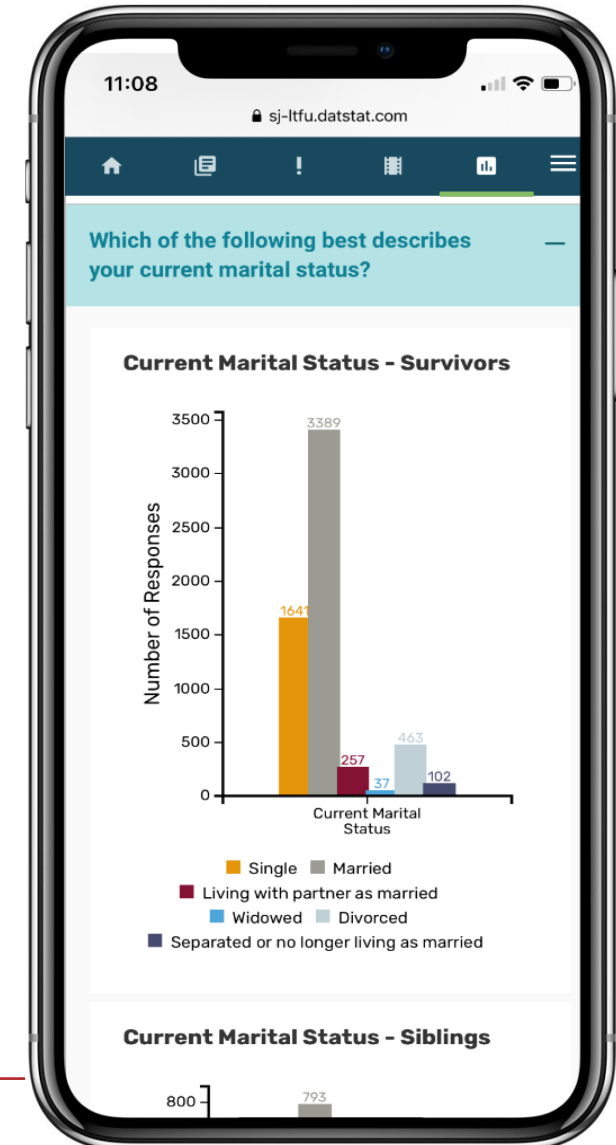
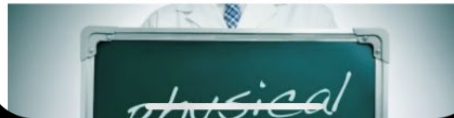
Important News

Important News from the Long-Term Follow-Up Study

The Long-Term Follow-Up Study has published more than 300 [publications](#) in scientific journals since it was launched in 1994. Some of these articles, on a wide range of topics, are summarized here.



[Regular screenings can help protect your heart](#)
Regular heart screenings can catch early signs of disease or damage for childhood cancer survivors.



myLTFU Participant Portal

CCSS

Invited participants to the portal with the Follow-Up 7 survey

Over 13,400 participants have activated their account

Used myLTFU to rapidly collect data regarding experiences during COVID-19

Four randomized, controlled intervention trials now funded that utilize myLTFU as the primary mode for interaction with participants

Priorities – Next 5 Years

CCSS

- Administer two follow-up surveys to the cohort
- Conduct an in-home assessment of 1000 participants to examine frailty/aging
- Administer online cognitive assessment to the cohort
- Conduct National Death Index search
- Continue subsequent neoplasm adjudication
- Continue collecting blood and tumor tissue specimens
- Coordinate recruitment and data collection for ancillary studies
- Continue participant engagement efforts while minimizing burden