

# Coordinating Center Report

## CCSS Investigator Meeting

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June 18, 2025

**CCSS**

Childhood Cancer  
Survivor Study



St. Jude Children's  
Research Hospital

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An NCI-funded Resource

# Outline

CCSS

- Provide a staffing overview
- Discuss the core activities of the CCSS Coordinating Center
- Review priorities for the next 5 years

# Overview and Staffing

CCSS

**Primary role:** coordinate the daily activities of the study

Three 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 and Nita Anderson, Lead CRA
- Phone-based recruitment and data collection, participant tracing
  - Led by Dustin Smith, Call Center Coordinator
- Survey creation, database design, data cleaning, myLTFU portal development
  - Led by Chris Vukadinovich, Director of Data and Systems

# Core Activities

CCSS

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
- Online, phone survey completion options
  - Future of paper TBD
- Format, mail, process, code, transcribe, scan
- Reminders (lots of reminders!)
  - Email, text messages, phone calls, mailings

# Follow-Up 8 Survey Status

CCSS

Survivors		
<i>Survivors</i>		
Invited	18,294	
Survey Completed	11,614	63.5%
	Paper (Total)	2,327
	Full survey	1,452
	Short survey	965
	Online (Total)	8,530
	Full survey	7,771
	Short survey	819
	2 <sup>nd</sup> Short survey (1,276 invited)	331
	Interviewer (Total)	667
	Full survey	378
	Short survey	289
myLTFU Activated, FU8 non-responder	2,237	12.2%
myLTFU Not Activated, FU8 non-responder	2,396	13.1%
Refused FU8	74	0.4%
Refused FU8 and CCSS	260	1.4%
Deceased	358	2.0%
Unavailable/No Proxy	32	0.2%

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# Core Activities

CCSS

- 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

# Core Activities

CCSS

- Participant tracing
- Coding questionnaires and SN
- Data checks and quality control for survey data
- Maintain participant ([LTFU.stjude.org](http://LTFU.stjude.org)) and researcher ([ccss.stjude.org](http://ccss.stjude.org)) websites
- Participant communication and education in coordination with the CCSS Education Committee (Kayla Foster, 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

## Update Winter/Spring 2025

### Discover ways to manage chronic pain

In this issue of LTFU Update, we focus on effective ways to manage pain. We hope you find that the tips, inspiring stories, and expert insights in this issue provide useful information on ways to treat chronic pain. Thank you for your participation in the LTFU Study. Our studies help us learn more about how to improve outcomes for childhood cancer patients and survivors in the United States and around the world.

Read more from Dr. Armstrong



Greg Armstrong, MD  
Principal Investigator

### Ways to manage chronic pain

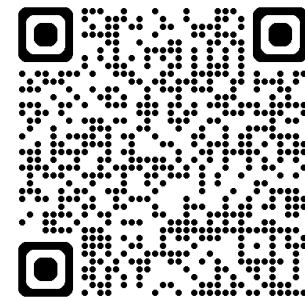
A Long-Term Follow-Up (LTFU) Study research study led by Nicole Alberts, PhD, of Concordia University in Montreal, Quebec, is the first to examine how many childhood cancer survivors deal with chronic pain.



Read about the study's findings

### Survivor shares how she deals with chronic pain

### CCSS Newsletters



<https://lifu.stjude.org/resources/newsletters.html>

# Priorities – Next 5 Years

CCSS

- Administer two follow-up surveys to the cohort
- Continue in-home assessment of 1000 participants to examine frailty/aging
- Administer repeat 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

# CCSS Coordinating Center Team

ccss

## **Shani Alston**

Lakisa Ards  
Arina Jackson  
Avnisha Patel  
Ramona Vejandla  
Nicole Wilson



## **Koko Kochar**

Ollie Battle  
Tolly Gillenwaters



## **Dustin Smith**

Erin Arnott  
Theresa Bailey  
Yaniz Booth  
Oakleigh Burkett  
Elizabeth Johnson  
Patricia Key  
Michael LaVoice  
Trinity LaVoice  
Kisten Lenoir  
Ashley Nelson  
Tishana Sharp  
Angela Sherrill  
Eman Sweileh  
Sharon Walker  
Porsceh Wright



## **Chris Vukadinovich**

Christie Cooper  
Ricardo Duran



## **Nita Anderson**

Shelia Crutcher  
Alexandria Hudson  
Carol Lee  
Victoria Lacey  
Suyena Poudel  
Weston Touliatos  
Stacey Wallace  
Lauren Williams



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