
CCSS

Coordinating Center

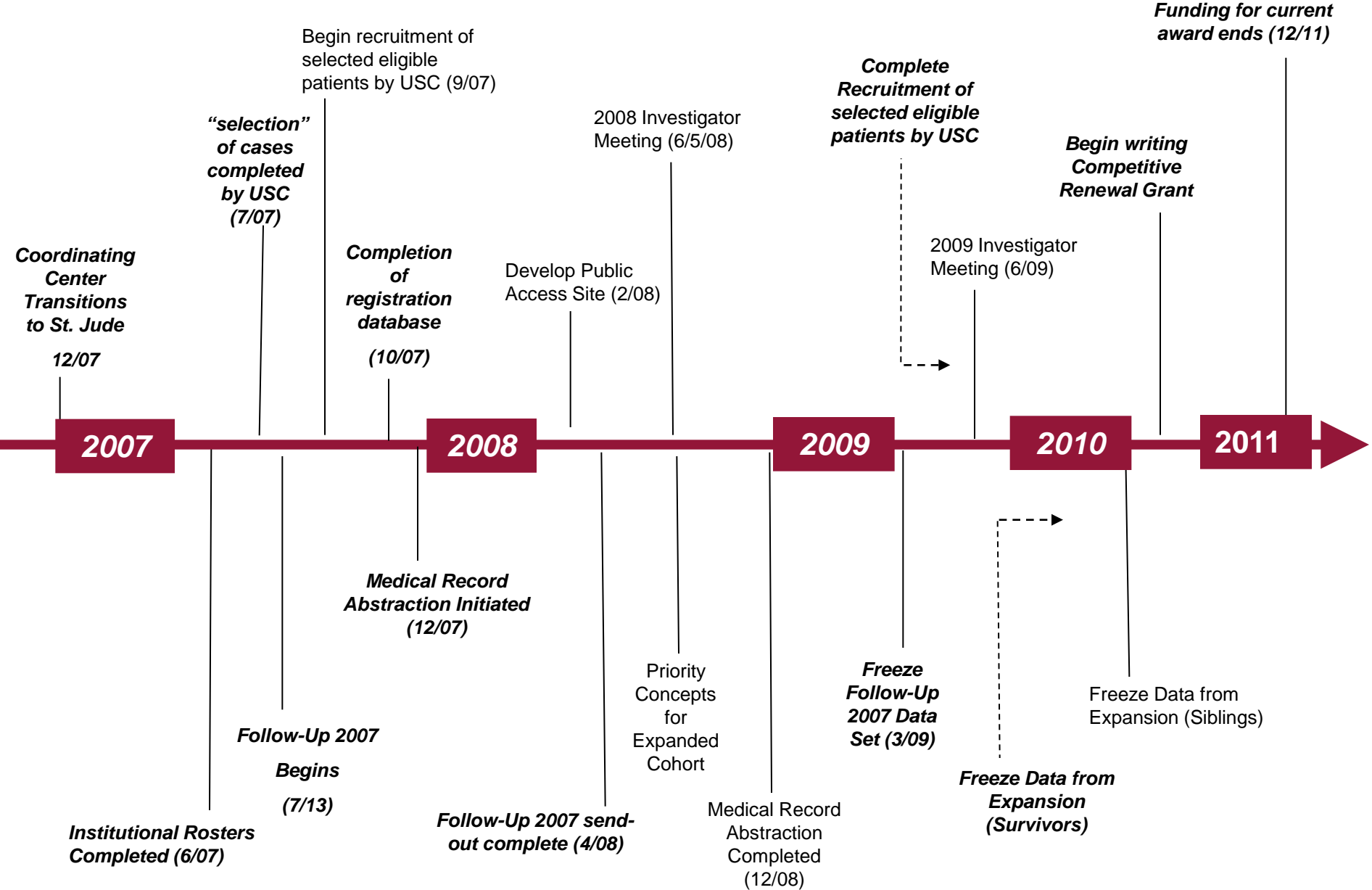
2008

Greg Armstrong MD, MSCE
Project Director

CCSS

CHILDHOOD CANCER SURVIVOR STUDY

Coordinating Center Timeline



Coordinating Center Activities

- **Data Collection**

- **Follow-Up 2007 (13,400)**
- **Cohort Expansion (20,729+)**
- **Men's Health Questionnaire (5,282)**
- **Oragene collection (37,000+)**
- **SMN: blood and tissue**
- **Telephone Interviews**

- **Other Activities**

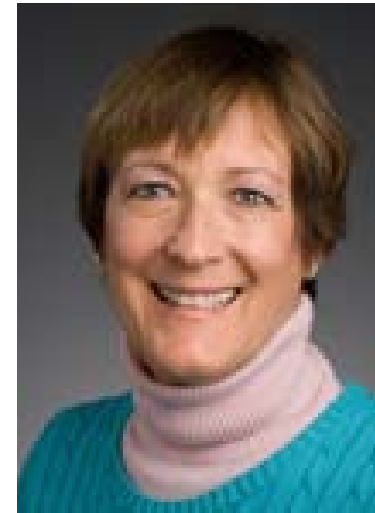
- **Spring Newsletter (13,400)**
- **Thank You Notes (13,400)**
- **Website "Rehabilitation"**
- **Support Ancillary Studies**
- **Concept Development**

Project Coordination



Jenny Lanctot, Ph.D.

Educational Research and Psychology



Becky Pack, Ph.D.

Epidemiology

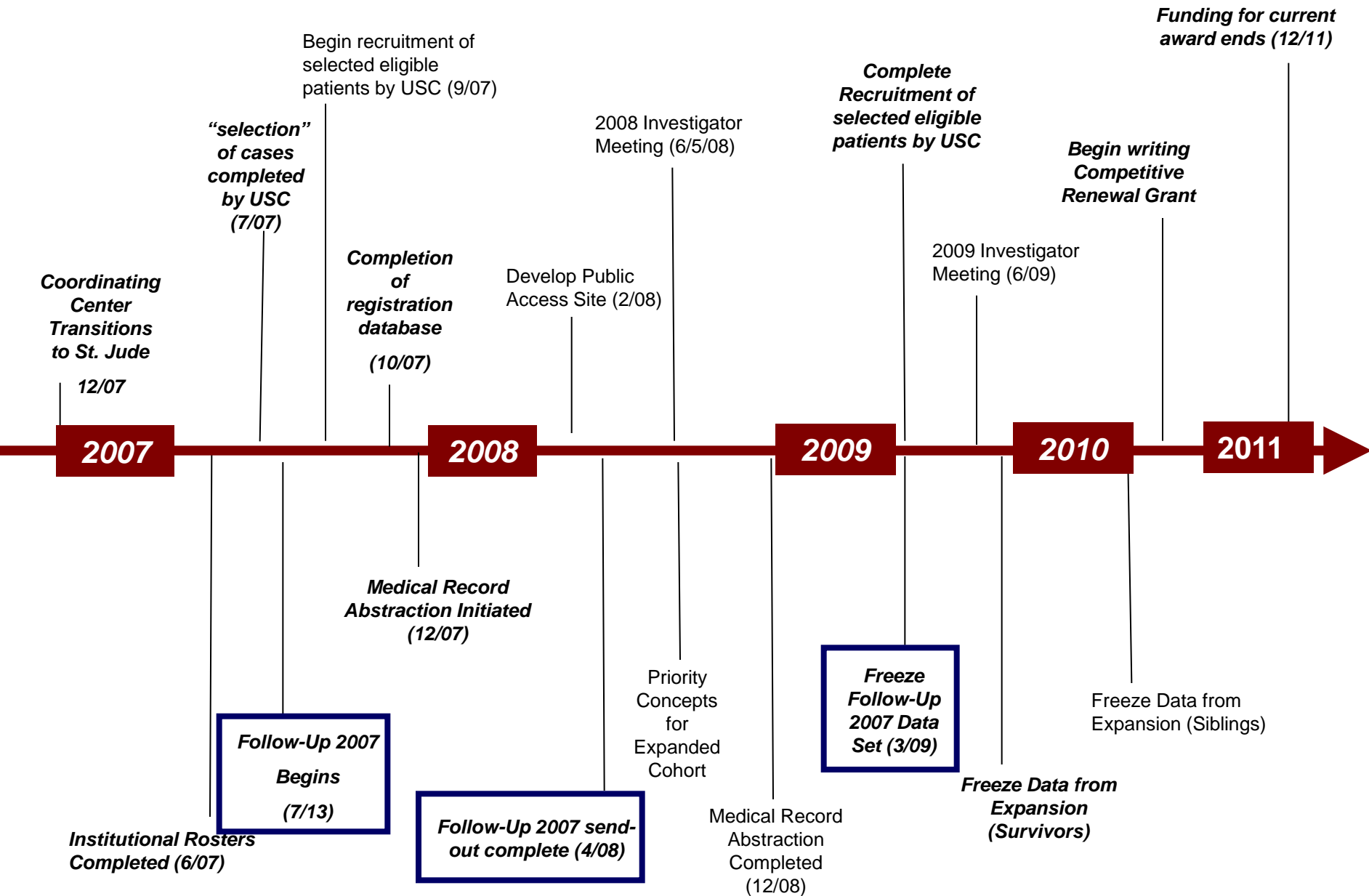
CCSS Project Coordinator

- 2 Lead Clinical Research Associates
- 2 Clinical Research Associates
- 3 Clinical Research Assistants

Phone Survey & Biology Coordinator

- 2 Clinical Research Associates
- 14 Survey Interviewers

Follow-up 2007 Survey



Follow-up 2007

- Goal: Comprehensive update of baseline data
- Survey
 - 28 pages
 - 10,254 eligible participants, 3,165 siblings
 - Update: demographics, medical care, chronic medical conditions, health habits, SMNs, pregnancy/offspring, additional chemo/RT
- Timeline
 - Began: July 2007
 - Send out complete: April 2008
 - Complete data collection/Freeze data: March 2009

	Female		Female		Male			
Send date	7/07-10/07		11/08-2/08		2/08-4/08		Total	
Number Sent	2747		2500		4454		9701	
	n	(%)	n	(%)	n	(%)	n	(%)
Total number completed	1972	(72)	1423	(57)	1202	(27)	4597	(47)
Number returned by mail	1758	(64)	1220	(49)	960	(22)	3938	(41)
Number completed by interviewers	246	(9)	203	(8)	151	(3)	600	(6)
Pending Response	749	(27)	690	(27)	1286	(29)	2725	(28)
Active refusals	46	(1.7)	47	(1.9)	25	(0.6)	118	(1.2)
Not yet in call rotation	0	0	0	0	1754	(40)	1754	(18)
In tracing	114	(4.2)	329	(13)	274	(6.2)	717	(7.4)
Deceased	21	(0.8)	21	(0.8)	20	(0.5)	62	(0.6)

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Survey Response Rate

- Potential barriers:
 - Cohort Fatigue
 - Screening calls
 - ↑ cell phone, ↓ land line usage
 - Change in interviewer core team
- Interventions
 - Interviewer QA: call monitoring, mentoring
 - Recontact plan: Fed Ex (300) vs. Bulk mail (300)

Follow-up 2007: Next Steps

- Contact info update (Experian batch)
- Females: re-send by bulk mail
- Males: complete phone follow, re-send by bulk mail
- All re-sends to include web-based option

THANK YOU



Thank you for completing the recent Long-Term Follow-Up Study questionnaire. We know that your time is valuable, and we appreciate your willingness to share your experiences and opinions. We are grateful for the role you have played in helping us to continue our work in learning more about the health of individuals like yourself.

Sincerely,

A handwritten signature in black ink, which appears to read "H. C. Roberts". The signature is written in a cursive style with a horizontal line at the end.

Men's Health Questionnaire

10/12/2007 04:14:27 PM

LTFU

Long-Term Follow-Up Study

Men's Health Questionnaire

*St. Jude Children's Research Hospital
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
Children's Hospital of Columbus
Children's Hospital of Orange County
Children's Hospital of Philadelphia
Children's Hospital of Los Angeles
Children's Hospital of Pittsburgh
Children's Hospitals & Clinics of Minnesota,
Minneapolis and St. Paul
Children's Medical Center of Dallas
Children's National Medical Center
City of Hope National Medical Center
Dana-Farber Cancer Institute
Loma Linda University
Mattel Children's Hospital at UCLA
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
Miller Children's Hospital
Riley Hospital for Children - Indiana University
Roswell Park Cancer Institute
Seattle Children's Hospital & Medical Center
St. Louis Children's Hospital
Texas Children's Hospital
The Denver Children's Hospital
Toronto Hospital for Sick Children
UAB/The Children's Hospital of Alabama
University of California at San Francisco
University of Michigan - Mott Children's Hospital
University of Minnesota
U.T.M.D. Anderson Cancer Center*

**Our mailing address is:
Long-Term Follow-Up Study
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
332 N. Lauderdale St.
Memphis, TN 38105-2794**

**Toll-free phone number:
1-800-775-2167**

e-mail: LTFU@stjude.org

The LTFU Men's Health Study
is funded by

LIVESTRONG
LANCIE ARMSTRONG FOUNDATION

Puberty, sexual development, infertility, and quality of life are important areas to study and understand in young adult survivors of pediatric cancer and other childhood illnesses. In a survey we sent you previously, you indicated your interest in participating in a study with this subject matter. Questions like these have already been asked of the female cancer survivors in the LTFU cohort. Important findings came from the female health questionnaire - for example the risk of premature menopause in female survivors of pediatric cancer and other childhood illnesses. This finding has been used to change clinical practice and counseling to female survivors of pediatric cancer and other childhood illnesses.

So, now it is your turn to teach us more about the health of male survivors of pediatric cancer and other childhood illnesses. Participation in this aspect of the study involves answering a series of questions that will take approximately 30 minutes to complete. You may feel these questions are very personal. Please be reassured your responses will remain confidential. We appreciate your willingness to answer this questionnaire.

Sincerely,

The LTFU study staff

Today's date: / / 2 0 0

CCSS

CHILDHOOD CANCER SURVIVOR STUDY

Men's Health Questionnaire

- Goal: Puberty, sexual development, infertility and QOL in male survivors
- Survey:
 - 16 pages (appendix)
 - 5,282 participants
- Timeline:
 - Begin Feb. 2008
 - Rolling send out (926 sent to date)
 - Web-based version available

DNA Collection

Purpose : To make available, genomic DNA for evaluation of genetic susceptibility and gene-therapy exposure interactions

- Saliva collection using Oragene DNA Kits





Collection Process

Mailing and Follow-Up Plan:

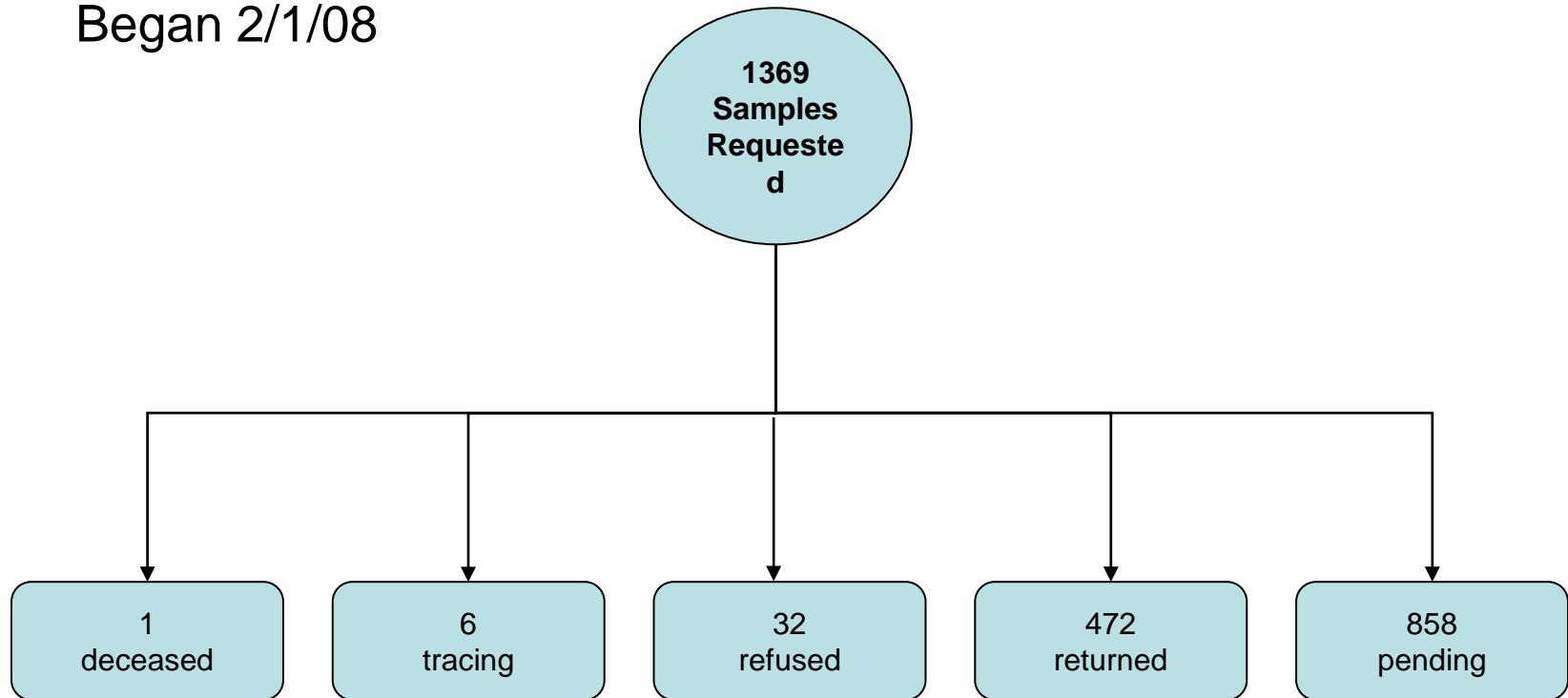
- Letter introducing collection, instruction sheet, Oragene kit, informed consents, pre-paid return mailer

- 400 kits/month

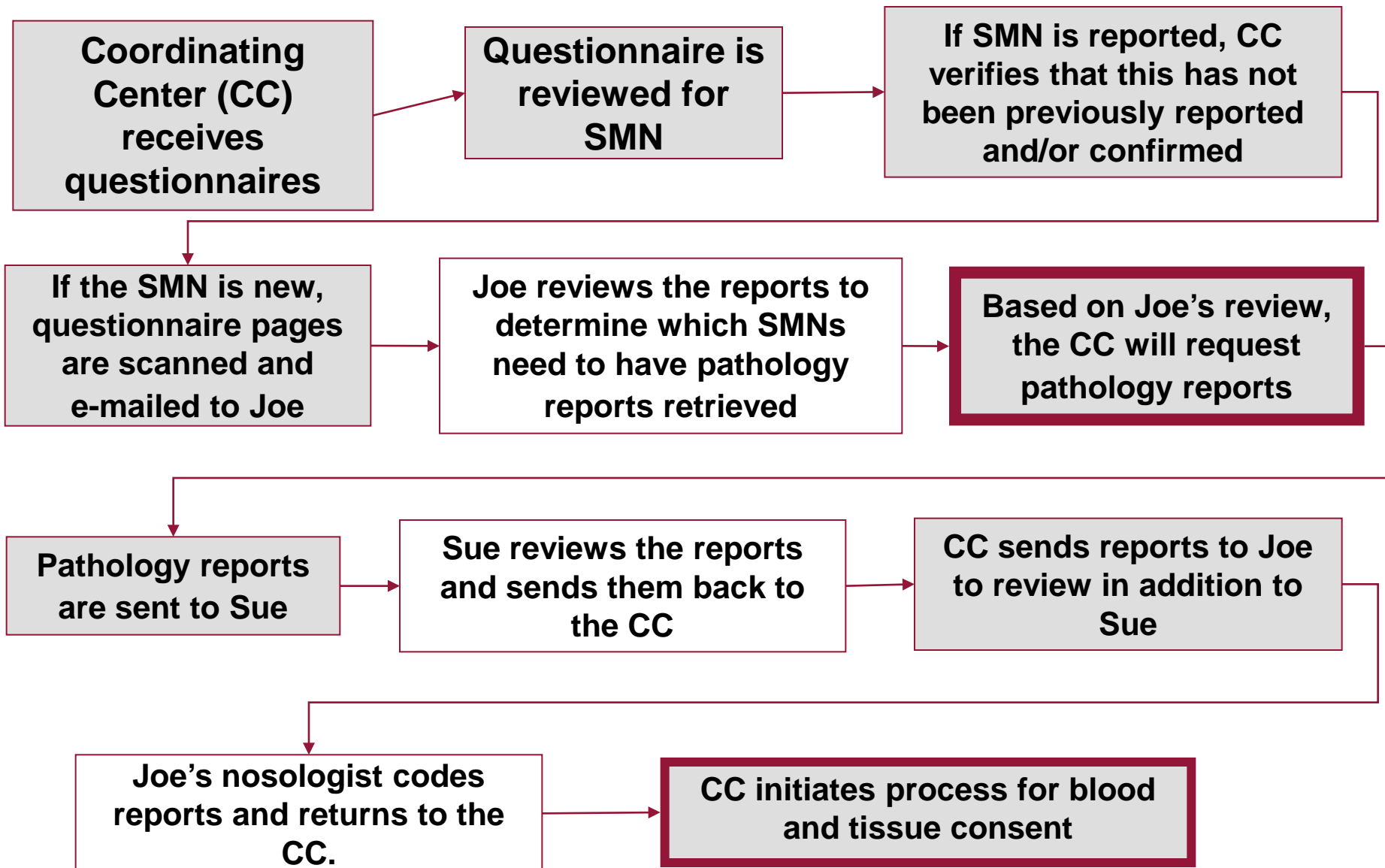
- Telephone call follow-up for non-responders

DNA Collection 2

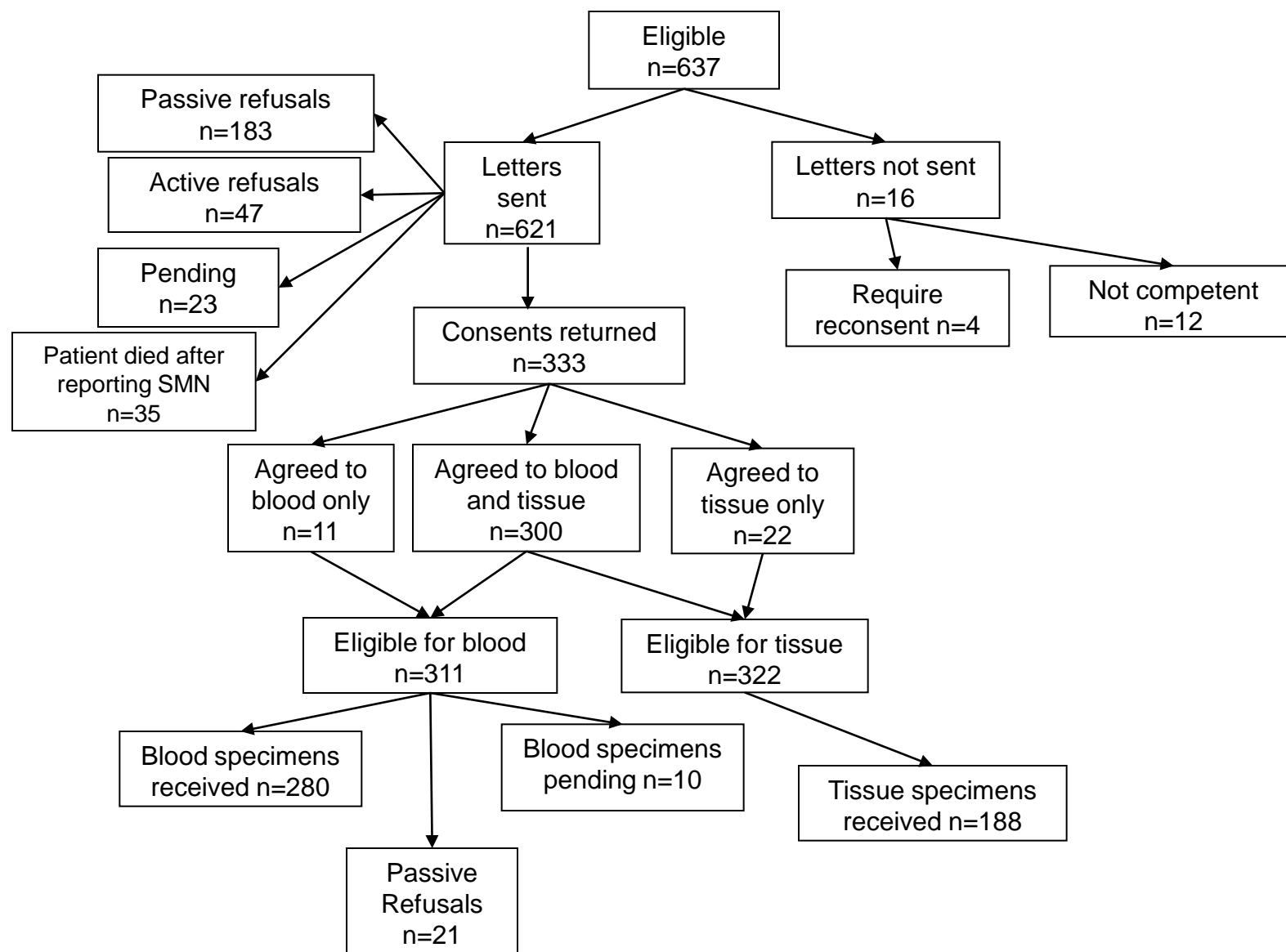
Ongoing send out:
Began 2/1/08



Second Malignant Neoplasms



Second Malignancies: Blood & Tissue



<http://www.stjude.org/ccss>



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Childhood Cancer Survivor Study

[Home](#) > [Clinical Science Home](#) > [Epidemiology & Cancer Control](#) > [Childhood Cancer Survivor Study](#)

Long-Term Follow-Up and Childhood Cancer Survivor Study

Participants, please visit our [Long-Term Follow-Up section](#).

Researchers, please visit our [Childhood Cancer Survivor Study section](#).

Investigators, please visit our [CCSS Investigator section](#) (password required).

[Click here for 2007 CCSS Investigators Meeting information.](#)

Related Topics

- [Cancer Survivorship](#)
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CHILDHOOD CANCER SURVIVOR STUDY

Epidemiology & Cancer Control

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- ▶ [Featured Research](#)
- ▶ [Childhood Cancer Survivor Study](#)

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CCSS Investigators' Page

You have reached the main investigators' page for the Childhood Cancer Survivor Study (CCSS).

[Click here for 2007 CCSS Investigators Meeting information.](#)

The links below provide access to a variety of study-related resources as well as Study Status Reports and Working Group minutes from the October, 2005, investigator meeting held in Memphis.

The files marked (PDF) require [Adobe Acrobat Reader](#) software.

Study Centers Status Reports

- [PI report](#) (PDF)
- [Coordinating Center](#) (PDF)
- [Molecular Genetics Bank](#) (PDF)
- [Bio-Pathology Center](#) (PDF)
- [Business Associate](#) (PDF)

Working Group Minutes

- [Genetics](#) (PDF)
- [Chronic Disease](#) (PDF)
- [Chemotherapy / Radiation / Surgery](#) (PDF)
- [Second Malignancy](#) (PDF)
- [Epidemiology / Biostatistics](#) (PDF)

[Cancer Control / Interventions](#) (PDF)

[Fertility / Reproduction](#) (PDF)

[Neurology / Psychosocial](#) (PDF)

General information about the CCSS and information prepared for members of the study cohort (including newsletters) can be found at www.stjude.org/ltfu.

Supplemental information for study publications can be found at www.stjude.org/ccss.

Related Topics

- [Data Analysis Concept Proposals](#)
- [Tumor tissue samples](#)
- [Published Research](#)
- [CCSS Ancillary Study Proposals](#)
- [Investigator Tools](#)
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Childhood Cancer Survivor Study



*An NCI-funded resource
for the study of long-term survivors
of childhood cancer*

CCSS Essentials

- [About the Study](#)
- [Investigator Meetings](#)
- [Participating Institutions](#)
- [Common Questions](#)
- [Publications](#)
- [Abstracts](#)
- [Information for Researcher](#)
- [Concept Proposal Information](#)
- [Supplemental Information for CCSS Publications](#)
- [Appendix for Publication](#)
- [Study Surveys](#)

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Childhood Cancer Survivor Study

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[Concept Proposal
Information](#)

[Supplemental
Information for
CCSS Publications](#)

[Appendix for
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[Study Surveys](#)

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The Childhood Cancer Survivor Study (CCSS) was created to take advantage of 1) the opportunity to gain new knowledge about the long-term effects of cancer and therapy, knowledge that can be used to help design treatment protocols and intervention strategies that will increase survival and minimize harmful health effects, and 2) the obligation to educate survivors about the potential impacts of cancer diagnosis and treatment on their health, and to provide follow-up care, for example, by creating and implementing programs for the prevention and early detection of late effects.

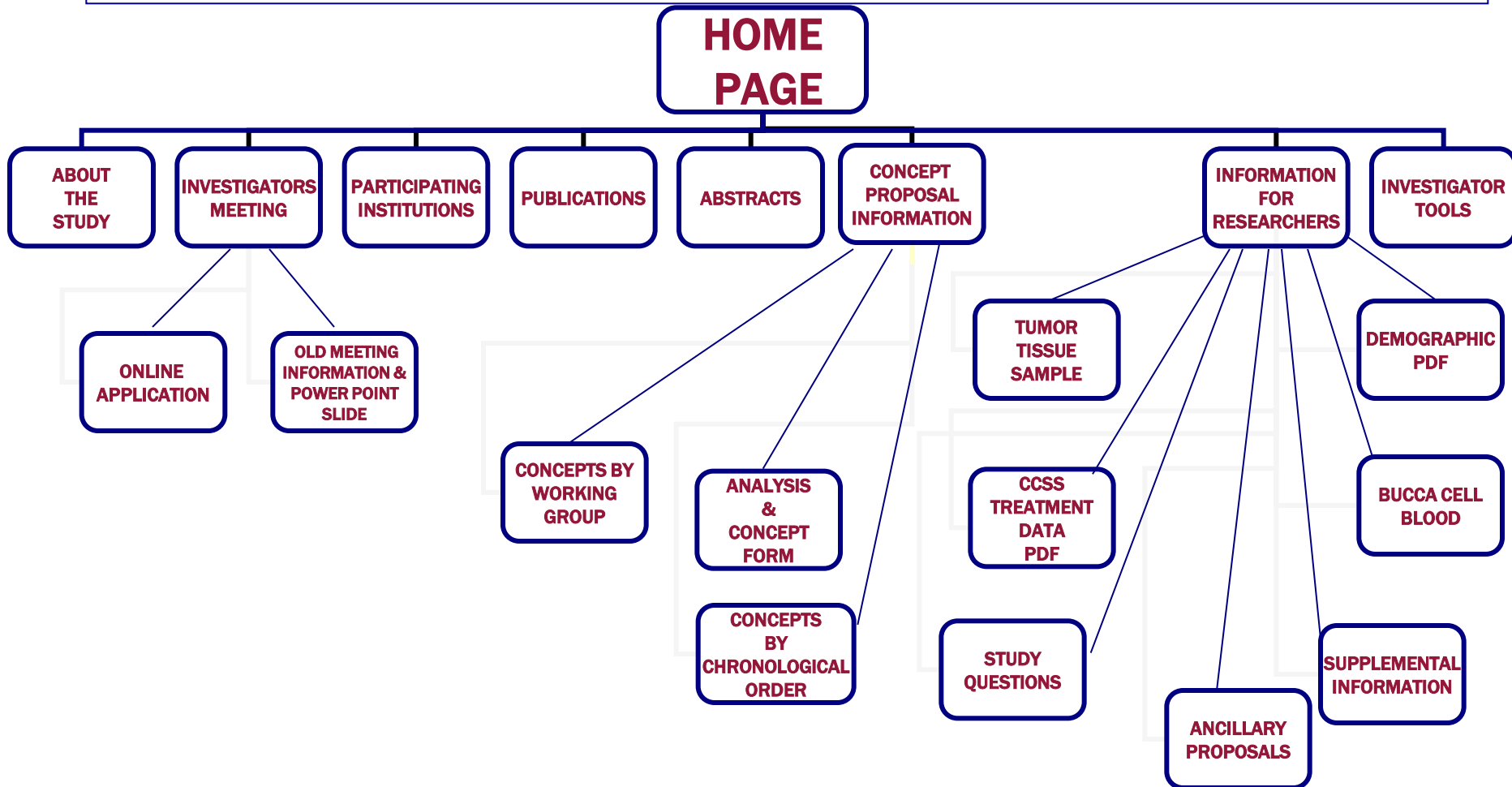
The CCSS is a component of the Long-Term Follow-Up Study. A collaborative, multi-institutional study funded by the National Cancer Institute, the CCSS is composed of individuals who survived five or more years after treatment for cancer, leukemia, tumor, or similar illness diagnosed during childhood or adolescence.

The CCSS, which includes all participants in the Long-Term Follow-Up Study with a confirmed diagnosis of cancer, is a retrospectively ascertained cohort of 20,346 childhood cancer survivors diagnosed between 1970 and 1986. It also includes approximately 4,000 siblings of survivors who serve as the comparison group for the study.

The CCSS cohort has been assembled through the efforts of 27 participating centers in the United States and Canada. It is coordinated through St. Jude Children's Research Hospital in Memphis, Tennessee. Other core facilities include the Statistical Center, located at the Fred Hutchinson Cancer Research Center (Seattle); the Biopathology Center (Columbus); and the Radiation Physics Center at MD Anderson Cancer Center (Houston). Initiated in 1993, the study is funded by a grant from the National Cancer Institute.

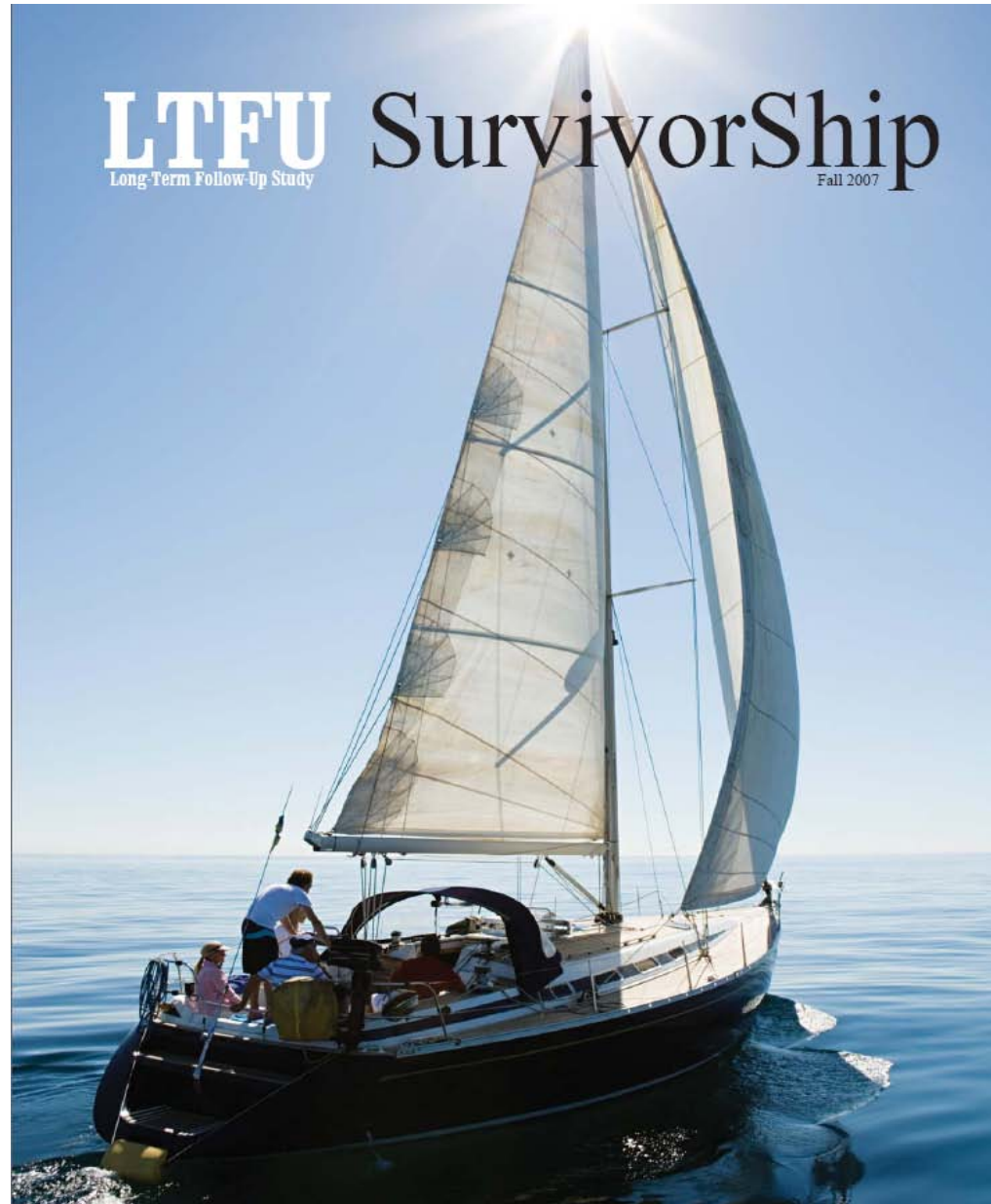
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LTFU
Long-Term Follow-Up Study

SurvivorShip
Fall 2007



CCSS

CHILDHOOD CANCER SURVIVOR STUDY

