



Childhood Cancer Survivor Study

Data and Statistical Center Update

Wendy Leisenring, Sc.D.

CCSS Investigator Meeting

June 10-11, 2015

Arlington, VA



FRED HUTCH
CURES START HERE™

Statistical Center sites

Primary:

-  **FRED HUTCH**
CURES START HERE™

Wendy Leisenring
Seattle ~4 FTE



Satellites:

-  **UNIVERSITY OF ALBERTA**
EDMONTON · ALBERTA · CANADA

Yutaka Yasui
Edmonton ~1.5 FTE



- 
**St. Jude Children's
Research Hospital**
ALSAC · Danny Thomas, Founder
Finding cures. Saving children.

Kumar Srivastava
Memphis ~3 FTE



Key Activities

- Statistical Analyses and Methodology
- Database Management
- Proposal Development
- Weekly Conference Call - all Statisticians, Coordinating Center and Radiation Dosimetry Center
- Regularly scheduled calls for ongoing projects

Expansion Data Cleaning

- Baseline Questionnaire frozen
- Medical Record Abstraction Forms (MRAF) frozen
- Incorporation of RT data from MD Anderson
- NDI Mortality data frozen
- SMN data frozen
- Grading chronic conditions well underway

Original Cohort SMN Data

- SMN data reviewed and frozen
- Conversion of SMNs from ICD-02 to ICD-03

UNOS Linkage

- Matched to ascertain solid organ transplants (original cohort + siblings)

Expansion Recruitment Gain

- Adds 10,004 participants with **Questionnaire data** available for analysis
- Of these, 9,747 have **Treatment data** abstracted from the medical records.

CCSS Expanded Cohort

- CCSS Expanded Cohort =
Original + Expansion recruitments
- Total of 24,368 participants
→ 22,703 with treatment data
- Good progress on high priority analyses in the
Expanded Cohort

Productive Analyses

Current Grant period (2012+)*:

Published Manuscripts: 75

Submitted Manuscripts: 8

Manuscripts in Preparation: 22

Analyses Ongoing/Data sent: 44

Approved, waiting for specific
data: 4

Approved Projects in Queue for
analyst: 5

Proposals under Development: 5+

*Projects with a CCSS Statistician involved.

Selected Recent Key Publications

Topic	Author, Journal
Long term outcomes among standard risk ALL patients	Essig et al, <i>Lancet Oncology</i>
Increasing cardiomyopathy screening in adult survivors: randomized study	Hudson et al, <i>JCO</i>
Individual prediction of heart failure in survivors	Chow et al, <i>JCO</i>
Factors associated with recruiting adult survivors	Mertens et al, <i>Ped Bld Ca</i>
Aging and risk of severe, disabling, life-threatening, and fatal events	Armstrong et al, <i>JCO</i>
Risk of SNs in fourth and fifth decade of life	Turcotte et al, <i>JCO</i>
Survivors in U.S.: Prevalence and burden of morbidity	Phillips et al, <i>CEBP</i>
Estimating the burden of recurrent events in the presence of competing risks: Mean Count Method	Dong et al, <i>Am J Epid</i>
Age-dependent changes in health status in survivors	Hudson et al, <i>JCO</i>

Proposals, Ancillary studies

- Assist with development of analysis proposals
- Collaborate on ancillary study grant proposals
 - To date have been involved in ~15
- Please include us early in process

Priorities emphasized in grant include:

- Aging among survivors
 - Utilize longitudinal data
- Characterize how temporal changes in treatment within the cohort impact risks of adverse health outcomes (not compare original vs. expansion)
- Genetic Studies
 - GWAS data

Priorities

- **Analyses:** Maintain productivity on analytic projects
- **Proposal Development:** Continue developing innovative plans for analyses
- **Competitive Renewal:** Planning and designing the future of CCSS
- **Cleaning Data:** Expansion sibling data and FU5 survey data coming need cleaning and freezing soon