



# **CCSS**

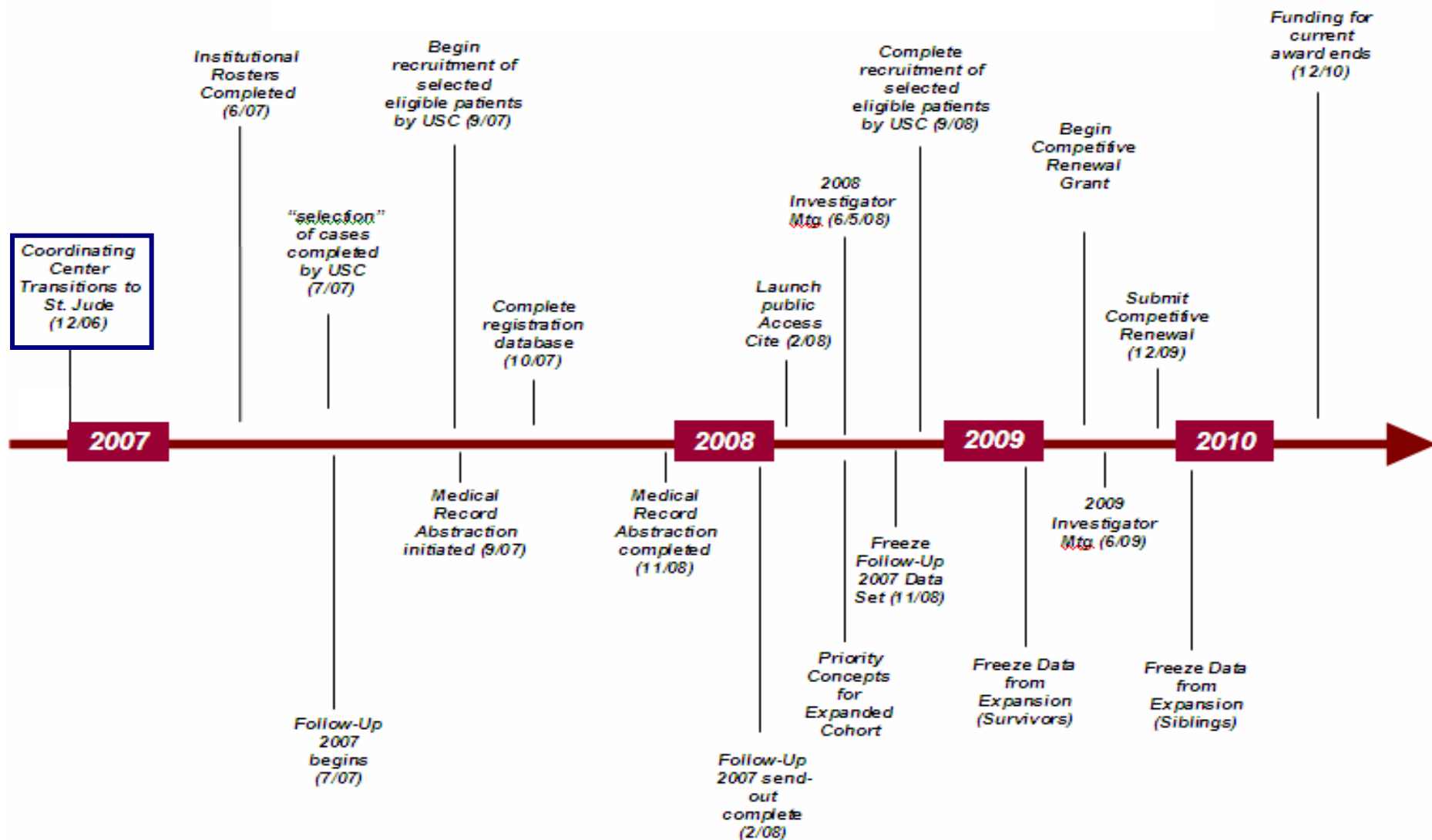
# **Coordinating Center**

## **2007**

# Purpose

- To **promote** and **facilitate** research among long-term survivors of cancer diagnosed during childhood and adolescence.
- To **provide** CCSS investigators access to expertise in **survey methodology**, subject **recruitment** and **retention**, **tracing** of study subjects, survey **instrument development**, **interviewing**, **data entry** and **storage**, **retrieval** of medical record information, and **data abstraction/coding**.

# Working Timeline



# CCSS Staff



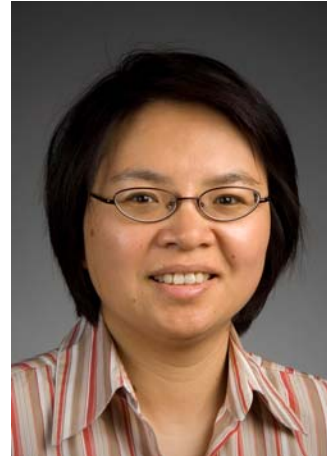
**Greg Armstrong, M.D.**  
**Project Director**



**Chris Vukadinovich, MS, CCRP**  
**Director of Databases and Systems**



**Jenny Lancot, Ph.D.**  
**Project Coordinator**



**June Ni, Ph.D.**  
**Clinical Research Scientist**  
**Coordinator of Database Management**



**Pam Young, BS, CIP**  
**IRB Coordinator**

**CCSS**

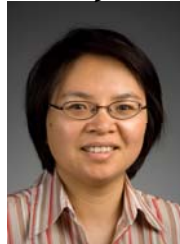
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**Christie Cooper, MPH**  
**Lead CRA**



**Zongying Xi**  
**Database Analyst**



**Judy O'Connell, RN, MSN**  
**Lead CRA**



**Bridgette Gipson**  
**CRA**



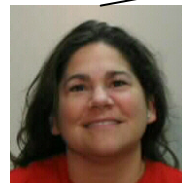
**Kristen Molina, MSc**  
**Lead CRA**



**Gena Garner**  
**CRA/Nosologist**



**Margaret Carbaugh**  
**Health Communications Specialist**



**Deanna Combs**  
**Interviewer**



**Stephen Dlouhy**  
**Interviewer**



**Shavon Dale**  
**Interviewer**

# Facilities



# Hardware & Software

- Verity TeleForm (v9.1) server
- TeleForm workstations with high-speed scanners
  - Questionnaire design, printing, and production
  - Scanning, reading and verification
- **DatStat IIume (v4.5)**
  - Web-based data entry capture and reporting
- Captaris Alchemy Gold dual-monitor workstation
  - Electronic document management system
- Konica Minolta c450 copier/printer
  - High-speed network color printing, booklet production, and scanning

# Data Entry

- 1) Paper (Teleform)
- 2) Telephone interview
- 3) **Web-based entry** (DatStat Illume)
  - Medical record abstraction
  - Survey completion
    - Follow-up 2007 roll-out: September 2007
    - Cohort expansion



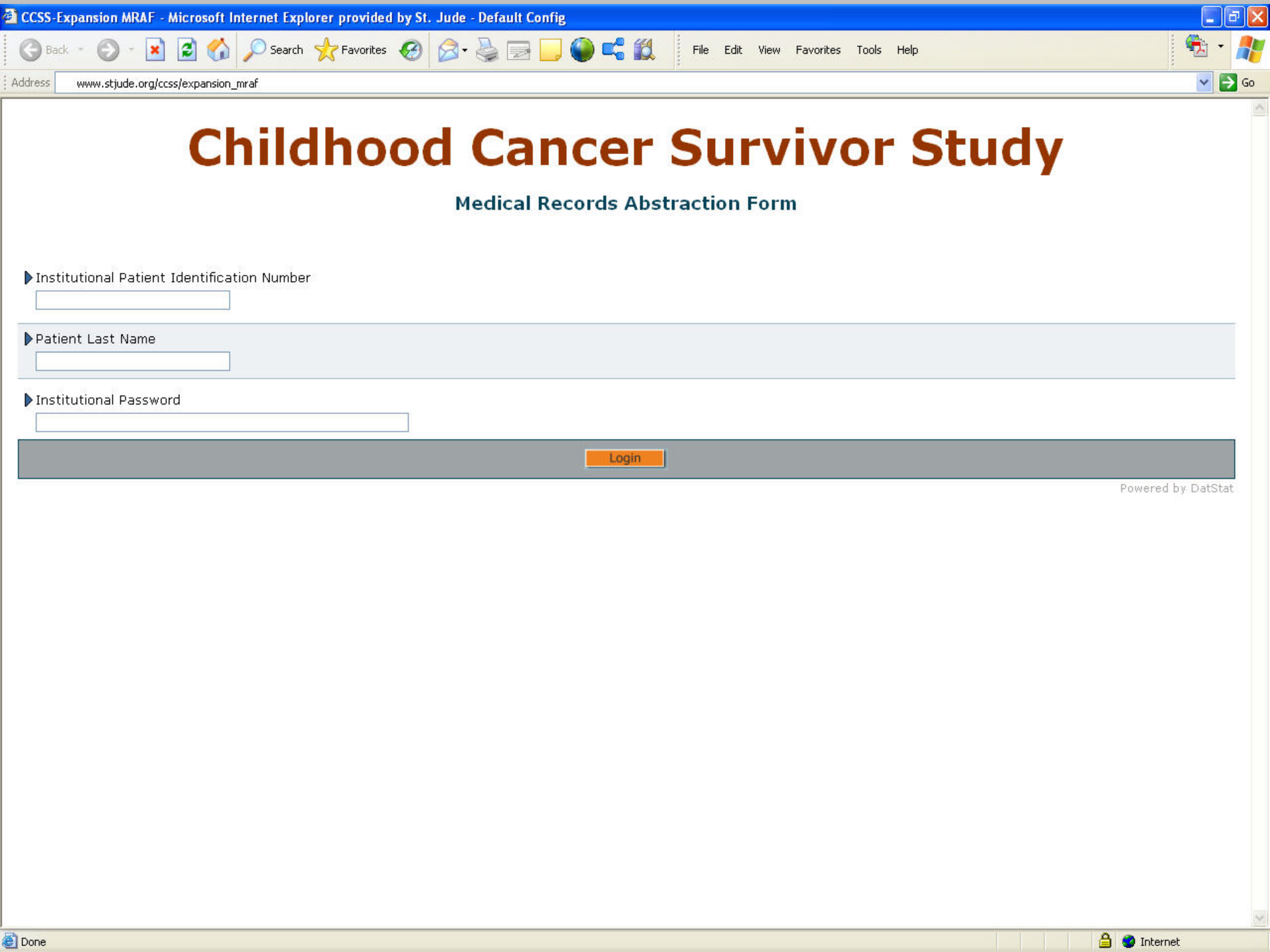
## II. Chemotherapy Information (exposure)

| Please indicate chemotherapies used and routes given. | No                       |                          | Yes                      |                          | Was this drug discontinued due to toxicity? | Route of Administration (Mark all that apply) |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|---|---|--------------------------|--------------------------|--------------------------|
|   | No                       | Yes                      | No                       | Yes                      |   | IV/IM   | Sub-Q                    | Oral                     | IT                       |
| Actinomycin-D   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Adenine Arabinoside (Ara A)                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m-AMSA (Amascrine)                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| AZQ (Diaziquone)                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5-Azacytidine   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| BCNU (Carmustine)                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bleomycin   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Busulfan  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Carboplatin   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| CCNU (Lomustine)                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Chlorambucil  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Cis-Platinum  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Cyclophosphamide (Cytoxan)                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Cytosine Arabinoside (Ara-C)                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Daunorubicin (Daunomycin)                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Deoxycoformycin                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Dexamethasone   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Doxorubicin (Adriamycin)                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| DTIC  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5-FU (5 Fluorouracil)                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Fludarabine phosphate                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Homoharringtonine                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hydroxyurea (Hydrea)                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Idarubicin  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Ifosfamide  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| L-asparaginase  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Melphalan   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6-Mercaptopurine (6 MP)                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Methotrexate  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mithramycin   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Myeleran  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Nitrogen Mustard                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Prednisone  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Procarbazine  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Retinoic Acid   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6-Thioguanine (6 TG)                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ThioTepa  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vinblastine (Velban)                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vincristine   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| VM-26 (Teniposide)                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| VP-16 (Etoposide)                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify):                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify):                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify):                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify):                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify):                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                    | <input type="checkbox"/>                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| OFFICE USE ONLY |   | 1 |   | 2 |   | 3 |   | 4 |   | 5 |   | 6 |   | 7 |   | 8 |   | 9 |   | 0 |   |   |   |   |   |   |   |   |   |
|-----------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 0               | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| 0               | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| 0               | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| 0               | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

00083

PLEASE DO NOT MARK IN THIS AREA



# Childhood Cancer Survivor Study

## Medical Records Abstraction Form

▶ Institutional Patient Identification Number

▶ Patient Last Name

▶ Institutional Password

Login

Powered by DatStat

# Web-based MRAF

## CCSS / Medical Record Abstraction Form

1%

14. Please indicate chemotherapies received

|                                    |                          |
|------------------------------------|--------------------------|
| (a) Actinomycin-D                  | <input type="checkbox"/> |
| (b) Ara-G (Nelarabine)             | <input type="checkbox"/> |
| (c) Anti- Thymocyte Globulin (ATG) | <input type="checkbox"/> |
| (d) 5-Azacytidine                  | <input type="checkbox"/> |
| (e) BCNU (Carmustine)              | <input type="checkbox"/> |
| (f) Bleomycin                      | <input type="checkbox"/> |
| (g) Busulfan                       | <input type="checkbox"/> |
| (h) Carboplatin                    | <input type="checkbox"/> |
| (i) Alemtuzumab (Campath)          | <input type="checkbox"/> |
| (j) CCNU (Lomustine)               | <input type="checkbox"/> |
| (k) Chlorambucil                   | <input type="checkbox"/> |
| (l) Cis-Platinum                   | <input type="checkbox"/> |
| (m) Cyclosporine (CSA)             | <input type="checkbox"/> |
| (n) Cyclophosphamide (Cytoxan)     | <input type="checkbox"/> |
| (o) Cytosine Arabinoside (Ara-C)   | <input type="checkbox"/> |
| (p) Daunorubicin (Daunomycin)      | <input type="checkbox"/> |
| (q) Dexamethasone                  | <input type="checkbox"/> |
| (r) Doxil                          | <input type="checkbox"/> |
| (s) Doxorubicin (Adriamycin)       | <input type="checkbox"/> |
| (t) DTIC (Dacarbazine)             | <input type="checkbox"/> |
| (u) Epirubicin                     | <input type="checkbox"/> |
| (v) Fenretinide                    | <input type="checkbox"/> |
| (w) 5-FU (5 Fluorouracil)          | <input type="checkbox"/> |
| (x) Fludarabine phosphor           | <input type="checkbox"/> |

# Web-based MRAF

**CCSS / Medical Record Abstraction Form**

6%

81. BCNU (Carmustine) Start Date (DDMMYYYY or DDMMYY or MM/DD/YYYY or MM/DD/YY)

82. BCNU (Carmustine) Stop Date (DDMMYYYY or DDMMYY or MM/DD/YYYY or MM/DD/YY)

83. BCNU (Carmustine) Cumulative Total Dose

84. BCNU (Carmustine) Dose Unit  
☐ microgram  
☐ milligram  
☐ gram  
☐ units

85. BSA at Start of BCNU (Carmustine) (x.xx)

86. Height (cm) at Start of BCNU (Carmustine)  
 cm

87. Weight (kg) at Start of BCNU (Carmustine)

88. BCNU (Carmustine) Data Quality  
☐ Total dose abstracted  
☐ Total dose, some estimated  
☐ Incomplete or partial dose  
☐ No dose data

Powered by DatStat

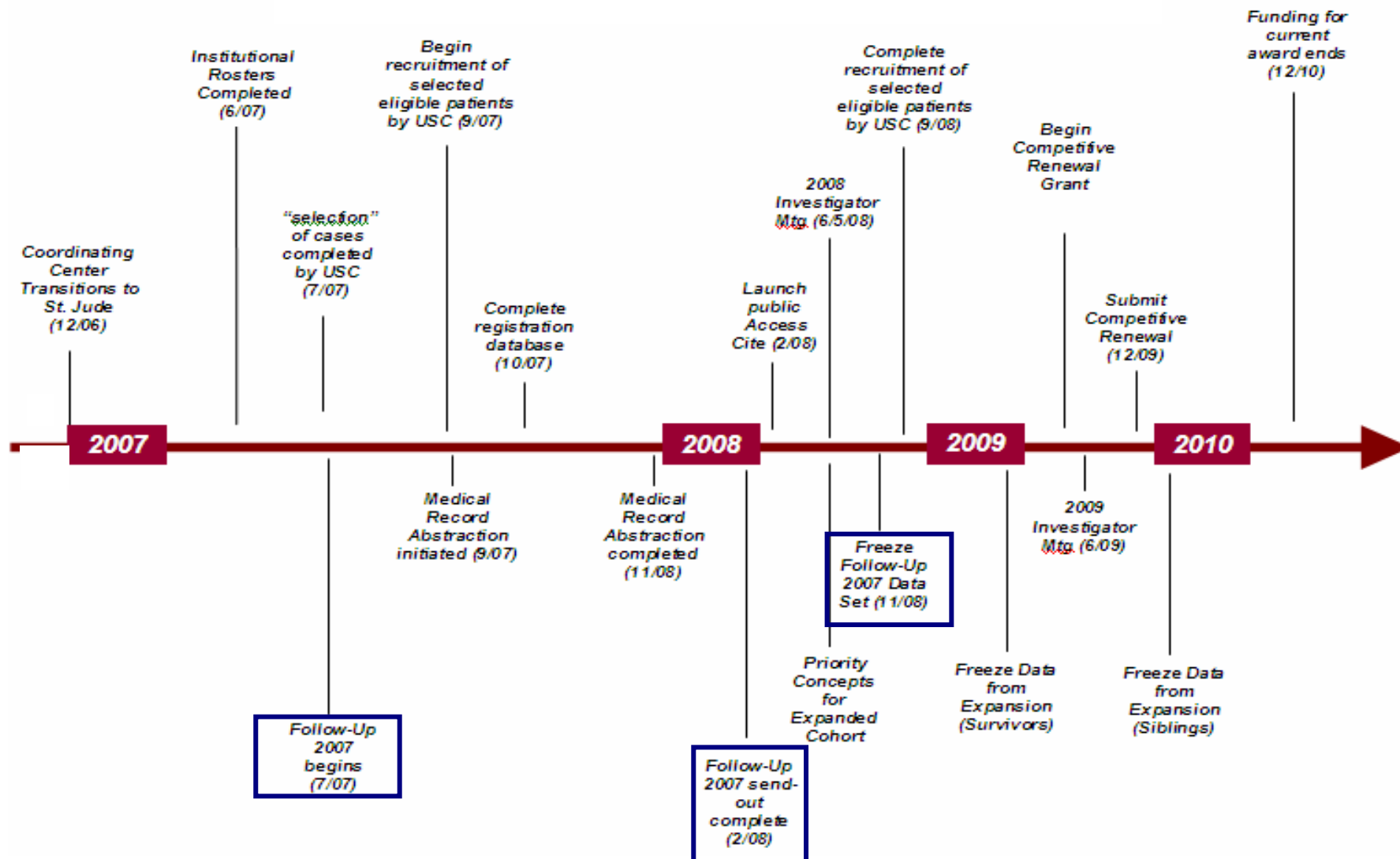
## Follow-up 3: Status Report

|                        | n      | %   |
|------------------------|--------|-----|
| Total sent             | 11,323 |     |
| Returned by mail       | 4282   | 38% |
| Completed by interview | 4626   | 41% |
| Passive refusal        | 646    | 6%  |
| Active refusal         | 68     | 1%  |
| Died                   | 93     | 1%  |
| Unavailable            | 76     | 2%  |
| Lost                   | 1602   | 13% |

**Data Freeze: September 2008**

**CCSS**


# Follow-Up 2007



# Follow-up 2007

- Goal: Comprehensive update of baseline data
- Survey
  - 28 pages
  - 10,254 Participants, 3,165 siblings
  - Update: demographics, medical care, chronic medical conditions, health habits, SMNs, pregnancy/offspring, additional chemo/RT
- Timeline
  - Begin July 1, 2007
  - Complete send out 2/08
  - Complete data collection/Freeze data 11/08

# Web-based Follow-Up 2007



0%

In the past we have asked you questions similar to those below. We would like to update this information.

▶ A1. What is your current height without shoes?

|        |                      |
|--------|----------------------|
| Feet   | <input type="text"/> |
| Inches | <input type="text"/> |

▶ A2. What is your current weight without shoes?

lbs.

▶ A3. What is the highest grade or level of schooling you have now completed?

- ☐ 1-8 years (grade school)
- ☐ 9-12 years (high school) but did not graduate
- ☐ Completed high school/GED
- ☐ Training after high school, other than college
- ☐ Some college
- ☐ College graduate
- ☐ Post graduate level
- ☐ Other

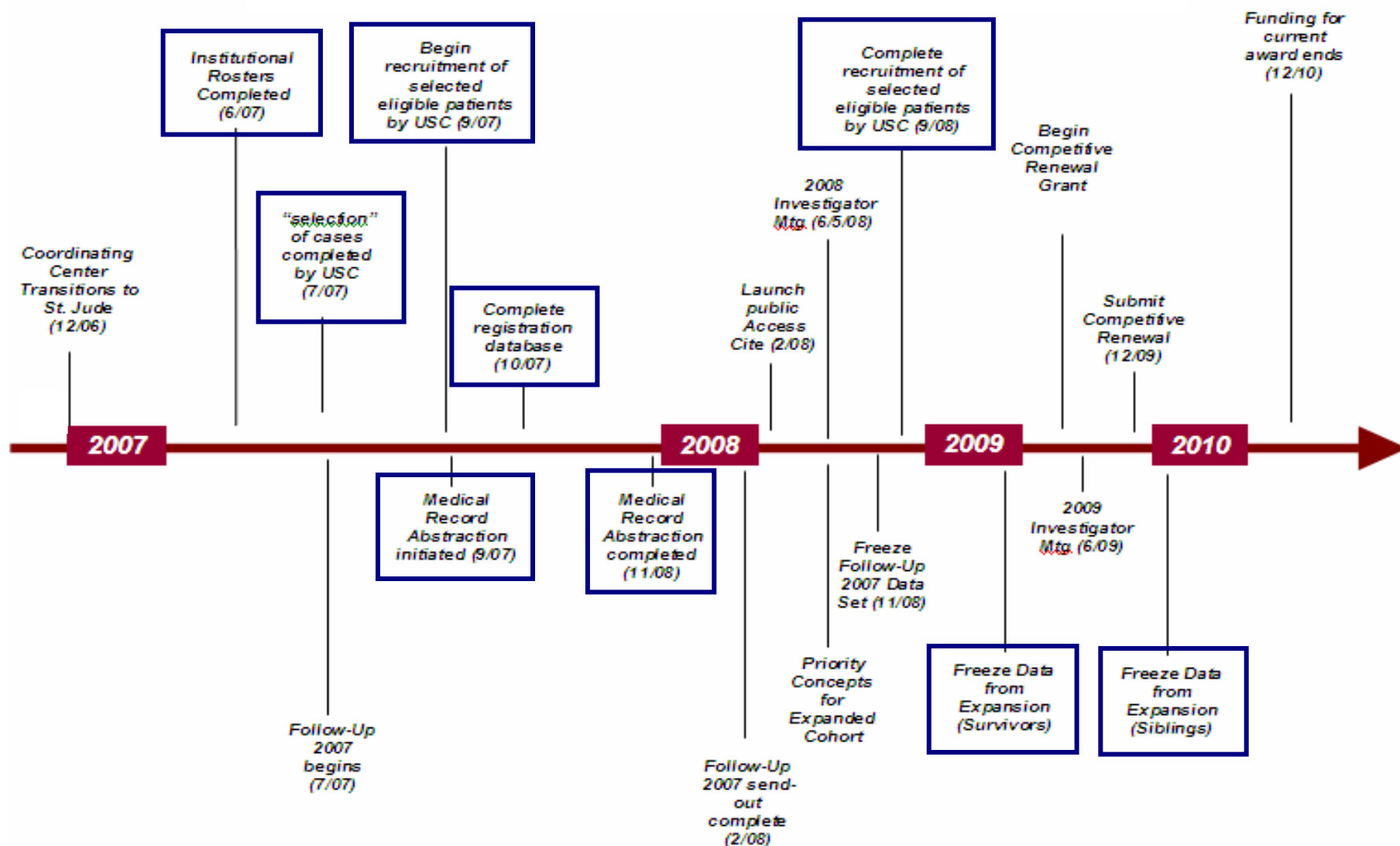
▶ A4. What is your current employment status? Include unpaid work in the family business or farm. *(Mark all that apply)*

- ☐ Working full-time (30 or more hours per week)
- ☐ Working part-time (less than 30 hours per week)
- ☐ Caring for home or family (not seeking paid work)
- ☐ Unemployed and looking for work
- ☐ Unable to work due to illness or disability
- ☐ Retired
- ☐ Student
- ☐ Other

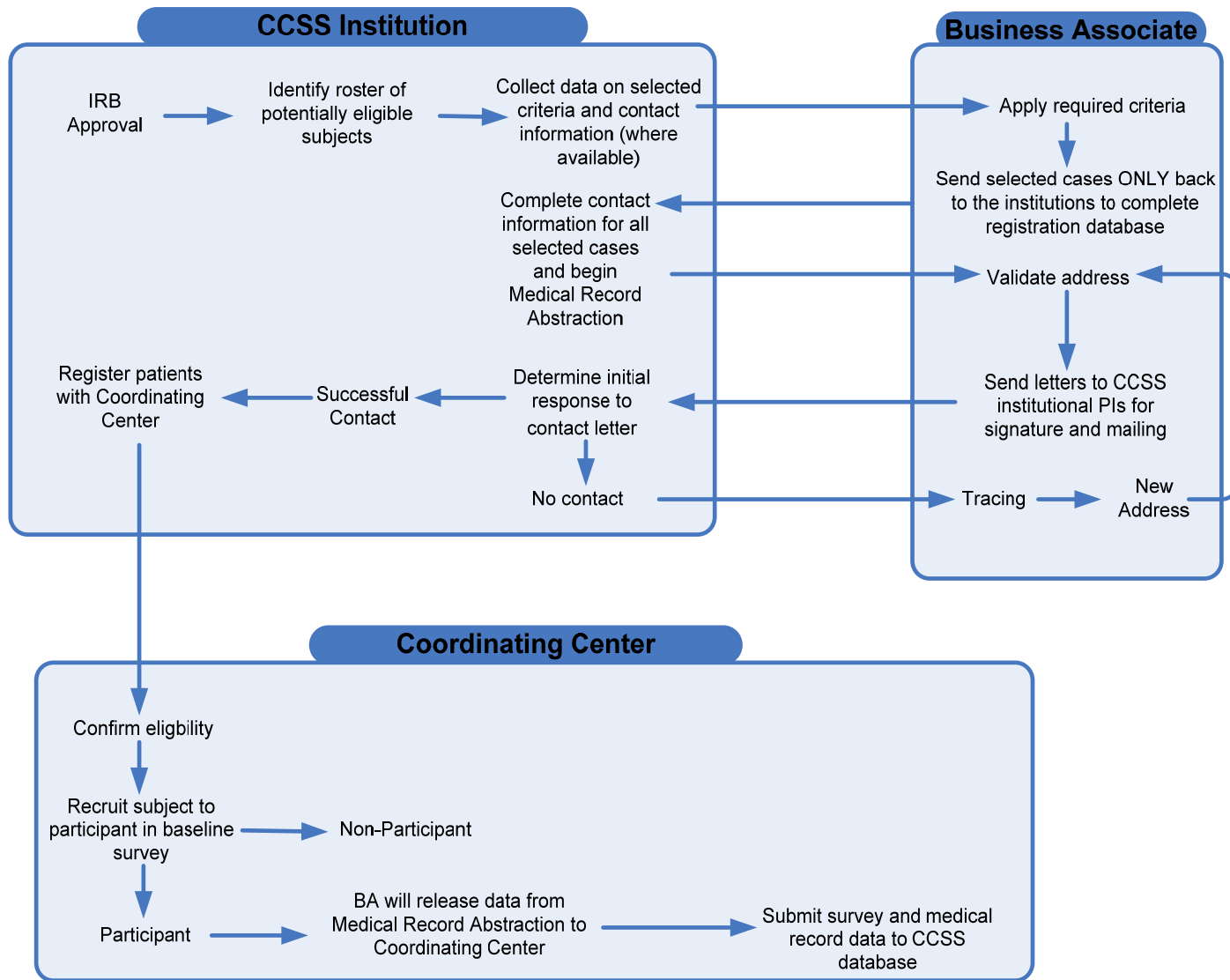
Powered by DatStat



# Cohort Expansion



# Cohort Expansion



# Cohort Expansion

- Survey Development
  - 24 pages
  - Maintain “comparability” to Original baseline
- Study Population → Key tasks for institutions
  - 1) Completion of registration database
  - 2) Medical record abstraction
  - 3) IRB approval of recent amendment

# Registration Database

CaseReg : Form

## CCSS Expansion Case Registration

Personal Information | Family Information | Physician Contacts | Additional Comments

☀ CCSS Site:

### IDENTIFICATION

☀ Med Record # or Unique ID:

Social Security Number:

Last Name:

First Name:

Middle Name:

☀ Date of Birth:  Sex:

☀ Is this person Hispanic?

☀ Race:

Other/Mixed Race - Describe:

### DIAGNOSIS

☀ Date of Diagnosis:

☀ Diagnosis (Click to Enter)

### CONTACT INFORMATION

☐ Address not located within United States

Address:

City:

State/Province:  Zip/Postal Code:

Phone 1:

Phone 2:

Email:

Date of Last Known Address:

Date of Last Contact:

☀ Vital Status:

☀ Date of Death:

**Add a New Record** **Delete This Record** **Go to Record:** **First** **Last** **Next** **Previous** **Email Frequency Report**

Record:  1 of 1

# Registration Database Completion

- Rolling timeline
  - First 250 participants...August 23, 2007
  - 150 participants/week until completion

# Medical Record Abstraction

- CRA Training
  - Web-based entry
  - Detailed instruction
    - Surgery
    - Radiation therapy
    - Chemotherapy
  - Dates:
    - July 20<sup>th</sup>
    - August 31<sup>st</sup>
    - September 12<sup>th</sup>

# Final Selection

| Institution                         | Submitted     | Eligible      | Selected      |
|-------------------------------------|---------------|---------------|---------------|
| University of Minnesota             | 492           | 447           | 356           |
| Denver Children's Hospital          | 816           | 797           | 625           |
| Pittsburgh Children's               | 1070          | 1049          | 875           |
| Stanford                            | 677           | 670           | 479           |
| Dana Farber                         | 1939          | 1904          | 1595          |
| Emory                               | 1240          | 1198          | 938           |
| Washington DC                       | 576           | 557           | 443           |
| MD Anderson                         | 762           | 750           | 654           |
| Memorial Sloan Kettering            | 1626          | 1548          | 1409          |
| UC San Francisco                    | 796           | 666           | 663           |
| Children's Seattle                  | 1161          | 1122          | 854           |
| Toronto                             | 2153          | 2153          | 1724          |
| St. Jude                            | 2387          | 2303          | 2303          |
| Columbus Children's                 | 687           | 666           | 506           |
| Roswell Park                        | 317           | 317           | 284           |
| Minneapolis Children's              | 761           | 750           | 593           |
| Children's Hospital of Philadelphia | 1505          | 1352          | 1128          |
| St. Louis Children's                | 618           | 589           | 473           |
| Children's Los Angeles              | 1184          | 1071          | 762           |
| UCLA                                | 133           | 133           | 95            |
| Riley University of Indiana         | 1253          | 1234          | 972           |
| University of Alabama               | 572           | 567           | 422           |
| Mott University of Michigan         | 932           | 890           | 736           |
| UT Southwestern Medical Center      | 977           | 955           | 750           |
| Texas Children's                    | 1174          | 1122          | 863           |
| City of Hope                        | 285           | 285           | 227           |
| <b>Total</b>                        | <b>26,093</b> | <b>25,095</b> | <b>20,729</b> |

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



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Patients & Parents | Clinical Science | Basic Science | Referring MDs | Careers | International | Volunteers | Ways to Help

**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.](#)

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**CCSS**

**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/lifu](http://www.stjude.org/lifu).

Supplemental information for study publications can be found at [www.stjude.org/ccss](http://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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## Chronic Diseases Working Group

| Proposal Number       | Concept Title  | Lead Author                      | Approved | Status*  |
|-----------------------|--|----------------------------------|----------|--|
| <a href="#">98-06</a> | Thyroid disease in survivors of childhood and adolescent Hodgkin's disease | Chuck Sklar                      | 8/19/98  | <a href="#">J Clin Endocrinol Metab. 2000 Sep;85(9):3227-32.</a> |
| <a href="#">98-14</a> | The health of long-term survivors of childhood and adolescent cancer       | H. Stacy Nicholson               | 5/26/98  | Inactive   |
| <a href="#">98-18</a> | Cardiac outcome in survivors of childhood Hodgkin's disease                | Dan Mulrooney / Mark Yeazel      | 10/20/98 | Analysis - Underway  |
| <a href="#">00-01</a> | Obesity in adult survivors of childhood cancer                             | Kevin Oeffinger                  | 8/25/00  | <a href="#">J Clin Oncol. 2003 Apr 1;21(7):1359-65.</a>          |
| <a href="#">00-02</a> | Pulmonary complications in survivors of childhood and adolescent cancer    | Ann Mertens                      | 8/25/00  | <a href="#">Cancer. 2002 Dec 1;95(11):2431-41.</a>               |
| <a href="#">00-07</a> | Post-treatment stroke  | Dan Bowers / D. Elizabeth McNeil | 12/8/00  | <a href="#">J Clin Oncol. 2005 Sep 20;23(27):6508-15.</a>        |
| <a href="#">02-01</a> | Hormonal and neurological late effects in Rhabdomyosarcoma                 | Judy Punyko                      | 5/14/02  | <a href="#">Psychooncology. 2007 16:26-37</a>                    |
| <a href="#">02-02</a> | Quality of life among survivors of pediatric lower extremity bone tumors   | Rajaram Nagarajan                | 5/14/02  | <a href="#">Br J Cancer. 2004 Nov 29;91(11):1858-65.</a>         |
| <a href="#">02-04</a> | Genetic polymorphisms in cardiac cases exposed to anthracyclines           | Richard Aplenc                   | 6/11/02  | Analysis Completed - Inactive                                    |

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## **Other Active Issues**

- **Men's Health Questionnaire**
- **Newsletter: Fall 2007**
- **Tracing of original cohort**
  - 3,058 lost at baseline
- **Staff recruitment/Development**





# Expansion Database

**CaseReg : Form**

**CCSS Expansion Case Registration**

Personal Information | Family Information | Physician Contacts | Additional Comments

CCSS Site:

**IDENTIFICATION**

Med Record # or Unique ID:   
Social Security Number:   
Last Name:   
First Name:   
Middle Name:   
Date of Birth:  Sex:   
Is this person Hispanic?   
Race:   
Other/Mixed Race - Describe:

**CONTACT INFORMATION**

☐ Address not located within United States  
Address:   
City:   
State/Province:  Zip/Postal Code:   
Phone 1:   
Phone 2:   
Email:   
Date of Last Known Address:   
Date of Last Contact:   
Vital Status:   
Date of Death:

**DIAGNOSIS**

Date of Diagnosis:   
Diagnosis (Click to Enter)

**Add a New Record** **Delete This Record** **Go to Record:** **First** **Last** **Next** **Previous** **Email Frequency Report**

**Show Error Report** **Import Data from Previous Database**

Record:  1 of 1