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Children's Hospital Colorado
Denver, CO
Children's Hospital of Los Angeles
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Children's Hospital of Orange County
Orange, CA
Children's Hospital of Philadelphia
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Children's Hospital of Pittsburgh
Pittsburgh, PA
Children's Hospitals and Clinics of Minnesota
Minneapolis-St. Paul, MN
Children's Medical Center of Dallas
Dallas, TX
Children's National Medical Center
Washington, DC
City of Hope National Medical Center
Duarte, CA
Cook Children's Hematology-Oncology Center
Fort Worth, TX
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Boston, MA
Mattel Children's Hospital at UCLA
Los Angeles, CA
Mayo Clinic
Rochester, MN
Memorial Sloan-Kettering Cancer Center
New York, NY
Miller Children's Hospital
Long Beach, CA
Nationwide Children's Hospital
Columbus, OH
Riley Hospital for Children - Indiana University
Indianapolis, IN
Roswell Park Cancer Institute
Buffalo, NY
Seattle Children's Hospital
Seattle, WA
St. Louis Children's Hospital
St. Louis, MO
Texas Children's Hospital
Houston, TX
Toronto Hospital for Sick Children
Toronto, ON
UAB/The Children's Hospital of Alabama
Birmingham, AL
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Chicago, IL
University of Michigan - Mott Children's Hospital
Ann Arbor, MI
University of Minnesota
Minneapolis, MN
U.T.M.D. Anderson Cancer Center
Houston, TX

CCSS Annual Investigators' Meeting
Williamsburg, VA
June 6 – 7, 2012

Childhood Cancer Survivor Study

*An NCI-funded resource for
outcome and intervention research*

U24 CA55727

<http://ccss.stjude.org>

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2012 CCSS Investigator Meeting At-A-Glance

The Williamsburg Lodge
Williamsburg, VA

<u>Day/Time</u>	<u>Meeting</u>	<u>Attendees</u>	<u>Room</u>
<i>Tuesday, June 5</i> 5:00 – 8:00pm	CCSS Executive Committee	Executive Committee	Allegheny B (Main Level)
<i>Wednesday, June 6</i>	<i>Conference Center – Lower Level</i>		
8:00 – 10:00am	CCSS Steering Committee (continental breakfast 7:00 – 8:00)	Steering Committee + Executive Committee	Piedmont
10:00am – 1:00pm	CCSS Principal Investigator	Steering Committee + Executive Committee + Institutional PI's	Piedmont
2:00 – 7:00pm	Plenary Session*	All Attendees	Virginia ABC
7:00 – 8:00pm	Reception	All Attendees	Oval Garden
<i>Thursday, June 7</i>	<i>Conference Center – Lower Level</i>		
7:00 – 8:00am	Continental Breakfast	All Attendees	Virginia D
8:00am – 12:00pm	Plenary Session*	All Attendees	Virginia ABC
12:00 – 1:00pm	Box Lunch Break-Out Sessions*	All Attendees	Piedmont ABC Virginia ABC and D
1:00pm	Adjourn		

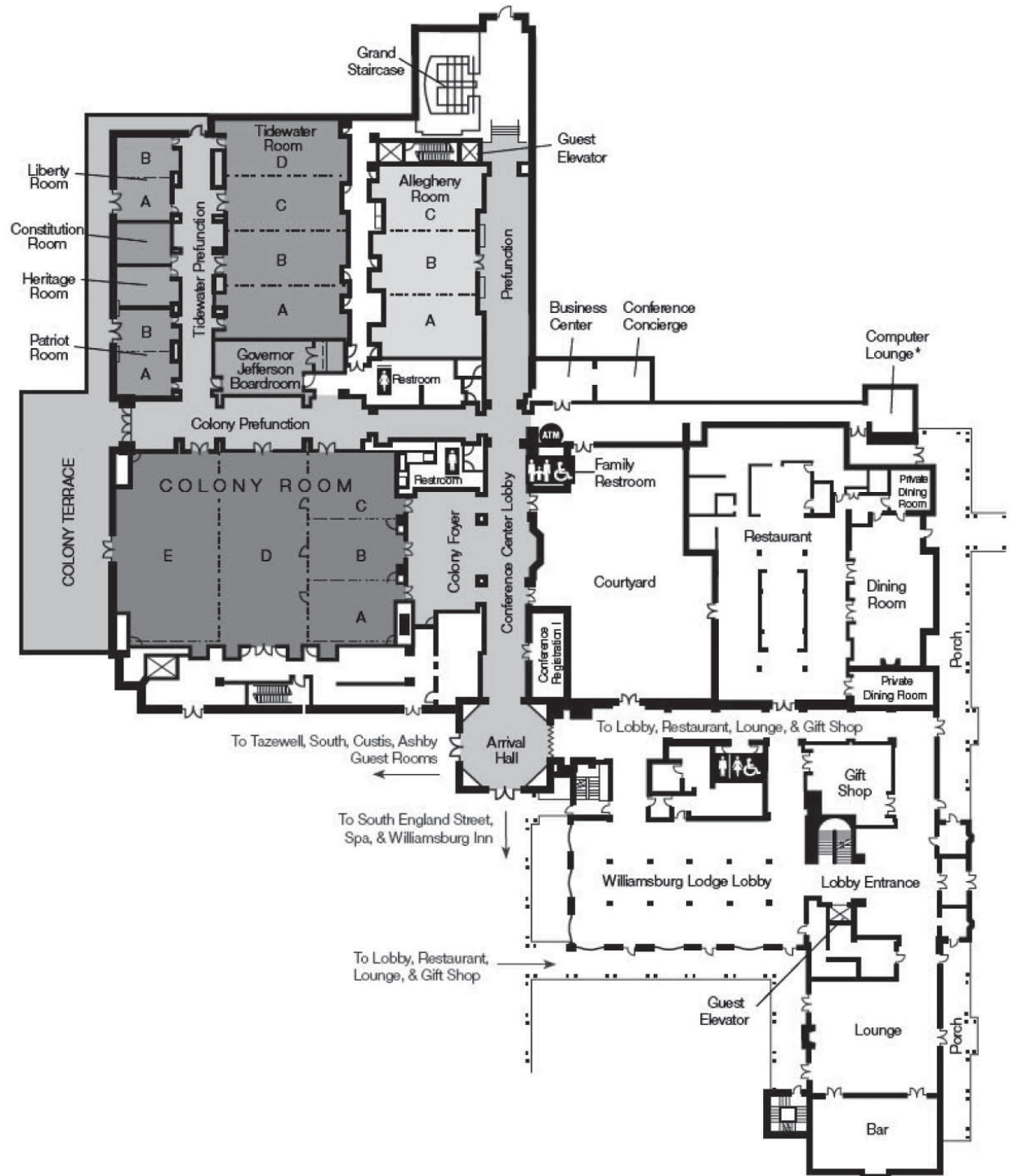
*See the Plenary Session Agenda on the following page for details

CCSS Investigator Meeting Plenary Session Agenda

<u>Day/Time</u>	<u>Topic</u>	<u>Presenter</u>	<u>Room</u>
Wednesday, June 6			
2:00 - 3:40pm	<u>Update Reports</u> Principal Investigator Data and Statistics Center Coordinating Center Radiation Physics Center Biorepository and Biopathology Centers Research and Publications Committee Education Committee	L. Robison W. Leisenring G. Armstrong M. Stovall L. Robison D. Green M. Hudson	Virginia ABC
3:40 – 4:00pm	Break		
4:00 – 5:45pm	<u>Research Presentations</u> Basal Cell Carcinoma and RT Exposure Colorectal Carcinoma as a Second Malignancy Cardiovascular Risk Factor Analysis Are Childhood Cancer Survivors Underinsured?	A. Mertens T. Henderson G. Armstrong E. Park	Virginia ABC
5:45 – 7:00pm	<u>Special Sessions</u> Introduction to CCSS (CCSS 101): How to utilize CCSS in research	E. Chow	Virginia ABC
Thursday, June 7			
8:00 – 9:30am	<u>International Cohorts</u> British CCSS Vancouver CAYACS Dutch LATER Danish ALICCS PanCareSurFup	M. Hawkins M. McBride L. Kremer J. Winthers L. Hjorth	Virginia ABC
9:30 - 10:20am	<u>Working Group Reports</u> Biostatistics/Epidemiology Genetics	A. Mertens L. Strong/L. Morton	Virginia ABC
10:20 – 10:40am	Break		
10:40a – 12:00p	<u>Working Group Reports</u> Chronic Disease Second Neoplasms Psychology Cancer Control	C. Sklar J. Neglia K. Krull K. Oeffinger	Virginia ABC
12:00 – 1:00pm	<u>Working Group Breakout Sessions (Box Lunch)</u> Genetics (L. Strong) Chronic Disease (C. Sklar) Second Neoplasm (J. Neglia) Cancer Control (K. Oeffinger) Psychology (K. Krull) Biostat/Epidemiology (A. Mertens)		Piedmont A Piedmont B Piedmont C Virginia D Virginia ABC Virginia ABC

Conference Center Main Level

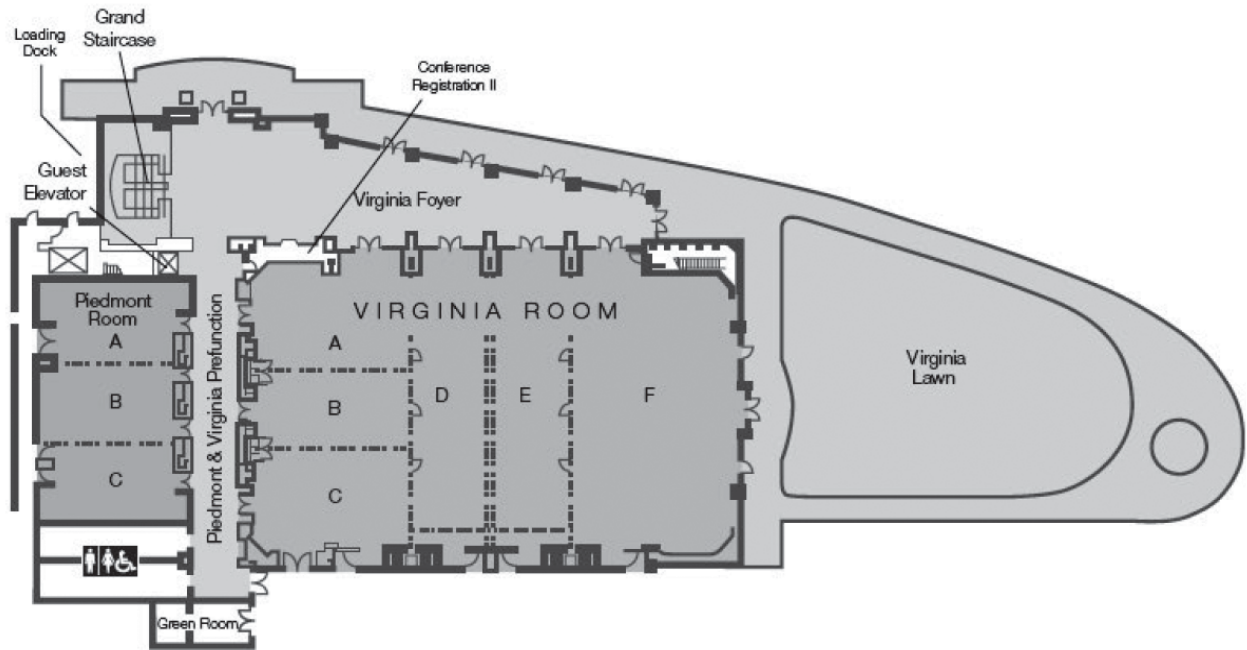
Tuesday, June 5 (Executive Committee Meeting – Room Allegheny B)



*guest must provide own computers

Conference Center Lower Level

June 6 – 7



CCSS Institutions and Investigators

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U.T.M.D. Anderson Cancer Center, Houston, TX	Louise Strong, MD ^{*‡} , Marilyn Stovall, MPH, PhD [‡]

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Project Principal Investigator

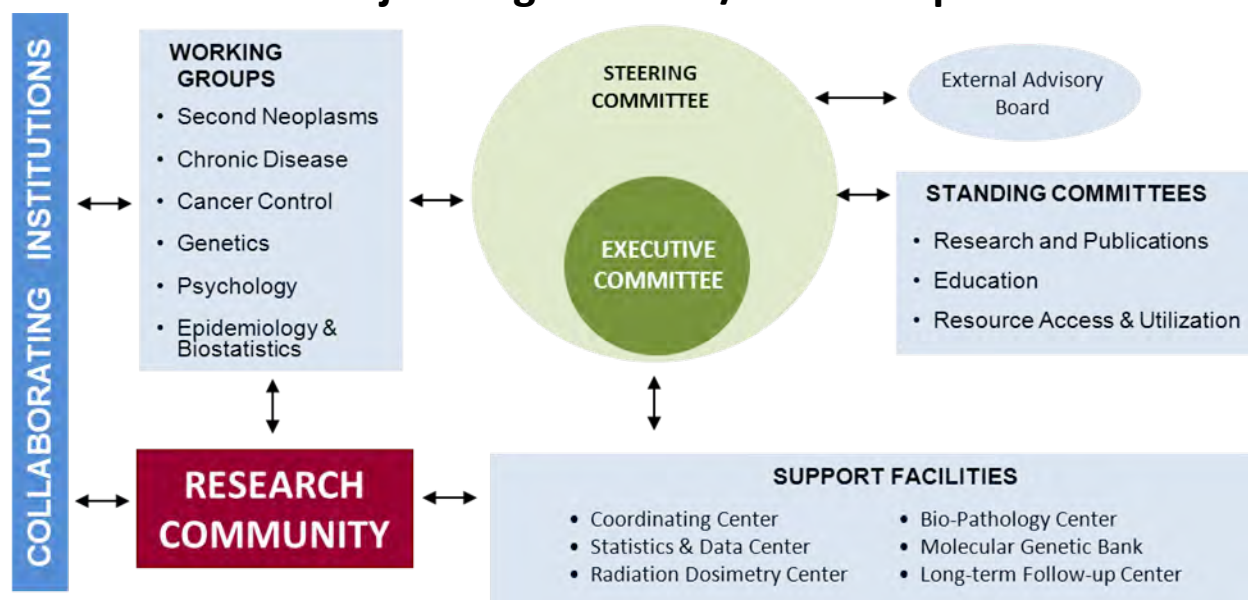
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Project Director	Greg Armstrong, MD, MSCE*
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Second Neoplasms	Joseph Neglia, MD, MPH*
Chronic Disease	Charles Sklar, MD*
Cancer Control	Kevin Oeffinger, MD*
Genetics	Smita Bhatia, MD, MPH*
Psychology	Kevin Krull, PhD*
Epidemiology/Biostatistics	Ann Mertens, PhD*/Wendy Leisenring, ScD*
<u>Standing Committee Chairs</u>	
Research and Publications Committee	Daniel Green, MD*
Education Committee	Melissa Hudson, MD*
Resource Access/Utilization Committee	Leslie Robison, PhD*
<u>Support Facilities</u>	
Coordinating Center Support Facility Director	Greg Armstrong, MD, MSCE*
Statistics & Data Support Facility Director	Wendy Leisenring, ScD*
Radiation Physics Support Facility Director	Marilyn Stovall, PhD*
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June 5-7, 2012

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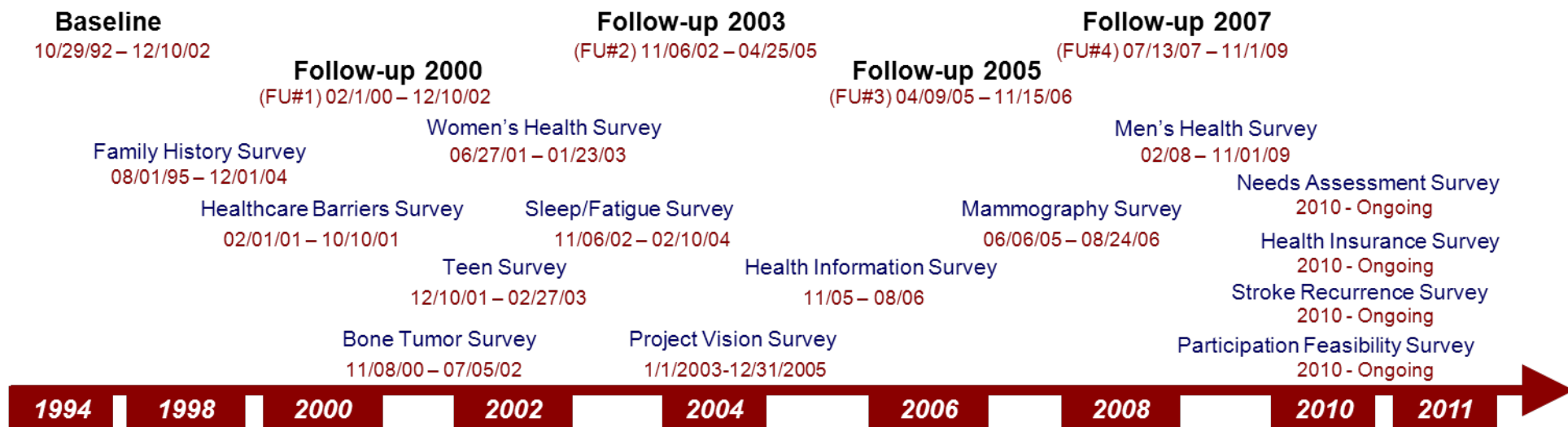
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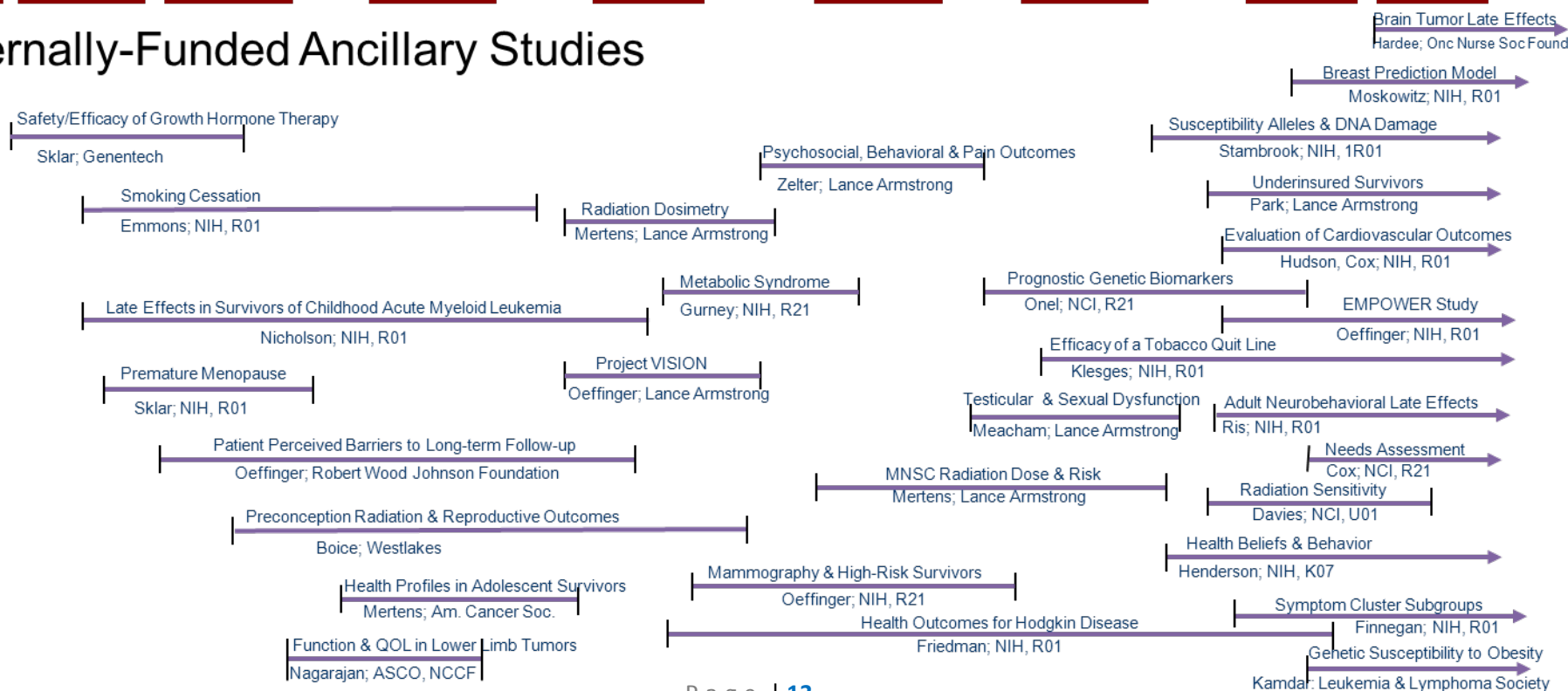
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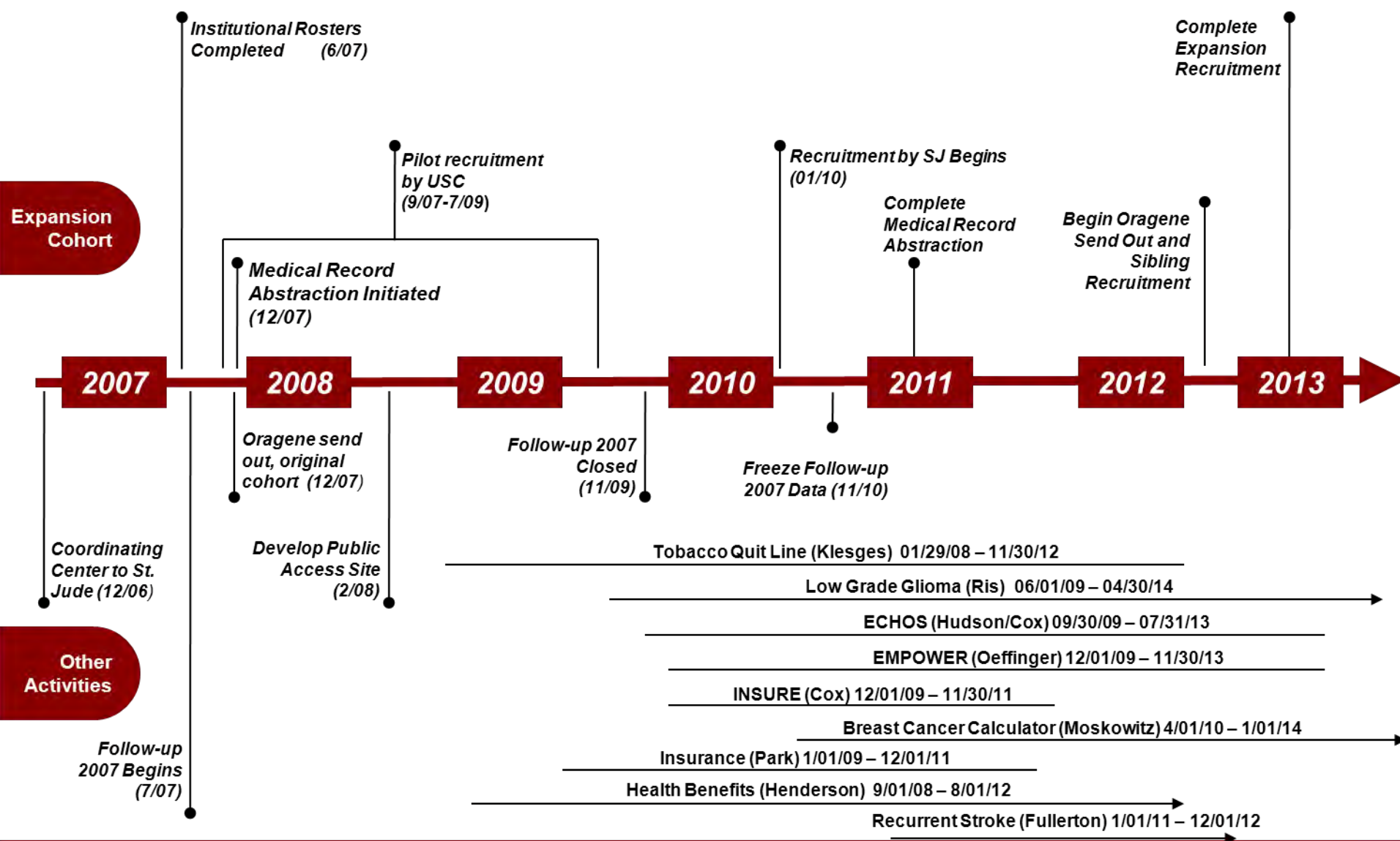
CCSS Cohort Surveys



Externally-Funded Ancillary Studies



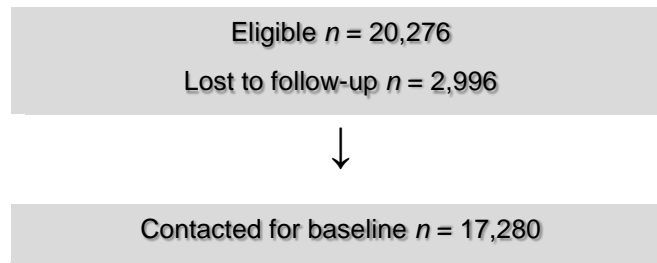
Childhood Cancer Survivor Study (U24 CA55727) Coordinating Center Timeline



Baseline Characteristics of Original (1970-1986) Survivor and Sibling Cohorts

Characteristic	Survivors n=14,357		Siblings n=3,899	
	No.	%	No.	%
Age at entry into the cohort (years)				
<9	175	1.2	76	2.0
10-14	1933	13.5	355	9.1
15-19	3126	21.8	656	16.8
20-24	3118	21.7	671	17.2
25-29	2770	19.3	709	18.2
30-34	1977	13.8	655	16.8
35-39	926	6.4	461	11.8
40+	332	2.3	316	8.1
Sex				
Male	7713	53.7	1875	48.1
Female	6644	46.3	2024	51.9
Race/ethnicity				
White non-Hispanic	11942	83.2	3414	87.6
Black non-Hispanic	668	4.7	102	2.6
American Indian/Alaska Native	88	0.6	15	0.4
Asian or Pacific Islander	167	1.2	41	1.1
Hispanic	397	2.8	60	1.5
Other	1045	7.3	130	3.3
Unknown	50	0.3	137	3.5
Age at cancer diagnosis (years)				
0-4	5754	40.1		
5-9	3200	22.3		
10-14	2912	20.3		
15-20	2491	17.4		
Diagnosis				
Acute lymphoblastic leukemia	4151	28.9		
Acute myeloid leukemia	356	2.5		
Other leukemia	320	2.2		
Astrocytoma	1184	8.2		
Medulloblastoma, PNET	381	2.7		
Other CNS malignancies	315	2.2		
Hodgkin lymphoma	1927	13.4		
Non-Hodgkin lymphoma	1083	7.5		
Kidney cancer	1258	8.8		
Neuroblastoma	951	6.6		
Soft tissue sarcoma	1243	8.7		
Ewings sarcoma	403	2.8		
Osteosarcoma	733	5.1		
Other bone malignancy	52	0.4		
Vital status at cohort entry				
Alive	13182	91.8		
Dead	1175	8.2		
Treatment				
Chemo + RT + surgery	5550	38.7		
Chemo + RT	1459	10.2		
Chemo + surgery	2274	15.8		
Chemo only	816	5.7		
RT + surgery	1497	10.4		
RT only	33	0.2		
Surgery only	910	6.3		
Medical records not available	1818	12.7		

Original Cohort Participation Among Contacted Participants



Questionnaire	Number of Pages	Presumed Eligible	Participation Rate	Non-Response	Refused Questionnaire	Dropout of Study	Lost to Follow-Up
Baseline	20	$n = 17,280^*$	83%	0%	17% [†]	0%	0%
Follow-Up 2000	16	$n = 12,884$	81%	6%	2%	4%	7%
Follow-Up 2003	24	$n = 11,859$	78%	8%	3%	5%	6%
Follow-Up 2005	4	$n = 11,393$	78%	5%	1%	3%	13%
Follow-Up 2007	28	$n = 10,143$ (9,769 sent)**	79%***	8.7%	2.4%	1.6%	5.1%

*Represents those who were successfully contacted at baseline

[†]Refusal of baseline = refusal to be part of the study

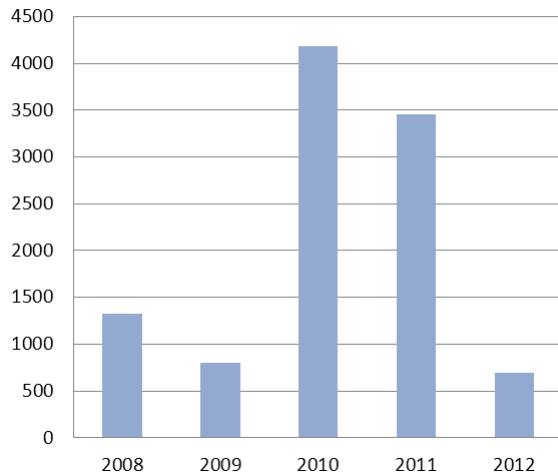
**374 eligible but contact information unknown (Follow-up 2007 not sent)

***Follow-Up 2007 participation rate was:

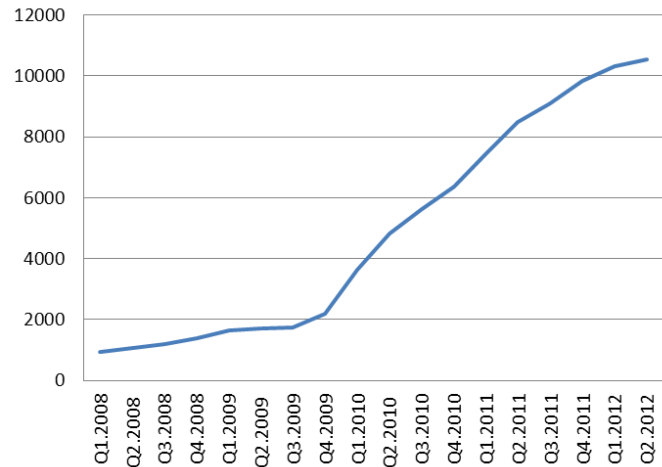
- 79% if “presumed eligible” is used as denominator, or
- 82% if “number sent” is used as denominator

Expansion Cohort: Recruitment Status by CCSS Institution as of 5/2012

Survivors Enrolled by Year



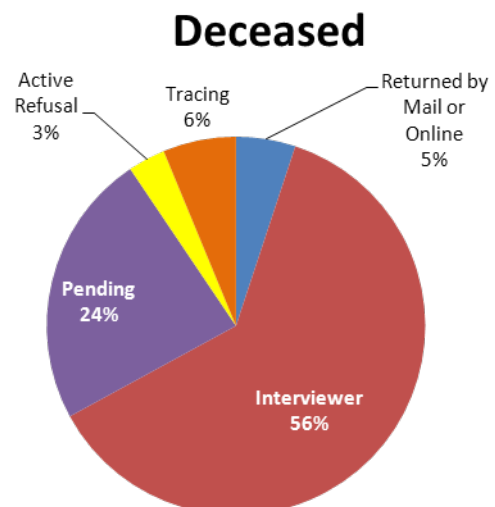
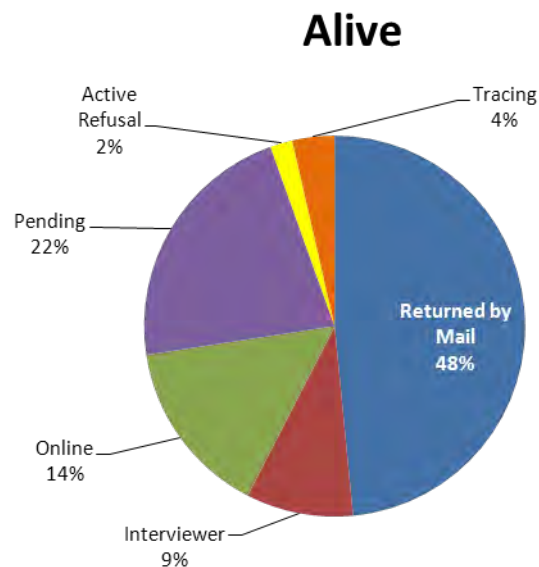
Cumulative Enrollment by Quarter



Institution Name	Eligible	HIPAA's	
		Returned	
St. Jude Children's Research Hospital	2,147	1,844	85.89%
Minneapolis Children's Medical Center	582	434	74.57%
Univ. of Michigan - Mott Children's Hospital	670	499	74.48%
University of California at San Francisco	419	311	74.22%
University of Minnesota	279	207	74.19%
Children's Hospital Colorado	597	442	74.04%
Children's Hospital at Stanford University	372	274	73.66%
St. Louis Children's Hospital	422	308	72.99%
Children's Hospital of Philadelphia	1,013	736	72.66%
Riley Hospital for Children, Indiana Univ.	860	618	71.86%
Emory University	720	506	70.28%
Children's Hospital of Pittsburgh	767	518	67.54%
U.T.M.D. Anderson Cancer Center	649	435	67.03%
Children's Hospital of Los Angeles	749	501	66.89%
Nationwide Children's Hospital	501	334	66.67%
Roswell Park Cancer Institute	241	160	66.39%
Dana-Farber Cancer Institute	919	597	64.96%
Memorial Sloan-Kettering Cancer Center	653	418	64.01%
Seattle Children's Hospital	831	529	63.66%
UCLA Mattel Children's Hospital	67	39	58.21%
UT Southwestern Medical Center	643	364	56.61%
City of Hope	132	73	55.30%
UAB/The Children's Hospital of Alabama	365	193	52.88%
Texas Children's Hospital	622	121	19.45%
Children's National Medical Center	317	51	16.09%
Toronto Hospital for Sick Kids	1,283	0	0.00%
Total	16,820	10,512	

Expansion Baseline Survey (as of 5/15/2012)

Survivors			
HIPAA's Received	10,512		
Questionnaires Sent	10,506		
Pending mailing	6		
Returned	7,587	72.2% (of sent)	
Alive	<i>n</i>	<i>% of Sent</i>	<i>% of Completed</i>
Number Sent	9,817		
Number Completed	7,125	72.6%	
Returned by Mail	4,757	48.5%	66.8%
Completed by Interviewers	894	9.1%	12.5%
Completed Online	1,474	15.0%	20.7%
Pending Return	2,155	22.0%	
Active Refusal	186	1.9%	
In Tracing	351	3.6%	
Deceased	<i>n</i>	<i>% of Sent</i>	<i>% of Completed</i>
Number Eligible	689		
Completed	462	67.9%	
Completed by Interviewers	427	62.0%	92.4%
Returned by Mail or Online	35	5.1%	7.6%
Pending Return	162	23.5%	
Active Refusal	22	3.2%	
In Tracing	43	6.2%	
Survey Period: 5/08 – Present			



Expansion Cohort: Medical Record Abstraction Summary

Inst Code	Institution	Submitted Cases	Selected	Ineligible	Eligible	MRAFs* Completed	% of Eligible Completed
1	University of Minnesota	492	356	77	279	279	100%
2	Children's Hospital Colorado	816	625	28	597	597	100%
3	Children's Hospital of Pittsburgh	1,070	874	107	767	767	100%
4	Children's Hospital at Stanford University	677	479	107	372	372	100%
5	Dana-Farber Cancer Institute	932	932	13	919	919	100%
6	Emory University	1,240	938	218	720	720	100%
7	Children's National Medical Center	576	443	126	317	285	90%
8	U.T.M.D. Anderson Cancer Center	762	654	5	649	649	100%
9	Memorial Sloan-Kettering Cancer Center	1,626	748	95	653	653	100%
11	University of California at San Francisco	796	663	244	419	381	91%
12	Seattle Children's Hospital	1,161	854	23	831	831	100%
13	Toronto Hospital for Sick Children	2,153	1,724	441	1,283	1,283	100%
15	St. Jude Children's Research Hospital	2,387	2,303	156	2,147	1,864	87%
16	Nationwide Children's Hospital	687	506	5	501	501	100%
17	Roswell Park Cancer Institute	317	284	43	241	241	100%
19	Minneapolis Children's Medical Center	761	592	10	582	582	100%
20	Children's Hospital of Philadelphia	1,505	1,128	115	1,013	1,013	100%
21	St. Louis Children's Hospital	618	473	51	422	422	100%
22	Children's Hospital of Los Angeles	1,184	762	13	749	749	100%
23	UCLA Medical Center	133	95	28	67	67	100%
24	Riley Hospital for Children, Indiana Univ.	1,253	972	112	860	722	83%
25	UAB/Children's Hospital of Alabama	572	422	57	365	365	100%
26	Univ. of MI/Mott Children's Hospital	932	736	66	670	670	100%
27	UT Southwestern Medical Center	977	750	107	643	643	100%
28	Texas Children's Hospital	1,174	863	241	622	622	100%
29	City of Hope National Medical Center	285	227	95	132	132	100%
Totals		25,086	19,403	2,583	16,820	16,329	
<i>Probationary Institutions (New Centers)</i>							
30	Children's Hospital of Orange County	690	593	0	593	0	0%
31	University of Chicago	464	459	107	352	352	100%
32	Lurie Children's Hospital of Chicago	1,176	1,114	2	1,112	530	48%
33	Cook Children's Hospital	620	551	4	547	227	41%
Totals		2,950	2,717	113	2,604	1,109	

*MRAF = Medical Record Abstraction Form

As of 4/2012

Oragene DNA Kit Summary: Original Cohort

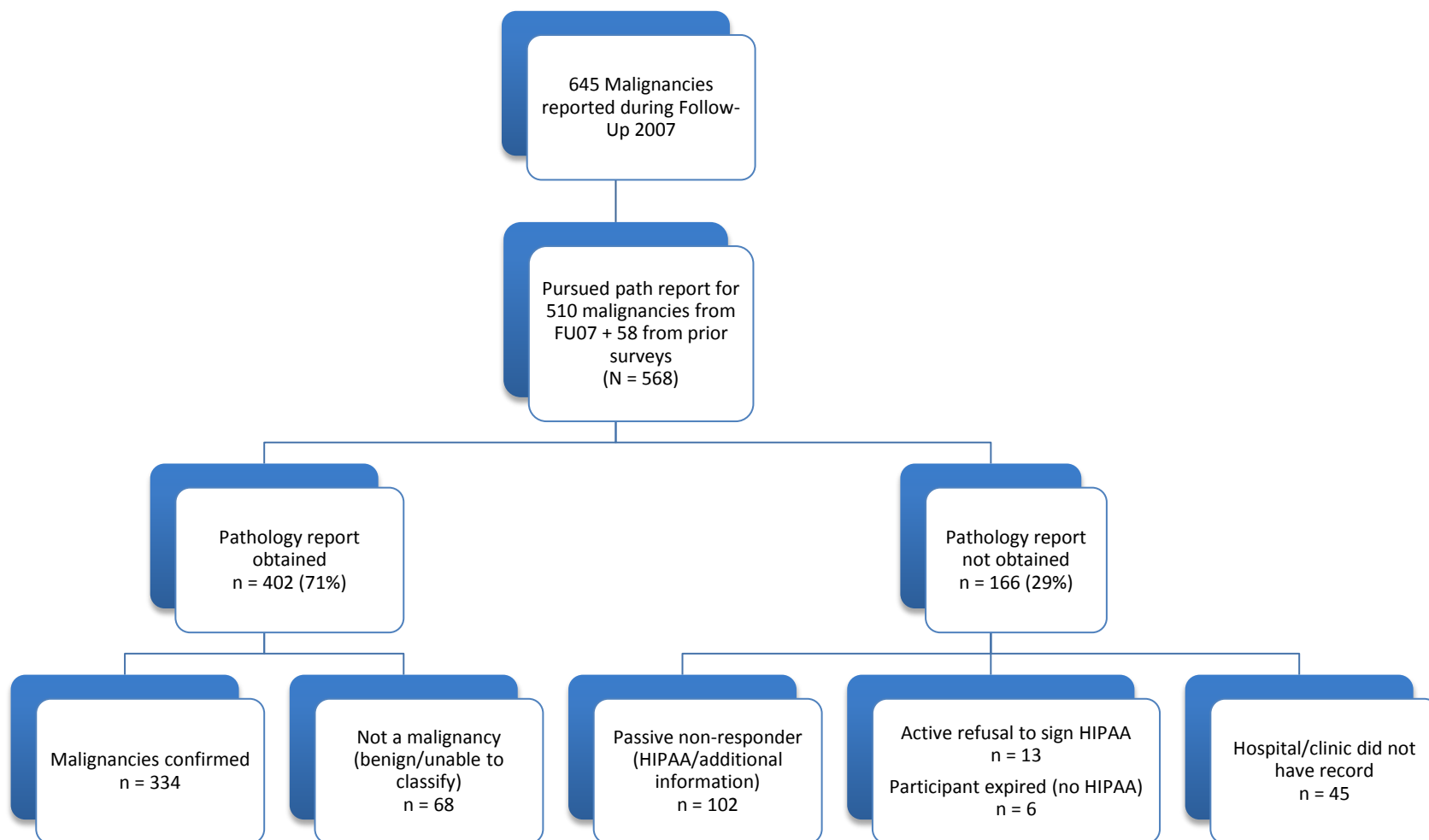
Kits Sent	Cases (n = 8,288)		Siblings (n = 2,710)	
	<i>n</i>	<i>% of Sent</i>	<i>n</i>	<i>% of Sent</i>
Returned	4,127	49.9%	737	27.2%
Refused	725	8.7%	96	3.5%
Pending	2,841	34.3%	1672	61.7%
In Tracing	472	5.7%	201	7.4%
Deceased	123	1.5%	4	0.1%

Methodology Summary

- Send letter, consent form and kit to active participants.
- Trace non-current addresses. Resend kit if new address found.
- Call non-responders 3-weeks after kit mailing date.
- Call until contact or until reminder message is left.
- Trace non-current phone numbers.
- Resend kit upon participant request.
- Mass resend to all non-responders occurred in January 2010.
- Second mass resend to cases (survivors) occurred March 2012.
- Pilot mailing with incentives to siblings and expanded cohort will occur in Summer 2012.

Report Date 5/2012

SMN Confirmation Status



Report Date 5/2012

Distribution of Biologic Material Available for Subsequent Neoplasm Cases

SMN	Total case reported	Total with path reports	# with host tissue			Host tissue (any kind) and MRAF data	Total with MRAF data	Total with SMN tissue	Number of Cases with Tissue Type			
			Buccal cells	Oragene	Blood				H&E Slides	Unstained Slides	Scrolls	Blocks
Breast	222	206	116	87	107	140	211	63	34	49	38	16
Meningioma*	210	186	126	102	103	142	191	39	10	29	13	13
Other CNS	78	70	23	17	18	27	74	21	8	19	5	2
Thyroid	157	144	81	63	76	106	150	32	18	28	17	7
Sarcoma	87	79	33	21	23	39	78	11	6	10	7	2
Leukemia	51	35	14	8	9	15	44	7	3	6	3	0
Bone	54	46	14	4	11	16	45	7	3	5	2	1
Melanoma	55	39	24	18	23	31	53	9	4	9	3	0
Lymphoma	45	41	18	16	18	25	42	8	2	6	4	1
Renal Cell	26	26	15	14	12	17	24	0	0	0	0	0
Other Carcinoma	114	109	48	31	38	56	112	31	18	26	14	7
NMSC*	1,295	1,147	832	658	311	906	1,219	2	2	1	1	0
All Other	64	41	18	16	13	21	51	9	5	9	4	1
TOTALS	2,458	2,169	1,362	1,055	762	1,541	2,294	239	113	197	111	50

As of 1/2012

RT Data/Analyses Summary as of May 2012

Study Title	Study PI	Number exposed to RT	Dosimetry required	Dosimetry status
Case control studies				
CNS SMNs	<i>Neglia</i>	452	Dose to specific tumor locations	Complete Sept 2003
Thyroid SMNs	<i>Sigurdson</i>	293	Dose to thyroid and pituitary.	Complete Mar 2003
Breast SMNs	<i>Inskip</i>	463	Dose to specific breast locations	Complete Jul 2005
Pregnancy Outcomes	<i>Boice</i>	2100	Dose to gonads, uterus, pituitary	Complete Jul 2004
Bone/ Soft Tissue SMNs	<i>Henderson</i>	438	Dose to specific tumor locations	Complete Apr 2007
Non-melanoma Skin Ca	<i>Mertens</i>	612	Dose to specific tumor locations	Complete Apr 2010
Renal carcinoma	<i>Wilson / Ness</i>	~8500	Average kidney doses (left and right reported separately)	Complete Aug 2011
Breast SMNs/expanded	<i>Inskip</i>	451	Dose to specific breast locations	In progress
Cohort studies				
Thyroid Function	<i>Sklar</i>	1415	Dose to thyroid	Complete Mar 1999
Obesity	<i>Oeffinger</i>	3931	Brain dose in 500 cGy categories	Complete Nov 2000
CNS Non-Neurological Outcomes	<i>Gurney</i>	1219	Dose categories for brain, spine, thyroid, ovaries	Complete Oct 2001
CNS Neurological Outcomes	<i>Packer</i>	1219	Dose to 4 regions of brain	Complete Oct 2001
CNS Psychological	<i>Zebrack / Turk</i>	1219	Dose to 4 regions of the brain	Complete Aug 2002
Pregnancy Outcomes	<i>Green</i>	1327	Pituitary dose categories: females	Complete Sept 2002
Growth Hormone	<i>Sklar</i>	176	Dose for pituitary and direct spine	Complete Sept 2002
Premature Menopause	<i>Sklar</i>	1565	Pituitary, uterus and ovaries.	Complete Mar 2003
Stroke	<i>Oeffinger</i>	8583	Dose to 4 brain regions	Complete Dec 2003
Low birth weight and premature births	<i>Boice</i>	728	Proximity of gonads to treatment field	Complete Jun 2004
Ovarian Failure	<i>Sklar</i>	203	Dose to ovaries, uterus & pituitary	Complete Aug 2004
Wilms	<i>Breslow</i>	678	Dose to chest, abdomen, pelvis	Complete Jan 2004
Growth hormone use and meningiomas	<i>Sklar</i>	~8500	Maximum dose to any part of the brain	Complete Jul 2005

Study Title	Study PI	Number exposed to RT	Dosimetry required	Dosimetry status
Cohort studies (continued)				
Pulmonary Function	<i>Mertens</i>	~8500	First-pass regions treated	Complete 2005
Osteoporosis and avascular necrosis	<i>Kadan-Lottick</i>	~8500	Dose to gonads and pituitary and maximum brain dose	Complete Dec 2005
Fertility among survivors	<i>Green</i>	5624	Dose to gonads and pituitary	Complete Oct 2005, Jan 2006, Sept 2007
Bone Marrow Transplant	<i>Baker / Chow</i>	379	Dose to cranium	Complete Mar 2006
Dental Outcomes	<i>Kaste</i>	5632	Total average dose to the teeth	Complete Nov 2006
Thyroid exposure /ALL patients	<i>Chow</i>	2389	Dose to thyroid and pituitary	Complete Feb 2007
Stillbirth and neonatal death	<i>Boice / Signorello</i>	2805	Dose to ovaries, uterus, testes, pituitary	Complete Jun 2006
Menarche timing	<i>Armstrong</i>	299	Dose to ovaries and pituitary	Complete Feb 2007
Hodgkin Disease Outcomes	<i>Castellino</i>	1551	Dose range to body regions	Complete Jun 2007
Carotid Artery Dose	<i>Ness / Gurney</i>	50	Dose to the carotid artery	Complete Jul 2007
Thyroid exposure /entire cohort	<i>Bhatti / Sigurdson</i>	8494	Dose to thyroid	Complete Nov 2007
BRIEF neuro-psych outcomes	<i>Ness</i>	~8500	Dose to 4 brain regions	Complete Nov 2007
Cardiac outcomes	<i>Mulrooney</i>	~8500	Average dose to heart	Complete Feb 2008
Cataract cohort	<i>Chodick / Inskip</i>	~8500	Dose to lens	Complete Feb 2008
Visual complications	<i>Mertens / Whelan</i>	~8500	Dose to eye and brain	Complete Feb 2008
Breast screening	<i>Oeffinger</i>	3913	Yes/No and body region treated	Complete Feb 2008
Pain	<i>Ness</i>	~8300	Body sites, dose to 4 brain regions	Complete Apr 2008
Salivary gland tumors	<i>Inskip</i>	~8500	Dose to salivary glands or sites of treatment	Complete May 2008
Psychosexual outcomes/ females	<i>Sklar</i>	1412	Dose to ovaries and pituitary	Complete Feb 2009
Wilms Tumor long term follow-up	<i>Termuhlen</i>	717	Dose to heart and kidneys	Complete Oct 2009

Study Title	Study PI	Number exposed to RT	Dosimetry required	Dosimetry status
Cohort studies (continued)				
TBI/BMT Leukemia Cohort	<i>Baker and Chow</i>	2722	Dose to thyroid, gonads, brain, spine	Complete Jan 2010
Obesity	<i>Green</i>	5632	Pituitary	Complete Jan 2010
Fertility	<i>Green</i>	4023	Ovaries and pituitary	Complete Jan 2010
GI second cancers	<i>Henderson</i>	46	SMN site in/near/out treatment field	Complete Jan 2010
ECHOS	<i>Cox / Hudson</i>	883	Treatment dose and body region	Complete Jun 2010
Pregnancies during treatment	<i>Mulvihill</i>	16	Therapy records	Complete Sept 2010
GU complications	<i>Shnorhavorian/ Sklar</i>	8507	Dose to kidneys, ureters, bladder	Complete Dec 2010
Stroke – first and recurrent	<i>Fullerton / Mueller</i>	8633	Maximum dose to brain – existing dosimetry CNS, HD, Leukemia	Complete Dec 2010
Functional Outcomes	<i>Ness / Marina</i>	1094	Maximum dose to limb, pelvis, chest	Complete Feb 2011
Pulmonary complications	<i>Huang</i>	1876	Average dose to heart and lungs for CNS patients	Complete Apr 2011
Cranial Radiation	<i>Brinkman</i>	6875	Maximum TD by brain region	Complete May 2011
Oocyte radiosensitivity	<i>Hamish</i>	4324	Dose to ovaries	Complete Mar 2011
CNS Longitudinal Patterns of Late Effects	<i>Hardie</i>	923	Maximum TD by brain region	Complete Oct 2011
Longitudinal Changes in Health Status	<i>Hudson / Oeffinger</i>	8507	Use existing maximum TD by region	Complete Feb 2011
Male Infertility	<i>Seidel</i>	7717	Dose to testes and pituitary	Complete Mar 2011
Obesity among ALL survivors	<i>Kamdar</i>	1215	Maximum TD to spine and brain regions	Complete Nov 2011
Cardiac Outcomes – Risk model	<i>Chow</i>	8507	Maximum TD to chest and abdomen, heart average	Complete Jan 2012
BCC SMN – Genetic Risk	<i>Davies</i>	1282	Maximum TD by body region and brain region	In Progress
NCI-GWA SMN risk	<i>Morton</i>	8507	Maximum TD by body region and brain region	In Progress

Radiation Therapy Record Status as of May 2012: Original (diagnosed 1970-1986) & Expanded Cohorts (diagnosed 1987-1999)*

INSTITUTION	Records received		Records processed ¹		Status	
Cohort:	Original	Expanded	Original	Expanded	Original	Expanded
Children’s Hospital at Stanford University	386	101	386	0	Complete	Ongoing
Nationwide Children’s Hospital	391	114	391	48	Complete	Ongoing
Children’s Hospital of Los Angeles	279	81	279	0	Complete	Ongoing
Children’s Hospital of Philadelphia	493	311	493	2	Complete	Ongoing
Children’s Hospital of Pittsburgh	387	185	387	9	Complete	Ongoing
Children’s National Medical Center	113	9	113	0	Complete	Ongoing
City of Hope	-	41	-	2	-	Ongoing
Dana-Farber Cancer Institute	427	52	427	0	Complete	Ongoing
Emory University	68	126	68	77	Complete	Ongoing
Mayo Clinic	299	-	299	-	Complete	Ongoing
Memorial Sloan-Kettering Cancer Center	377	186	377	143	Complete	Ongoing
Minneapolis Children’s Medical Center	145	161	145	117	Complete	Ongoing
Riley Hospital for Children, Indiana University	209	116	209	105	Complete	Ongoing
Roswell Park Cancer Institute	221	80	221	63	Complete	Ongoing
Seattle Children’s Hospital	274	114	274	17	Complete	Ongoing
St. Jude Children’s Research Hospital	977	191	977	56	Complete	Ongoing
St. Louis Children’s Hospital	228	116	228	42	Complete	Ongoing
Texas Children’s (Baylor)	220	31	220	0	Complete	Ongoing
Children’s Hospital Colorado	377	34	377	0	Complete	Ongoing
Toronto Hospital for Sick Children	697	0	697	0	Complete	Ongoing
U.T.M.D. Anderson Cancer Center	408	143	408	60	Complete	Ongoing
UAB/The Children’s Hospital of Alabama	97	16	97	0	Complete	Ongoing
UCLA Mattel Children’s Hospital	250	10	250	0	Complete	Ongoing
University of California at San Francisco	236	56	236	39	Complete	Ongoing
University of Michigan - Mott Children’s Hospital	431	187	431	50	Complete	Ongoing
University of Minnesota	370	67	370	32	Complete	Ongoing
UT - Southwestern Medical Center	147	122	147	52	Complete	Ongoing
Total by cohort	8507	2650	8507	914	Complete	Ongoing
Combined Total	11,157		9,421			

* Counts are for "participants" only. Prospective participants who are in the recruitment process are not included in the counts.

[1] "Processed" includes all steps in data management, such as coding, quality control, computer entry, and verification.

Applications of Intent (AOI) to Conduct Research

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CANCER CONTROL						
05.21.08	The Influence of Geographical Proximity to a Cancer Center on Risk Based Care among Childhood Cancer Survivors	Caplin/Utah Oeffinger/MSKCC		06.10.08	Approved	Approved
05.27.08	Longitudinal Changes in Health Status	Hudson/SJCRH	Chronic Disease Psychology	07.16.08	Approved	Approved
06.02.08	Risk-Based Health Evaluation of CCSS Participants (CPIR)	Green/SJCRH	Chronic Disease	07.16.08	Approved	Approved
06.05.08	A Comparison of Functional Outcomes between Sarcoma Survivors with Surgery or Radiation As Their Local Control	Marina/Stanford	Chronic Disease	07.16.08	Approved	Approved
06.05.08	Physical Activity in Lower Extremity Sarcoma Survivors with Amputation	Ness/SJCRH	Chronic Disease	07.16.08	Approved	Approved
06.05.08	A Comparison of Functional Outcomes between UE and LE Sarcoma Survivors	Marina/Stanford	Chronic Disease	07.16.08	Approved	Approved
06.05.08	Neurocognitive Problems and Health Behavior Outcomes	Krull/SJCRH	Psychology	07.16.08	Approved	Approved
06.18.08	Understanding Health Care Utilization Patterns and Changes Occurring over a Decade: A Report from the Childhood Cancer Survivor Study	Casillias/UCLA		07.16.08	Approved	Approved
10.14.08	Investigating the Needs of Childhood Cancer Survivors: Understanding Residual Treatment Effects (INSURE)	Cox/SJCRH	Chronic Disease	11.12.08	Approved	Ancillary Study Approved
04.07.09	Predictors of Smokeless Tobacco Use among Survivors of Childhood Cancer	Klosky/SJCRH		05.12.09	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CANCER CONTROL (continued)						
06.21.09	Mental Health and Tobacco Use Among Childhood Cancer Survivors: A Longitudinal Analysis	Lown/Alcohol Research Group	Psychology	07.10.09	Approved	Approved
08.06.09	Identifying Intervention Targets to Increase Mammography Screening among At-Risk Childhood Cancer Survivors	Cox/SJCRH	SMN	09.09.09	Approved	Approved
11.13.09	Prevalence and Predictors of Smoking Cessation in Childhood Cancer Survivors	Klesges/SJCRH		12.22.09	Approved	Pending
02.12.10	Mental Health, Tobacco & Alcohol use in Survivors and Siblings (Ancillary Study)	Lown/Alcohol Research Group		03.03.10	Approved	Not Funded
03.08.10	Determinants of Employment	Stone/UCLA			Withdrawn due to overlap	—
06.10.10	Longitudinal assessment of physical activity	Ness/SJCRH	Chronic Disease Psychology	06.25.10	Approved	Approved
03.16.11	Diet and insulin resistance in survivors of childhood leukemia	Tonorezos/MSKCC	Chronic Disease	03.29.11	Approved	Pending
03.16.11	Risk reduction strategies to prevent subsequent skin cancer	Mertens/CHOA	SMN Epi/Biostats	03.29.11	Approved	Pending
03.22.11	Longitudinal changes of Health Risk Factor Clusters and Relationship to Morbidity in Adult Survivors of Childhood Cancer	Hijiya/Northwestern	Chronic Disease	04.13.11	Approved	Pending
04.13.11	Modifiable lifestyle factors and risk of a secondary breast cancer	Rosenberg/Harvard	SMN		Withdrawn	
04.14.11	Cost-effectiveness of Colorectal Cancer Screening Among Survivors Treated with Abdominal Radiation Therapy	Hodgson/Princess Margaret Hospital	SMN	05.30.11	Approved	Pending
06.15.11	Chronic Health Conditions and Employment Status Transitions for Childhood Cancer Survivors	Kirchhoff/Huntsman Cancer Institute Salt Lake City	Chronic Disease	07.26.11	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CANCER CONTROL (continued)						
06.30.11	The impact of location and type of follow-up care on morbidity and mortality in childhood cancer survivors	Nathan/Sick Kids	Chronic Disease Epi/Biostats	07.13.11	Approved	Pending
08.01.11	Health behaviors and Mammogram Utilization in the CCSS	Rosenberg/Harvard School of Public Health	Psychology	08.16.11	Approved	Approved
09.09.11	The Health System Use and Cost Implications of Amputation vs. Limb Salvage Surgery	Conti/University of Chicago	Psychology	09.23.11	Approved	Pending
09.29.11	Colorectal Screening Practices of Survivors of Childhood Cancer at Risk for Secondary Colorectal Malignancies	Kohler/UAB	SMN Psychology	11.07.11	Approved	Approved
12.02.11	Health Status Outcomes in Survivors of Hodgkin Lymphoma	Marina/Stanford			Withdrawn	—
12.06.11	Evaluation of the association between lifestyle factors and pregnancy outcomes	Gawade/SJCRH	Epi/Biostats	01.04.12	Approved	Pending
12.09.11	Information Needs of Childhood Cancer Survivors and their Families	Mendonca/U. of Wisconsin	Epi/Biostats	01.04.12	Approved	Pending
01.27.12	Influence of lifestyle on site-specific cumulative incidence for second primary malignancies in five-year survivors of a childhood cancer	Kovalchik/NIH	SMN	03.07.12	Approved	Pending
03.01.12	Tobacco Use Among Adult Siblings of Childhood Cancer Survivors	Buchbinder/CHOC	Psychology	03.21.12	Approved	Pending
04.26.12	Association Between Exercise Behavior and Incidence of non-cancer Chronic Health Conditions	Jones/Duke	Chronic Disease Psychology		Approved	Pending
CHRONIC DISEASE						
05.02.08	Genitourinary Complications in Survivors of Childhood Cancer	Shnorhavorian/FHRC		06.10.08	Approved	Approved
06.05.08	The Risk of Osteoporosis and Fracture among Survivors of Childhood Cancer	Kadan-Lottick/Yale University			Approved	Approved

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CHRONIC DISEASE (continued)						
06.06.08	Cardiovascular Risk Factors and CV Events	Meacham/Emory University	Epi/Biostats	07.16.08	Approved	Approved
06.06.08	Solid Organ Transplantation in 5-year Survivors of Childhood Cancer	Termuhlen/Nationwide Children's Hospital		07.11.08	Approved	Approved
06.11.08	Infectious Complications in Childhood Cancer Survivors	Perkins/Children's Hospitals & Clinics of Minnesota		07.11.08	Approved	Approved
06.12.08	A Comparison of Mortality and Morbidity in Hodgkin's Survivors of Contemporary Therapy	Castellino/Wake Forest University	SMN	07.11.08	Approved	Pending
06.13.08	Determination of Risk Factors for Stroke Among Survivors of Childhood Hodgkin's Disease - A Case: Control Study	Bowers/U.T. Southwestern Medical Center at Dallas		07.11.08	Approved	Withdrawn
07.01.08	Adverse Neurologic Sequelae Are Predictors of Poor Outcome in Survivors of Childhood Central Nervous System Tumors and Leukemia: A Report from the Childhood Cancer Survivor Study	Ulrich/Children's Hospital Boston/Dana-Farber Cancer Center	Psychology	08.11.08	Approved	Withdrawn
09.02.08	Long-term Outcomes in Adult Survivors of Childhood Cancer: A Comparison of Conventional Therapy and Hematopoietic Cell Transplantation (HCT)	Armenian/City of Hope	Psychology Cancer Control Epi/Biostats	09.19.08	Approved	Approved
09.25.08	Fertility of Female Survivors of Acute Lymphoblastic Leukemia	Green/SJCRH		10.14.08	Approved	Approved
11.11.08	Late DVT Risk in Cancer Survivors	Setia/Memorial Sloan Kettering		12.02.08	Approved	Withdrawn
03.11.09	Creation of a Risk Score Algorithm to Predict Individual Risk of Future Serious Cardiovascular Disease	Chow/FHRC	Cancer Control	04.03.09	Approved	Approved
06.11.09	Outcome of Pregnancies Exposed to Cancer Therapy	Mulvihill/U. of Oklahoma	Genetics	07.10.09	Approved	Approved
06.19.09	The Multifactorial Etiology of Obesity among CCSS Participants	Green/SJCRH	Psychology	07.10.09	Approved	Approved

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CHRONIC DISEASE (continued)						
07.14.09	Renal Outcomes	Nottage/SJCRH			Withdrawn due to overlap	—
09.08.09	Pulmonary complications in Long-term Survivors of Childhood CNS Tumors with Craniospinal Irradiation	Tein/SJCRH	Psychology	10.06.09	Approved	Approved
11.09.09	Diseases of the Thyroid Gland Associated with Radiation Therapy: A Report from the Childhood Cancer Survivor Study	Viega/NCI	SMN		Approved	Approved
01.29.10	Longitudinal Assessment of Chronic Health Conditions	Armstrong/SJCRH		02.12.10	Approved	Approved
02.26.10	Health and Functional Status of Long Term Adult Medulloblastoma Survivors	King/Wash. U.	Psychology SMN	03.31.10	Approved	Pending
03.04.10	Health Status of Older Adult Survivors of Childhood Cancer	Kenney/DFCI	Psychology Epi/Biostats	03.31.10	Approved	Pending
04.20.10	Scoring Alkylating Agent Exposure: Evaluation of the Cyclophosphamide Equivalent Dose Score	Green/SJCRH	SMN Epi/Biostat	5.18.10	Approved	Approved
05.12.10	Evaluation of Long-term Outcomes in Ewing Sarcoma Survivors	Marina/Stanford	SMN	06.17.10	Approved	Approved
06.10.10	Neurologic and Neurosensory Deficits in Long-term Survivors of Childhood Brain Tumors: Occurrence of New Deficits and Effects of Aging in Occurrence as Assessed in 2007 Survey	Wells/Children's National	SMN Psychology	6.25.10	Approved	Approved
06.24.10	Premature Menopause in Survivors of Childhood Cancer	Levine/Columbia		07.06.10	Approved	Approved
11.05.10	Infertility and Use of Fertility Treatments	Barton/Brigham & Women's		11.23.10	Approved	Approved
02.18.11	BMI and Diabetes Mellitus in Survivors of ALL	Tonorezos/MSKCC	Cancer Control	03.16.11	Approved	Pending
04.22.11	Changes in BMI Among Adult Survivors of Childhood CNS Tumors	Chang/MD Anderson	Psychology	05.03.11	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CHRONIC DISEASE (continued)						
05.23.11	Longitudinal Analysis of Outcomes for Acute Lymphoblastic Leukemia Survivors	Dilley/Northwestern	Cancer Control	05.30.11	On Hold	Pending
12.21.11	Hypertension	Tonorezos/MSKCC	Cancer Control			
05.06.12	Chronic Medical Conditions Among Long-term Survivors of Pediatric Non-Hodgkin Lymphoma	Bluhm/Washington Hospital	Epi/Biostats			
EPIDEMIOLOGY / BIostatISTICS						
04.21.08	Conditional Survival in Pediatric and Adolescent Malignancies	Wasilewski-Masker/Emory/CHOA		06.10.08	Approved	Approved
04.21.08	Analysis of Late Mortality by Treatment Era: Brief Report	Armstrong/SJCRH		06.10.08	Approved	Not Approved
06.19.08	Cardiac Mortality	Armstrong/SJCRH		07.16.08	Approved	Approved
09.23.08	Assessing Bias Associated with Missing Data from the Childhood Cancer Survivor Study	Huang/SJCRH		10.14.08	Approved	Pending
02.12.09	Predicting Late Effects of Individual Cancer Survivors: A Pilot Methodological Study	Yasui/Edmonton Alberta		03.16.09	Approved	Pending
05.12.09	Impact of Health Behaviors and Health Perceptions on Subsequent Mortality in Childhood Cancer Survivors	Cox/SJCRH		05.28.09	Approved	Ancillary Study Approved
05.26.09	Cost Effectiveness of Cardiac Guideline for Survivors of Pediatric Cancers	Wong/City of Hope		06.10.09	Approved	Approved
10.07.09	Computational Dose Reconstruction for Breast Cancer Patients after Hodgkin Lymphoma: Dose Comparison and Sensitivity Study	Lee/NCI	SMN	11.05.09	Not Approved	—
11.16.09	Congenital Heart Disease	Gruber/U. of Michigan	Genetics	12.22.09	Approved	Not Approved
11.19.10	Exercise and prevention of late cardiac outcomes after anthracyclines	Ryerson/Emory	Chronic Disease Cancer Control	12.10.10	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
EPIDEMIOLOGY / BIOSTATISTICS (continued)						
06.18.10	Long-term outcomes in survivors of retinoblastoma (the New York cohort): a comparison of survivors versus non-cancer controls	Dunkel/MSKCC		07.01.10	Approved	—
07.07.10	Late Mortality by Treatment Era	Armstrong/SJCRH			Approved	Pending
10.27.10	Prediction of Risk of Serious Health Conditions	Salz/MSKCC		11.10.10	Approved	Pending
05.16.11	Cost Effectiveness of COG Breast Cancer Screening Guidelines for Female Survivors of Pediatric Cancers	Wong/City of Hope	SMN Cancer Control	06.02.11	Approved	Pending
06.13.11	Predictors of Healthy Aging	Ness/SJCRH	SMN/ Chronic Disease Genetics Psychology Cancer Control	07.13.11	Approved	Pending
09.08.11	Statistical Analysis of a Mixture of Recurrent Event and Panel Count data	Zhu/SJCRH		09.23.11	Approved	Pending
10.06.11	Estimating long-term risks in children newly diagnosed with ALL based on survivor clusters in the CCSS cohort	Essig/University of Bern	Cancer Control Chronic Disease SMN	11.07.11	Approved	Pending
05.15.12	Predicting the risk of SMN among childhood cancer survivors with NMSC as a second malignancy	Ojha/SJCRH	SMN			
GENETICS						
05.02.08	Characterization of Genomic Alterations in Radiation-Related Breast Cancer Using ArrayCGH (Comparative Genomic Hybridization)	Yang/NCI	SMN	06.02.08	Approved	Approved
05.27.08	Incidence of Familial Hodgkin Lymphoma	Metzger/SJCRH			Approved	Hold
06.05.08	Genetic Predictors of Impaired and Enhanced Neurocognitive and Psychological Functioning among Survivors of Childhood Leukemia and Lymphoma	Kadan-Lottick/Yale University	Psychology	03.16.09	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
GENETICS (continued)						
06.25.08	Genetic Polymorphisms and Metabolic Outcomes in Childhood Leukemia Survivors	Kamdar/Texas Children's Hospital	Chronic Disease	08.11.08	Approved	Ancillary Study Approved
09.25.08	Late Effects in Childhood Cancer Survivors and Vitamin D Polymorphisms	Ocku/Baylor	SMN	10.14.08	Approved	Not Approved
11.13.08	Long-Term Morbidity in Childhood Cancer Survivors with Down Syndrome	Raber/UCSF	Chronic Disease	12.02.08	Approved	Approved
12.02.08	Evaluation of SNPs in the EWS Breakpoint Region in People with and without Ewing Sarcoma	DuBois/UCSF		12.18.08	Approved	Ancillary Study Approved
06.15.09	Telomere Length and Risk for Second Malignancy in Pediatric Cancer Survivors	Gramatges/Baylor	SMN	07.10.09	Approved	Approved
10.15.09	Polymorphisms of Cardiomyocyte Genes in CCSS Participants with Congestive Heart Failure or Subclinical Left Ventricular Dysfunction After Treatment with Anthracyclines	Green/SJCRH		11.05.09	Approved	Withdrawn
07.28.10	Detecting Germ Cell Mutation by Family DNA Sequencing	Mulvihill/U of Oklahoma			Hold	Hold
08.21.10	Genetic Alterations in Second Malignant Neoplasms	Nakamura/UCSF	SMN	11.10.10	Approved	Approved
12.15.10	Multiple SMNs & Genomic Instability/DNA Repair	Bhatia/City of Hope	Epi/Biostats	02.03.11	Approved	Pending
02.09.11	Molecular variation between spontaneous breast cancers and breast cancers induced by radiation in survivors of Hodgkin's Lymphoma	Pelloski/Ohio State	SMN	03.09.11	Approved	Pending
04.04.11	Genome-Wide Association Study of Subsequent Malignancies	Morton/NCI	SMN Epi/Biostats	04.21.11	Approved	Approved
04.14.11	Identification of susceptibility loci in radiation-induced breast cancer by exome and CNV analysis	Hodgson/Princess Margaret Hospital	SMN	05.03.11	Approved	Pending
05.03.11	Genetic susceptibility to anthracycline-related CHF	Bhatia/City of Hope	Chronic Disease Epi/Biostats	06.02.11	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
GENETICS (continued)						
07.08.11	Genetic Susceptibilities to Second Cancers	Onel/University of Chicago	SMN	08.16.11	Approved	Pending
07.08.11	PRDM1 and Somatic Mutations in SMNs after Hodgkin Lymphoma	Onel/University of Chicago	SMN	08.16.11	Approved	Pending
10.05.11	Host and demographic factors associated with solid second malignant neoplasms in un-irradiated childhood cancer survivors	Henderson/University of Chicago	SMN	11.07.11	Withdrawn	—
PSYCHOLOGY						
05.05.08	Psychosexual Adjustment in Long-Term Female Survivors of Childhood Cancer	Carpentier/ Indiana University School of Medicine			Withdrawn	—
06.05.08	Predictors of Future QOL in Adolescent Survivors of Childhood Cancer	Nolan/SJCRH	Chronic Disease	07.11.08	Approved	Approved
06.07.08	Quality of Life Associated with Fertility Status in Childhood Cancer Survivors	Warwick/Medical College of Wisconsin	Chronic Disease	07.11.08	Withdrawn	
06.09.08	QOL in Long-Term Survivors	Schapmire/University of Louisville		07.11.08	Withdrawn	—
06.11.08	Health Behaviors and Chronic Disease	Hudson/SJCRH			Withdrawn	—
07.10.08	The Psychological and General Health Status Impact of Late Sibling Death: A Report from the Childhood Cancer Survivor Study	Raber/UCSF Children's Hospital		08.11.08	Withdrawn	—
08.25.08	Impact of Chronic Disease on Neurocognitive and Psychosocial Functions	Krull/SJCRH	Chronic Disease	09.19.08	Approved	Approved
10.10.08	An Examination of the Relationship Between Fatigue/Sleep Disturbance and Neurocognitive Functioning in Adult Survivors of Childhood Cancer	Clanton/Baylor		11.12.08	Approved	Approved
11.24.08	Outcome after Stroke among Long-Term Survivors of Childhood Leukemia and Brain Tumors	Fullerton/UCSF	Chronic Disease	12.18.08	Approved	Approved
01.26.09	Localization of CNS Directed Radiotherapy and Neurocognitive, Psychological and Quality of Life Outcomes in Survivors of CNS Tumors	Armstrong/SJCRH		02.12.09	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
PSYCHOLOGY (continued)						
01.27.09	Chronic Pain and Psychosexual Function in Adult Survivors of Childhood Cancer	Randolph-Frye/SJCRH		02.12.09	Withdrawn	—
05.05.09	Dermatological Issues in Adult Survivors of Childhood Cancer	Kinahan/Northwestern	Cancer Control	05.28.09	Approved	Approved
06.16.09	Predictors of Psychoactive Medication Use	Brinkman/SJCRH	Epi/Biostats	07.10.09	Approved	Approved
08.12.09	Causal Associations Between Psychological and Quality of Life Outcomes in CCSS	Krull/SJCRH		09.09.09	Approved	Withdrawn
08.15.09	Health Related Quality of Life in Adult Survivors of Relapsed ALL	Essig/U. of Bern		09.09.09	Withdrawn	—
01.18.10	Psychological and Neurocognitive outcomes in those diagnosed with cancer as adolescent and young adults in the CCSS	Prasad/Vanderbilt		02.12.10	Approved	Pending
09.29.10	Longitudinal Patterns of Late Effects in Adult Survivors of Childhood Brain Tumors	Hardie/Drexel	Epi/Biostats Chronic Disease	10.21.10	Approved	Approved
10.21.10	Longitudinal Psychological Distress	Brinkman/SJCRH		11.10.10	Approved	Approved
04.22.11	Sensory-motor problems and associated functional outcomes in survivors of childhood central nervous system (CNS) tumors	Walsh/ Children's National Medical Center	Chronic Disease	05.03.11	Approved	Pending
06.23.11	Physical Activity and Risky Behavior Patterns Among Teenage Survivors of Childhood Cancers	Devine/U. of Rochester	Cancer Control	07.13.11	Approved	Approved
07.23.11	Measurement invariance in health-related quality of life between young adult survivors of childhood cancer and their siblings	Huang/ University of Florida	Epi/Biostats	08.16.11	Approved	Pending
01.19.12	Post-traumatic stress symptoms, adherence to screening guidelines and health-related behaviors in adult survivors of childhood cancer	Kimberg/SJCRH	Cancer Control		Hold	Hold
01.19.12	Health Related Locus of Control	Kimberg/SJCRH	Cancer Control	02.02.11	Approved	Pending
03.27.12	Chronic alcohol consumption and neurocognitive function in adult survivors of childhood cancer	Brinkman/SJCRH	Cancer Control	04.26.12	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
PSYCHOLOGY (continued)						
04.25.12	Psychosocial and physical factors influencing fatigue in survivors of childhood Hodgkin Lymphoma	Crabtree/SJCRH	Epi/Biostats	05.15.12	Approved	
05.07.12	Identifying Longitudinal Predictors of Quality of Life in Adolescent Survivors of Pediatric Cancer	Stern/VCU				
05.08.12	Fatigue reported by childhood cancer survivors and its relationship to health outcomes	Lai/Northwestern University	Epi/Biostats			
SECOND MALIGNANT NEOPLASMS						
04.10.08	Multiple Subsequent Neoplasms	Robison/SJCRH		04.20.08	Approved	Approved
06.20.08	GH Therapy and Brain Tumors as SMNs	Patterson/Emory University	Chronic Disease	03.16.09	Approved	Not Approved
12.18.08	Colorectal Cancer as SMN	Henderson/Univ. of Chicago		01.12.09	Approved	Approved
09.11.09	Late Occurring Secondary Leukemia's in Survivors of Childhood Cancers	Nottage/SJCRH		10.06.09	Approved	Approved
05.25.10	Melanoma as a second malignant neoplasm	Pappo/SJCRH	Genetics	06.14.10	Approved	Approved
06.18.10	Breast cancer following chest RT	Oeffinger/MSKCC	Chronic Disease	07.01.10	Approved	Approved
10.28.10	Primary Tumor Recurrence and SMN After Pregnancy	Rokitka/Roswell Park		11.10.10	Approved	Pending
11.09.10	SMN After Diabetes Mellitus	Chang/UCSF	Chronic Disease	11.23.10	Approved	Pending
11.11.10	Breast Cancer Risk Factors	Inskip/NCI		12.07.10	Approved	Approved
11.16.10	Radiation Dose and Risk of Meningioma	Rajaraman/NCI	Epi/Biostats		Hold	
02.03.11	Renal Cell Carcinoma	Wilson/SJCRH		03.09.11	Approved	Approved
04.13.11	Gynecological Malignancies	Nathan/Sick Kids		05.03.11	Approved	Pending
04.20.11	Development and validation of an absolute risk prediction model for thyroid cancer in childhood cancer survivors	Ronckers/Netherlands	Epi/Biostats	05.03.11	Approved	Approved
04.27.11	Testicular Cancer Following Pediatric Cancer	Oeffinger/MSKCC	Chronic Disease	05.10.11	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
SECOND MALIGNANT NEOPLASMS (continued)						
05.03.11	Development of Radiobiologic Models of Second Cancer Risk for Childhood Cancer Patients Treated with Radiation Therapy	Hodgson/Princess Margaret	Epi/Biostats	06.02.11	Approved	Pending
05.09.11	Risk of Breast Cancer in Survivors Not Exposed to Chest Radiation	Henderson/Univ. of Chicago	Genetics	06.02.11	Approved	Approved
05.30.11	Breast Cancer Following Spinal Radiation	Moskowitz/MSKCC	Cancer Control Epi/Biostats	06.22.11	Approved	Approved
08.11.11	Subsequent neoplasms in adult survivors of childhood cancer in relation to weight and physical activity	George/NCI	Cancer Control Epi/Biostats Psychology	08.21.11	Approved	Pending
08.31.11	Lymphoma as SMN	Suh/University of Chicago		09.21.11	Approved	Pending
04.03.12	Late Second Neoplasms in Long-Term Survivors of Childhood Cancer	Turcotte/University of Minnesota	Epi/Biostats	04.26.12	Approved	Pending

INSTITUTION KEY

CHOA – Children's Hospital of Atlanta
 DFCI – Dana Farber Cancer Institute
 FHRC – Fred Hutchinson Research Center
 MSKCC – Memorial Sloan Kettering Cancer Center
 NCI – National Cancer Institute
 SJCHR – St. Jude Children's Research Hospital
 UCLA – University California Los Angeles
 UCSF – University California San Francisco
 VCU – Virginia Commonwealth University

Statistical Center Current Project List

Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Submitted & Draft Manuscripts				
Long term outcomes in ALL survivors who received HSCT	Scott Baker/Eric Chow	Wei Liu	Kumar	Minor Revision resubmitted - Pediatric Blood and Cancer
BCC Lance Armstrong dosimetry case-control	Ann Mertens	Kayla	Wendy	Revised and resubmitted - JNCI
Randomized trial identifies predictors of appropriate screening	Jeanne Steele/Ann Mertens	Toana	Melanie Wall (Minnesota)	Submitted - Psycho-oncology
Stroke in Childhood cancer survivors	Sabine Mueller/Heather Fullerton	Kayla	Wendy	Submitted - Circulation
Prediction model for thyroid SMN risk	Kovalchik/Sigurdson	Wendy	Stephanie Kovalchik	Submitted - JCO
Melanoma as SMN	Pappo	Wei Liu	Kumar	Submitted - Cancer
Psychosocial predictors of psychoactive medication	Tara Brinkman/ Kevin Krull	Nan Zhang	Kumar	Submitted - Cancer
Employer-Sponsored Health Insurance Coverage Limitations in Adult Survivors of Childhood Cancer	Kirchhoff/Park	Wendy	Anne Kirchhoff	Submitted - Supportive Care in Cancer
COG L9704 / CCSS Collaboration - AML Downs' Syndrome	Joe Neglia / Kris Ann Schulz	Toana	COG Statistician	Submitted - JCO
Scoring alkylating agent exposure: evaluation of the CED	Dan Green	Wendy	Vikki	Submitted - JCO
Infectious Complications	Joanna Perkins	Yan Chen	Yutaka	Manuscript in Preparation
Longitudinal Health care	Jackie Casillas	Qi Liu	Yutaka	Manuscript in Preparation
Psychosexual functioning	Jennifer Ford / Chuck Sklar	Toana	Wendy/John	Manuscript in preparation
Missing data imputation (methodology)	Leah Martin/Qi Liu	Yutaka	Wendy	Manuscript in Preparation
Multiple Risk Factor Behaviors	Melissa Hudson	Sue Huang	Kiri	Manuscript in preparation
Relationship between PTSS and PTG	Mary Randolph-Frye/Krull	Toana	Wendy	Manuscript in preparation
Health outcomes for infant cancer survivors	Lynda Vrooman/ Lisa Diller	Pam/Wendy	Julie Najita (Harvard)	Manuscript in preparation

Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Submitted & Draft Manuscripts (continued)				
Male infertility - Male Health Questionnaire	Wasilewski/Meacham	Kristy	Wendy	Manuscript in Preparation
Comparison of Health Status between upper and lower extremity Sarcoma survivors	Neyssa Marina	Wendy	Kiri	Manuscript in Preparation
Cost effectiveness of cardiac guidelines	Lennie Wong	Kayla/Wendy	Lennie Wong (COH)	Manuscript in Preparation
Telomere length case/control study	Monica Gramatages	Qi Liu	Yutaka	Manuscript in Preparation
Conditional Survival: A Comparison of CCSS and SEER Data	Karen Wasilewski-Masker	Erin	Yutaka	Manuscript in Preparation
Cardiovascular risk factor clusters and outcomes	Greg Armstrong	Yan Chen	Yutaka	Manuscript in Preparation
Risk of Breast Cancer Following Spinal Irradiation for a Pediatric Malignancy	Chaya Moskowitz	Wendy	Chaya Moskowitz (MSKCC)	Manuscript in Preparation
Regional Access	Dierdre Caplin/ Kevin Oeffinger	Kiri	Dierdre Caplan	Manuscript in Preparation
Renal Carcinoma following therapy for cancer	Carmen Wilson	Kumar	Wendy	Manuscript in Preparation
Pulmonary outcomes among CNS survivors	Tseng Huang/ Kiri Ness	Yan Chen	Yutaka	Manuscript in Preparation
Predictors of smokeless and dual tobacco use among survivors of childhood cancer	James Klosky	Nan Zhang	Kumar	Manuscript in Preparation
Predictors of quality of life in adolescent survivors of childhood cancer	Vikki Nolan	Vikki Nolan	Kiri	Manuscript in Preparation
Analyses Ongoing				
MDM2 risk factor for BC	Stella Davies	John	Wendy	Analyses completed
ARL111 risk for multiple SMN	Stella Davies	Kayla	John / Wendy	Analyses completed
Conditional Survival: A Comparison of CCSS and SEER Data.	Karen Wasilewski	Yutaka		Analyses completed
Growth Hormone and subsequent CNS Neoplasms	Briana Patterson	Yan Chen	Yutaka	Analyses Completed
Psychosocial sequelae after cancer in infancy vs. after infancy	Marc Bornstein (Axia)	John / Wendy	NCI Statistician	Analyses Ongoing

Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Analyses Ongoing (continued)				
BCC risks due to sun exposure and radiation	Ann Mertens	Wendy	Wendy	Analyses Ongoing
Impact of Chronic disease on NCQ and psychosocial functions	Neelam Jain	Wei Liu	Kumar	Analyses pending for additional data
Inverse probability censored weighting (IPCW) to adjust for selection bias and drop out	Chonghzi Di	Toana / Kayla	Wendy	Analyses Ongoing
Breast cancer risk calculator after chest radiation	Chaya Moskowitz	Wendy	Chaya (MSKCC)	Analyses Ongoing
GU outcomes	Margarett Shnoorhavian	Pam	Wendy	Analyses Ongoing
Predictors of quality of life in adolescent survivors of childhood cancer	Vikki Nolan	Vikki Nolan	Kiri	Analyses Ongoing
A longitudinal assessment of physical activity	Carmen Wilson	Kayla	Wendy	Analyses Ongoing
Incidence of cataract in relation of radiation dose	Gabriel Chodick	Yan Chen /Yutaka	Gabriel / Peter Inskip	Data sent.
Longitudinal Patterns of Late Effects in Adult Survivors of Childhood Brain Tumors	Thomas Hardie	Kristy	Penn Statistician	Data sent.
MSK Retinoblastoma survivor study w/sibling data from CCSS	Ira Dunkel	Kayla	Wendy	Partial Data sent, pending additional data.
Non-Surgical Premature Menopause in CCSS Update	Levine/ Sklar	John	Wendy	Analyses Initiated and data review underway.
Outcomes of Pregnancies Exposed to Cancer Therapy	John Mulvihill	John	Wendy	Data sent.
Predictors of smokeless and dual tobacco use among survivors of childhood cancer	James Klosky	Nan Zhang	Kumar	Analyses Ongoing
Health Behaviors and Mortality	Cheryl Cox	Wendy	Vikki Nolan	Analyses Ongoing
Incidence of Breast Cancer after Chest radiation	Kevin Oeffinger	Wendy	Chaya Moskowitz (MSKCC)	Analyses Ongoing
Predicting cardiovascular disease; creation of a risk score model	Eric Chow	Yan Chen	Yutaka	Analyses Ongoing
Longitudinal Health Status	Melissa Hudson	Kiri	Wendy/Kiri	Analyses Ongoing

Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Analyses Ongoing (continued)				
Longitudinal Chronic Health conditions	Greg Armstrong/ Kevin Oeffinger	Toana	Wendy	Analyses Ongoing
Neurologic/neurosensory sequelae in CNS survivors	Elizabeth Wells	Kristy	Wendy	Analyses Ongoing
Morbidity in Survivors of Childhood Leukemia with Down Syndrome	Shannon Raber/ Rob Goldsby	Kayla	Wendy	Analyses pending additional data.
Infertility and the use of fertility treatments in female survivors	Sara Barton/ Lisa Diller	Wendy/Pam	Julie Najita (Harvard)	Analyses Ongoing
Health behaviors and mammogram utilization	Shoshana Rosenberg	Wendy	Chaya Moskowitz (MSKCC)	Data Sent.
Chronic Health Conditions and Employment Status Transitions	Anne Kirchhoff	Wendy	Anne K.	Analyses Ongoing
Breast Cancer in Survivors Not Exposed to Chest Radiation	Tara Henderson	Wendy	Chaya Moskowitz (MSKCC)	Initiating data preparation
Direct and indirect effects of anthracycline exposure on cardiac outcomes	Blythe Ryerson	Wendy/Kayla	Blythe Ryerson	Data sent.
Joint effects of treatment and host factors on second primary breast cancers	Peter Inskip	Wendy	Chaya/John	Data planning with MSKCC/NCI/MDA
Thyroid cancer SNP study	Yuri Nikiforov / Smita Bhatia	John	Wendy	Case / Control selection, data sent.
Genetic susceptibility to Obesity After Treatment for Childhood Cancer	Kala Kamdar	Kristy	Local Statistician	Subjects selected, data sent.
Characterization of genomic alterations in radiation-related breast cancer using array-CGH (comparative genomic hybridization).	Rose Yang	Kayla	NCI group	Subjects selected, data sent.
Physical Activity and Psychological Functioning Among Teenage Survivors	Katie Devine	John	Wendy	Analyses Ongoing
Solid Organ transplant after Childhood Cancer	Amanda Termuhlen	Toana	Wendy	Analyses Initiated
Male sexual health	Chad Ritenour/ Lillian Meacham	Kristy	Wendy	Analyses Ongoing

Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Analyses Ongoing (continued)				
Association between lifestyle factors, psychological status and adverse pregnancy outcomes	Prasad Gawade	Kiri	Wendy	Analyses Ongoing
GWAS of Subsequent Neoplasms in CCSS	Lindsey Morton	Wendy	NCI group	Project Underway
Participation Feasibility Study	Dan Green/Ann Mertens	Wei Liu	Kumar	Analysis ongoing
Approved Concepts in Queue				
Physical Activity and Psychological Functioning Among Teenage Survivors	Katie Devine	Wendy		
Measurement invariance in health-related quality of life between survivors and siblings	I-Chang Huang	Wendy		
Proposals Under Development				
Prevalence and Predictors of Smoking Initiation and Cessation in Childhood Cancer Survivors	Bob Klesges	Kumar		
Health and Functional Status of Adult Medulloblastoma Survivors	Allison King	Wendy/Kristy		
Predictors of Colorectal Cancer Screening Practices	Connie Kohler/Casey Daniel	Wendy		
Psychological and neurocognitive outcomes in adolescents and young adults	Pinki Prasad	Wendy		
Prediction of risk of serious health conditions among survivors	Talya Salz	Wendy/Chaya		
Risk of SMN in long-term survivors of childhood cancer with Diabetes mellitus	Rob Goldsby	Wendy		
Long term outcomes among standard risk ALL patients	Stefan Essig	Wendy		
Longitudinal changes in health risk factor clusters	Nobuko Hijiya	Wendy/Kiri		
Health Status Outcomes in HL survivors	Karen Effinger	Wendy		

Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Ancillary Study Grant Proposals				
ECHOS (Cardiovascular risk factor monitoring) - Ancillary	Hudson	Wendy		Funded
Insure (Needs Assessment) - Ancillary	Cox	Wendy		Complete - 1st Manuscript draft prepared
Low-grade Neuroblastoma Survivors	Doug Ris	Wendy		Funded
Projecting breast cancer risk	Moskowitz/Oeffinger			Funded
Mammography and high risk survivors	Oeffinger			Funded
Data Management				
Created Frozen data through FU2007 data (Q's, Mortality 2009, SMN)	John Whitton	Kiri/Aaron	Wendy	Most recent Freeze, Jan, 2011
CCSS MHQ data error check	John/Chris	John	Kumar/Wendy	Complete.
Creation of Web based Public Use tables	Jim Gurney	Kayla	John	Complete - Tables on St Jude Website
"Toolbox" variable creation	John Whitton	John	Toana/Pam/Kayla	Ongoing.
Documentation of all data sets	John Whitton	Pam/Kayla/Toana	Wendy	Developing comprehensive documentation for Q'naires.
Creation of Chest RT/ Breast Ca related database	Kevin Oeffinger	John	Wendy	Data set created May, 2010.
Creating frozen data set on participation for use in Consort diagrams	Kayla Stratton	Kayla/Aaron McDonald	Wendy	Survivors complete, Siblings Ongoing.
Creation of frozen data set for DNA samples	Stella Davies	Sue Huang/Zhenghong Li	Kiri	Data Frozen May, 2010
Cleaning of Elyse Park RO1 Insurance Study Data	Elyse Park	John Whitton/Chris Vukadinovich	Wendy	Underway

Publications and Manuscripts

Peer-reviewed Manuscripts and Reviews

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185. Chow EJ, Wiu W, Srivastava DK, Leisenring WM, Hayashi RJ, Sklar CA, Stovall M, Robison LL, Baker KS. Differential effects of radiotherapy on growth and endocrine function among acute leukemia survivors: A Childhood Cancer Survivor Study report. *Pediatr Blood Cancer*, 2012 (In Press)

Manuscripts Submitted for Publication

1. Boukheris H, Stovall M, Gilbert ES, Stratton KL, Smith SA, Weathers R, Hammond S, Mertens AC, Donaldson SS, Armstrong GT, Robison LL, Neglia JP, Inskip PD. Risk of Salivary Gland Cancer Following Childhood Cancer: A Report from the Childhood Cancer Survivor Study. *Submitted Int J Radiat Oncol Biol Phys*
2. Brinkman TM, Ullrich NJ, Zhang N, Green DM, Zeltzer LK, Lommel KM, Brouwers P, Srivastava DK, Jain N, Robison LL, Krull KR. Prevalence and predictors of prescriptions psychoactive medication use in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Submitted Cancer Epidemiol Biomarkers Prev*
3. Brinkman T, Zhang N, Ullrich NJ, Brouwers P, Green DM, Drivastava DK, Zeltzer LK, Stovall M, Robison LL, Krull KR. Psychoactive medication use and neurocognitive function in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Submitted Pediatr Blood Cancer*
4. Henderson TO, Rajaraman P, Stovall M, Constone LS, Olive A, Smith SA, Mertens A, Meadows A, Neglia JP, Hammond S, Whitton J, Inskip PD, Robison LL, Diller L. Risk factors associated with secondary sarcomas in Childhood Cancer Survivors: A report from the Childhood Cancer Survivor Study. *Submitted Int J Radiat Oncol*
5. Kirchhoff AC, Kuhlthau K, Pajolek H, Leisenring W, Armstrong GT, Robison LL, Park ER. Employer-Sponsored Health Insurance Coverage Limitations: Results from the Childhood Cancer Survivor Study. *Submitted Support Care Cancer*
6. Kovalchik S, Ronckers C, Veiga L, Sigurdson A, Inskip P, De Vathaire F, Sklar C, Donaldson S, Anderson H, Bhatti P, Hammond S, Leisenring W, Mertens A, Neglia J, Smith S, Stovall M, Tucker M, Weathers R, Robison LL, Pfeiffer R. Absolute risk of second primary thyroid cancer for 5-year survivors of a childhood cancer. *Submitted J Clin Oncol*
7. Mueller S, Fullerton HJ, Stratton K, Leisenring W, Weathers RE, Stovall M, Armstrong GT, Goldsby RE, Packer RJ, Sklar CA, Bowers DC, Robison LL, Krull KR. Radiation, atherosclerotic risk factors and stroke risk in young adult survivors of pediatric cancer: Report from the Childhood Cancer Survivor Study. *Submitted Circulation*
8. Pappo AS, Armstrong GT, Liu W, Srivastava DK, McDonald A, Leisenring W, Hammond S, Stovall M, Neglia JP, Robison LL. Melanoma as a subsequent neoplasm in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Submitted Pediatr Blood Cancer*
9. Watt TC, Inskip PD, Stratton K, Smith SA, Kry SF, Sigurdson AJ, Stovall M, Leisenring W, Robison LL, Mertens AC. Radiation-related risk of basal cell carcinoma in the Childhood Cancer Survivor Study Cohort. *Submitted J Natl Cancer Inst*

Investigator-Initiated, Ancillary Studies for External-Funding That Utilize the CCSS Resource as of 5/2012

Ancillary Studies: Completed

Principal Investigator: Charles Sklar (Memorial Sloan Kettering Cancer Center)

Title: Safety/Efficacy of Growth Hormone Therapy in Survivors of Childhood Cancer

Dates of Funding: 9/96-8/00

Funding Source: Genentech Foundation

Award: \$222,150 total direct

Study Aims: Evaluate the use of growth hormone therapy in survivors of childhood cancer to determine potential impact on final height, risk of cancer-recurrence, and risk of second neoplasm.

Principal Investigator: Karen Emmons (Harvard University)

Title: Smoking Cessation among Childhood Cancer Survivors

Dates of Funding: 9/98- 7/03

Funding Source: National Institutes of Health (R01 CA77780-04S1)

Award: \$2,174,161

Study Aims: Conduct a randomized intervention trial to test a peer-based smoking cessation program for long-term survivors of childhood cancer.

Principal Investigator: H. Stacy Nicholson (Oregon Health Sciences Center)

Title: Quality of Life after Successful Treatment for Acute Myelogenous Leukemia

Dates of Funding: 7/98 – 6/04

Funding Source: National Institutes of Health (R01 CA78960-01)

Award: \$732,679 total direct

Publications to Date: None

Study Aims: Evaluate the occurrence of late effects among five-year survivors of childhood acute myeloid leukemia to compare the risks associated with intensive therapy, including bone marrow transplantation.

Principal Investigator: Charles Sklar (Memorial Sloan Kettering Cancer Center)

Title: Premature Menopause in Survivors of Childhood Cancer

Dates of Funding: 9/98 – 8/01

Funding Source: National Institutes of Health (R01 CA79024)

Award: \$482,000 total direct

Study Aims: Examine the prevalence and risk factors for premature menopause and associated psychosexual functioning in a cohort of 5500 young adult female survivors of cancer diagnosed during childhood and adolescence.

Principal Investigator: Kevin Oeffinger (Memorial Sloan Kettering Cancer Center)

Title: Patient Perceived Barriers to Long-Term Follow-up for Adult Survivors of Childhood Cancer

Dates of Funding: 7/99 – 6/04

Funding Source: Robert Wood Johnson Foundation

Award: \$232,010

Study Aims: Determine the spectrum of, and characteristics predictive for barriers to cancer-related health care of adult survivors of childhood cancer.

Principal Investigator: John Boice (International Epidemiology Institute)

Title: Preconception Radiation and Reproductive Outcomes among Survivors of Childhood Cancer

Dates of Funding: 2000 - 2005

Funding Source: Westlakes Research Institute

Award: \$450,000

Study Aims: Investigate the potential risk of transgenerational effects among the offspring of survivors of childhood cancer in the USA and Denmark who were treated with radiation.

Ancillary Studies: Completed (continued)

Principal Investigator: Ann Mertens (University of Minnesota)

Title: Health Profiles in Adolescent Survivors of Childhood Cancer

Dates of Funding: 1/01 – 12/03

Funding Source: American Cancer Society

Award: \$565,000

Study Aims: Investigate the physical, cognitive and emotional development of adolescent survivors of childhood cancer to aid in development interventions to improve quality of life.

Principal Investigator: Rajaram Nagarajan (University of Minnesota)

Title: Function and Quality of Life of Survivors of Pediatric Lower Limb Tumors

Dates of Funding: 7/01 – 6/02

Funding Source: ASCO (Young Investigator Award)

Study Aims: Investigate the function, quality of life, and psychosocial outcomes of adult survivors of pediatric lower extremity bone tumors to compare amputation and limb-sparing surgeries within age-specific groups.

Principal Investigator: Ann Mertens (University of Minnesota)

Title: Radiation Dosimetry for Childhood Cancer Survivors

Dates of Funding: 1/03 – 12/05

Funding Source: Lance Armstrong Foundation

Award: \$148,984

Study Aims: Estimate tissue-specific dose of radiation received by survivors of childhood cancer who experience selected adverse outcomes within the context of a nested case-control study.

Principal Investigator: Kevin Oeffinger (Memorial Sloan Kettering Cancer Center)

Title: Feasibility Study for Project VISION: A Virtual Information Center for Survivors

Dates of Funding: 1/03 – 12/05

Funding Source: Lance Armstrong Foundation

Award: \$90,190

Study Aims: Assess the feasibility of a randomized clinical trial using a virtual information center as a cognitive-based intervention with survivors and health care providers.

Principal Investigator: James Gurney (University of Minnesota)

Title: Metabolic Syndrome in Adult Survivors of Childhood acute Lymphoblastic Leukemia

Dates of Funding: 7/04 – 6/06

Funding Source: National Institutes of Health (R21 CA1068778)

Award: \$225,000

Study Aims: Evaluate clinically the metabolic syndrome and associations with growth hormone deficiency and endothelial impairment as late effects of treatment for childhood acute lymphoblastic leukemia.

Principal Investigator: Kevin Oeffinger (Memorial Sloan Kettering Cancer Center)

Title: Mammography and High-Risk Survivors of Pediatric Cancer

Dates of Funding: 9/04 – 7/07

Funding Source: National Institute of Health (R21 CA106972)

Award: \$225,000

Study Aims: Evaluate the prevalence of and factors predictive for mammography among long-term survivors of childhood cancer who are at high-risk for radiation-induced breast cancer.

Principal Investigator: Lonnie Zeltzer (UCLA)

Title: Psychosocial, Behavioral and Pain Outcomes in Survivors of Childhood Cancer

Dates of Funding: 1/05 – 12/07

Funding Source: Lance Armstrong Foundation

Award: \$150,000 total direct

Study Aims: Determine, within the CCSS cohort, the prevalence and risk factors for psychosocial outcomes in long-term survivors of childhood and adolescent cancer.

Ancillary Studies: Completed (continued)

Principal Investigator: Ann Mertens (University of Minnesota)
Title: Radiation Dose and Risk of Non-Melanoma Skin Cancer in Cancer Survivors
Dates of Funding: 1/06 – 12/08
Funding Source: Lance Armstrong Foundation
Award: \$247,500
Study Aims: Investigate radiation doses and the subsequent risk of non-melanoma skin cancer in cancer survivors.

Principal Investigator: Kenan Onel (University of Chicago)
Title: Prognostic Genetic Biomarkers for Cancer
Dates of Funding: 7/07 – 6/10
Funding Source: National Cancer Institute (R21 CA129045-02)
Award: \$220,000
Study Aims: Detailed genomic and functional analysis of inborn susceptibilities in another SMN, IR-induced SMN in Hodgkin disease survivors.

Ancillary Studies: Active

Principal Investigator: Debra Friedman (University of Washington)
Title: Health Outcomes for Hodgkin Disease Survivors
Dates of Funding: 9/04 – 6/10
Funding Source: National Institutes of Health (R01 CA106750-05)
Study Aims: Examine the cumulative incidence and characterize the spectrum of selected adverse physiologic and psychosocial outcomes in contemporarily treated Hodgkin disease survivors.

Principal Investigator: Yuri Nikiforov (University of Pittsburgh)
Title: Mechanisms of RET/PTC Rearrangements in Thyroid Cancer
Dates of Funding: 4/07 – 3/12
Funding Source: National Institutes of Health
Award: \$1,706,391
Study Aims: To test whether alterations in one or more DNA repair genes lead to an increased rate of RET/PTC rearrangement in vitro and to thyroid cancer in patients exposed to radiation.

Principal Investigator: Lillian Meacham (Emory University)
Title: Testicular and sexual dysfunction in adult survivors of childhood cancer
Dates of Funding: 1/07 – 12/09
Funding Source: Lance Armstrong Foundation
Award: \$199,715
Study Aims: Investigate the psychosexual function of male long-term survivors of childhood cancer to determine the prevalence of and risk factors for physiological and psychological adverse outcomes.

Principal Investigator: Robert Klesges (St. Jude Children's Research Hospital)
Title: Efficacy of a Tobacco Quit Line for Childhood Cancer Survivors
Dates of Funding: 1/08 – 11/12
Funding Source: National Institutes of Health (R01 CA127964-04)
Award: \$3,087,994
Study Aims: To conduct a randomized intervention trial designed to test the efficacy of Pro-active versus Reactive approach for smoking cessation.

Principal Investigator: Tara Henderson (University of Chicago)
Title: Health Beliefs and Behavior: Cohort Studies in Pediatric Cancer Survivorship
Dates of Funding: 9/08 – 8/12
Funding Source: National Institutes of Health (K07 CA134935-02)
Award: \$480,000
Study Aims: Characterize barriers and facilitators of breast cancer surveillance, diagnosis and therapy in women with secondary breast cancer, and explore associations between breast cancer surveillance practices, initial method of detection, health beliefs and breast cancer outcomes.

Ancillary Studies: Active (continued)

Principal Investigator: Peter Stambrook (University of Cincinnati)

Title: Environmental Exposure: Susceptibility alleles in a DNA damage response pathway

Dates of Funding: 12/08 – 11/13

Funding Source: National Institutes of Health (1R01 ES016625-01A1)

Award: \$2,537,000

Study Aims: Define genetic changes a signaling pathway that contribute to susceptibility to breast cancer after environmental exposure.

Principal Investigator: Elyse Park (Massachusetts General Hospital)

Title: Are Adult Survivors of Childhood Cancer Underinsured?

Dates of Funding: 1/09 – 12/11

Funding Source: Lance Armstrong Foundation

Award: \$240,367

Study Aims: To compare survivor's and sibling's quality of coverage, perceptions of coverage, consequences of inadequate coverage and coverage-related concerns. To examine survivors' and siblings' knowledge regarding relevant legislations.

Principal Investigator: Douglas Ris (Baylor College of Medicine)

Title: Adult Neurobehavioral Late Effects of Pediatric Low Grade Brain Tumors

Dates of Funding: 6/09 – 4/14

Funding Source: National Institutes of Health (R01 – CA132899-01A1)

Award: \$1,827,576

Study Aims: Ascertain the presence, degree and nature of neuropsychological dysfunction in adults treated as children for low grade brain tumors and to investigate accelerated cognitive aging.

Principal Investigator: Stella Davies (Cincinnati Children's Hospital Medical Center)

Title: Prediction Model for Radiation Sensitivity in Children with Cancer

Dates of Funding: 7/09 – 6/11

Funding Source: National Cancer Institute (U01 CA139275-01)

Award: \$410,944

Study Aims: To identify genetic polymorphisms related to BCC following radiation.

Principal Investigator: Lorna Finnegan (University of Illinois at Chicago)

Title: Symptom Cluster Subgroups in Adult Survivors of Childhood Cancer

Dates of Funding: 7/09 – 6/11

Proposed Funding Source: National Institutes of Health (R01 CA136912-02)

Award: \$487,066

Study Aims: Identify subgroups using a five-symptom cluster including pain, fatigue, sleep disturbance, psychological stress, difficulty concentrating to determine relations with influencing factors (e.g., cancer type, treatment modality, etc.).

Principal Investigator: Melissa Hudson, Cheryl Cox (St. Jude Children's Research Hospital)

Title: Evaluation of Cardiovascular Outcomes Among Childhood Cancer Survivors (ECHOS)

Dates of Funding: 9/09 – 7/13

Funding Source: National Institutes of Health (R01 NR011322-02)

Award: \$2,177,710

Study Aims: Assess the efficacy of the intervention in increasing the rate of CV screening and to identify changes in survivor behavioral characteristics in response to the intervention, their mediating effects on the primary outcome, and the cost-effectiveness of the intervention.

Principal Investigator: Kevin Oeffinger (Memorial Sloan Kettering Cancer Center)

Title: EMPOWER Study: Encourage Mammography and Prevention Opportunities for Women Exposed to Radiation

Dates of Funding: 9/09 – 7/14

Funding Source: National Institutes of Health (R01 CA134722)

Award: \$2,392,669

Study Aims: Determine efficacy of stepwise two-component intervention on mammography rates and explore moderating and mediating factors.

Ancillary Studies: Active (continued)

Principal Investigator: Cheryl Cox (St. Jude Children's Research Hospital)

Title: Investigating the needs of childhood cancer survivors: The unreported experience (INSURE)

Dates of Funding: 1/10 – 12/11

Funding Source: National Cancer Institute (R21 CA14292-01)

Award: \$401,603

Study Aims: Evaluate the psychometric and item-response performance of a needs assessment survey; evaluate sample selection participants and response rates to inform future longitudinal needs assessment surveys.

Principal Investigator: Chaya Moskowitz (Memorial Sloan Kettering Cancer Center)

Title: Prediction model: Breast Cancer in Women Irradiated for Pediatric Malignancy

Dates of Funding: 4/10 – 1/14

Funding Source: National Institutes of Health (R01 CA136783)

Award: \$1,630,970

Study Aims: Determine association of dose of chest radiation, additional treatment factors, and traditional breast cancer risk factors associated with risk of breast cancer among childhood cancer survivors, then develop a breast cancer risk prediction tool.

Principal Investigator: Kayla Kamdar (Baylor)

Title: Genetic Susceptibility to Obesity after Treatment for Childhood Leukemia

Dates of Funding: 10/10 – 9/13

Funding Source: Leukemia & Lymphoma Society Translational Research Award

Award: \$600,000

Study Aims: Using genome-wide and candidate pathway analyses, this study aims to identify genetic variants and ultimately key biological pathways that are involved in the development of obesity.

Principal Investigator: Thomas Hardee (Drexel University)

Title: Latent Trajectories of Late Treatment Effects in Pediatric Brain Tumor Survivors

Dates of Funding: 1/11 - 1/13

Funding Source: Oncology Nurse Society Foundation

Award: \$10,000

Study Aims: Identify longitudinal patterns of psychosocial outcomes in adult survivors of childhood brain tumors

Principal Investigator: David Hodgson (University of Toronto)

Title: Secondary prevention among childhood cancer survivors: a quantitative approach to facilitate the effective use of screening

Dates of Funding: 4/11 – 3/13

Funding Source: POGO: Pediatric Cancer Outcomes Initiative (PCOI)

Award: \$115,140

Study Aims: To quantify the benefit of selected health maneuvers among childhood cancer survivors (early onset breast and colorectal cancer screening, echocardiography) using Markov transition-state models.

Principal Investigator: Siv Sivaloganathan (University of Waterloo)

Title: Effective estimation of second cancer risks and resultant possible improvements in treatment protocols

Dates of Funding: 4/11 – 3/14

Funding Source: Canadian Institutes of Health Research – NSERC CHRP

Award: \$468,819

Study Aims: To develop predictive models of second cancer risk among adolescent Hodgkin lymphoma patients based on 3-dimensional normal tissue radiation dosimetry.

Principal Investigator: Emily Tonorezos (Memorial Sloan Kettering Cancer Center)

Title: Diet and insulin resistance in survivors of childhood leukemia

Dates of Funding: 4/12 – 4/14

Funding Source: American Cancer Society

Award: \$300,000

Study Aims: (1) Compare intake of dietary fat and dietary habits among ALL survivors to non-cancer participants, and (2) identify dietary features that contribute to insulin resistance among ALL survivors compared to non-cancer controls.

Ancillary Studies: Proposed

Principal Investigator: Whitney Witt (University of Wisconsin)

Title: The Impact of Childhood Cancer Survivorship on Parental Psychosocial Outcomes, Health, and Aging

Dates of Proposed Funding: NA

Proposed Funding Source: National Institutes of Health (R01)

Study Aims: Identify the factors related to poor psychosocial outcomes (stress and family burden) among parents of long-term survivors of childhood cancer.

Principal Investigator: Alan Geller (Harvard School of Public Health)

Title: Risk Reduction and Early Detection Strategies for Skin Cancer Control among Childhood Cancer Survivors

Dates of Proposed Funding: NA

Proposed Funding Source: National Institutes of Health (R01)

Study Aims: (1) Determine the impact of a patient activation and education intervention with and without physician education and teledermatology on skin cancer early detection practices and (2) Determine the impact of patient activation and education on utilization.

Principal Investigator: Jean Nakamura (University of California, San Francisco)

Title: Neurofibromin and response to genotoxins

Dates of Proposed Funding: 4/2012 – 3/2017

Proposed Funding Source: National Institutes of Health (R01)

Requested Funding: \$1,250,000 total direct

Study Aims: (1) Determine whether loss of heterozygosity in tumor suppressor genes identified in the *Nf1* mutant mouse model occurs in second malignant neoplasms of childhood cancer survivors, and (2) determine whether transcript levels of candidate tumor suppressor genes are reduced in second malignant neoplasms.

Ancillary Studies: Unfunded

Principal Investigator: Melissa Hudson (St. Jude Children's Research Hospital)

Title: Promoting Health Monitoring After Childhood Cancer

Proposed Funding Source: National Institutes of Health

Study Aims: Conduct a randomized trial to test generic health risk promotion versus tailored health risk promotion with proactive counseling to increase the rate of successful screening according to risk-based recommendations.

Principal Investigator: Debra L. Friedman (Fred Hutchinson Cancer Research Center)

Title: A Web-Based Approach to Familial Cancer Risk

Proposed Funding Source: Lance Armstrong Foundation

Study Aims: Develop and test a web-based strategy for the investigation of familial cancers and second cancer risks among pediatric cancer survivors.

Principal Investigator: Jin-Shei Lai (Northwestern University)

Title: Cancer Fatigue Monitoring from Childhood into Adulthood

Proposed Funding Source: National Institutes of Health (Application submitted to RFA)

Study Aims: Development of a valid, lifespan assessment of fatigue.

Principal Investigator: Anne Lown (San Francisco State University)

Title: Alcohol Consumption Among Childhood Cancer Survivors

Proposed Funding Source: National Institutes of Health (K07 application)

Study Aims: Describe the prevalence and risk factors for survivors and sibling drinking and health-risk behaviors over time.

Principal Investigator: Craig Lustig (Children's Cause for Cancer Advocacy)

Title: Childhood Cancer Survivor Study Partners

Proposed Funding Source: National Institutes of Health (Application submitted for RFA)

Study Aims: Establish a formal collaboration between an informed, responsible core of CCSS participants and investigators.

Ancillary Studies: Unfunded (continued)

Principal Investigator: Andrea Patenaude (Dana Farber Cancer Institute)

Title: Understanding Genetic Medicine: Towards a Guide for Survivors

Proposed Funding Source: Lance Armstrong Foundation

Study Aims: To evaluate the potential genetic factors that may modify risk for adverse late effects in childhood cancer survivors.

Principal Investigator: Qian Lu (UCLA)

Title: A Longitudinal Study of Pain in Long-term Survivors of Childhood Cancer

Proposed Funding Source: Lance Armstrong Foundation

Study Aims: To determine the potential impact of chronic pain on overall quality of life among cancer survivors.

Principal Investigator: Richard Sposto (Children's Hospital Los Angeles)

Title: Statistical Models for Risk/Benefit Analysis of Targeted Treatment Strategies in Childhood Cancer

Proposed Funding Source: National Institutes of Health (R21)

Study Aims: Statistical/methodological research addressing issues of acute toxicities and long-term sequelae of therapy, potentially providing new approaches for predicting the potential treatment-specific risks within pediatric cancer survivor populations.

Childhood Cancer Survivor Study (CCSS)

Presented Abstracts 1997 – 2012

Year	Number
2012	14
2011	14
2010	18
2009	6
2008	25
2007	9
2006	14
2005	12
2004	16
2003	6
2002	17
2001	9
2000	2
1999	6
1998	1
1997	1

2012

A1201 Mueller S, Fullerton HJ, Stratton K, Leisenring W, Weathers R, Stovall M, Armstrong GT, Goldsby RE, Packer RJ, Robison LL, Krull KR. Radiation and modifiable stroke risk factors in adult survivors of pediatric cancer: Results from the Childhood Cancer Survivor Study. 2012 International Stroke Conference, February 2012, oral presentation, 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.

A1202 Wasilewski-Masker K, Seidel KD, Leisenring W, Mertens A, Shnorhavorian M, Ritenour MD, Stovall M, Green DM, Sklar CA, Armstrong GT, Robison LL, Meacham LR. Male Infertility in childhood and adolescent cancer survivors diagnosed from 1970-1986: A report from the Childhood Cancer Survivor Study. 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.

A1203 Wilson CL, Ness KK, Neglia JP, Hammond S, Leisenring W, Srivastava DK, Stovall M, Robison LL, Armstrong GT. Renal carcinoma following therapy for cancer in childhood: A report from the Childhood Cancer Survivor Study. 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation, American Society of Clinical Oncology Annual Meeting, June 2012.

A1204 Chow EJ, Chen Y, Armstrong GT, Border W, Meacham L, Meeske KA, Mulrooney D, Oeffinger KC, Sklar CA, Stovall M, Robison LL, Yasui Y. Predicting future cardiovascular disease after cancer: A Childhood Cancer Survivor Study report. 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012.

- A1205** Shnorhavorian M, Leisenring W, Goodman P, Friedman D, Stovall M, Meacham LR, Chow E, Sklar CA, Diller L, Ferrer F, Armstrong GT, Robison LL. Genito-urinary second malignant neoplasms in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation, American Academy of Pediatrics National Conference and Exhibition, 2012.
- A1206** Wong FL, Bhatia S, Kurian Seira, Landier W, Francisco L, Leisenring W, Hudson, MM, Armstrong GT, Mertens A, Stovall M, Robison LL, Lipshultz ST, Armenian S. Cost-Effectiveness of the Children's Oncology Group (COG) Long-Term Follow-Up (LTFU) guidelines in reducing the risk of congestive heart failure (CHF) in long-term childhood cancer survivors (CCS). 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.
- A1207** Wong FL, Bhatia S, Kurian Seira, Landier W, Francisco L, Leisenring W, Hudson, MM, Armstrong GT, Mertens A, Stovall M, Robison LL, Lipshultz ST, Armenian S. Efficacy of the Children's Oncology Group (COG) Long-Term Follow-Up (LTFU) guidelines in reducing the risk of congestive heart failure(CHF) in long-term childhood cancer survivors (CCS). American Society of Clinical Oncology Annual Meeting, June 2012, oral presentation.
- A1208** Perkins JL, Chen Y, Harris A, Sklar C, Diller L, Stovall M, Armstrong GT, Yasui Y, Robison LL. Infectious complications in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivors Study (CCSS). 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012.
- A1209** Casillas J, Liu Q, Hudson MM, Greenberg ML, Yeazel MW, Ness K, Robison LL, Armstrong GT, Leisenring W, Yasui Y, Oeffinger KC, Nathan PC. Longitudinal Changes in health care utilization by adult survivors of childhood cancer in the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2012, 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.
- A1210** Buchbinder D, Mertens AC, Zeltzer LK, Leisenring W, Goodman P, Lown EA, Alderfer MA, Recklitis C, Oeffinger K, Armstrong GT, Hudson MM, Robison L, Casillas J. Cancer prevention and screening practices of siblings of childhood cancer survivors: A report from the Childhood Cancer Survivor Study. 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012.
- A1211** Moskowitz CS, Chou JF, Wolden SL, Bernstein JL, Malhotra J, Friedman DN, Mubdi NZ, Henderson TO, Leisenring WM, Stovall M, Hammond S, Boice JD, Hudson MM, Diller LR, Bhatia S, Neglia JP, The WECARE Study Collaborative Group, Begg CB, Robison LL, Oeffinger KC. New insights into the risk of breast cancer in childhood cancer survivors treated with chest radiation: A Report from the Childhood Cancer Survivor Study (CCSS) and the Women's Environmental Cancer and Radiation Epidemiology (WECARE) Study. ASCO Annual Meeting, June 2012, oral presentation, 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.
- A1212** Armstrong GT, Kawashima T, Leisenring W, Stovall M, Sklar CA, Robison LL, Oeffinger KC. Increasing risk of severe, life-threatening and fatal chronic health conditions in aging survivors of childhood CNS tumors: A Report from the Childhood Cancer Survivor Study. International Symposium on Pediatric Neuro-Oncology, June 2012, oral presentation.
- A1213** Wells EM, Seidel K, Ullrich NJ, Leisenring WM, Armstrong GT, Diller LR, King AA, Krull KR, Neglia JP, Stovall M, Whelan K, Sklar C, Packer RJ. Neurologic Sequelae in Long-Term survivors of Childhood Brain Tumors: A Childhood Cancer Survivor Study (CCSS) Update and Expanded Risk Factor Analysis. International Symposium on Pediatric Neuro-Oncology, June 2012, oral presentation.
- A1214** Armstrong GT, Kawashima T, Leisenring W, Stovall M, Sklar CA, Robison LL, Oeffinger KC. Increasing risk of chronic health conditions in aging survivors of childhood cancer: A Report from the Childhood Cancer Survivor Study. ASCO Annual Meeting, June 2012, oral presentation, 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.

2011

- A1101** Park ER, Kirchoff AC, Pandiscio BA, Armstrong GT, Robison LL, Mertens A, Recklitis C, Diller L, Kuhlthau K. Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: implications for the 2010 Health Care Reform Law. 32nd Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine, April 2011, platform presentation.

- A1102** Kinahan KE, Sharp LK, Didwania A, Seidel K, Leigsring W, Lacouture ME, Stovall M, Robison LL, Krull KR, Lurie RH. Scarring, disfigurement and quality of life in long-term survivors of childhood cancer: A report from the childhood cancer survivor study. 2011 ASCO Annual Meeting, June 2011, poster presentation, 12th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012.
- A1103** Pappo AS, Armstrong GT, Liu W, Srivastava DK, Leisenring W, Hammond S, Stovall M, Neglia JP, Robison LL. Melanoma as a subsequent neoplasm in survivors of childhood cancer: A report from the childhood cancer survivor study. 2011 ASCO Annual Meeting, June 2011, oral presentation.
- A1104** Best T, Skol AD, Gamazon E, Onel K. A functional analysis of variants associated with therapy-induced second malignancies after Hodgkin lymphoma identified by genome-wide scan. 2011 ASCO Annual Meeting, June 2011, oral presentation.
- A1105** Armstrong, GT, Chen Y, Kawashima T, Sklar C, Mulroney DA, Chow E, Border W, Durand JB, Mertens A, Stovall M, Leisenring W, Yasui Y, Robison LL, Oeffinger K, Meacham L. Impact of Traditional Cardiovascular Disease Risk Factors on Long-term Cardiovascular Outcomes in Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. 2011 ASCO Annual Meeting, June 2011, oral presentation.
- A1106** Mueller S, Fullerton, HJ, Stratton K, Leisenring W, Weathers R, Stovall M, Armstrong GT, Goldsby RE, Packer RJ, Robison LL, Krull KR. Excess strong risk in adult survivors of childhood CNS tumors, leukemia and Hodgkin's lymphoma: Results of the Childhood Cancer Survivor Study. 2011 Child Neurology Annual Meeting, October 2011.
- A1107** Meacham L. Longitudinal assessment of cardiovascular risk factors (CVRF) in adult survivors of pediatric cancer: a report from the childhood cancer survivor study (CCSS). 50th Annual Meeting of the European Society for Pediatric Endocrinology (ESPE), September 2011, oral presentation.
- A1108** Hudson M, Oeffinger K, Nathan P, Mertens A, Castellino S, Casillas J, Mulrooney D, Gurney J, Armstrong G, Leisenring W, Robison L, Ness K. Longitudinal changes in health status of the Childhood Cancer Survivor Cohort. Congress of the International Society for Pediatric Oncology (SIOP), October 2011, oral presentation.
- A1109** Wong FL, Bhatia S, Surian S, Landier W, Francisco L, Leisenring W, Hudson M, Armstrong GT, Mertens A, Stovall M, Yasui Y, Robison LL, Lipshultz SE, Armenian S. Evaluation of the effectiveness of the Children's Oncology Groups (COG) long-term follow-up guidelines in reducing the risk of Anthracycline-related congestive heart failure (CHF) in long-term survivors of childhood cancer. European Symposium on Late Complications after Childhood Cancer (ESLCCC), September 2011, oral presentation.
- A1110** Marina N, Hudson M, Mulrooney DA, Avedian R, Donaldson S, Fisher P, Leisenring W, Stovall M, Robison LL, Ness KK. Comparison of health status between upper and lower extremity sarcoma survivors: A report from the Childhood Cancer Survivor Study. Congress of the International Society for Pediatric Oncology (SIOP), October 2011, oral presentation.
- A1111** Klosky JL, Howell C, Li Z, Foster R, Mertens AC, Robison LL, Ness KK. Risky health behavior in adolescent survivors of childhood cancer and their siblings: A report from the Childhood Cancer Survivor Study. Congress of the International Society for Pediatric Oncology (SIOP), October 2011, oral presentation.
- A1112** Klosky JL, Hum A, Zhang N, Ali K, Srivastava DK, Klesges RC, Ness KK, Robison LL, Hudson MM. Smokeless and dual tobacco use among males surviving childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). Congress of the International Society for Pediatric Oncology (SIOP), October 2011, oral presentation.
- A1113** Cox CL, Zhu L, Steen BD, Hudson MM, Robison LL, Oeffinger KC. Survivor profiles of health-related concerns, fear and motivation predict participation in medical surveillance: The Childhood Cancer Study. American Public Health Association 139th Annual Meeting and Exposition, October 2011, platform presentation.
- A1114** Kirchhoff AC, Krull KR, Robison LL, Leisenring W. Physical, Mental and Neurocognitive Status and Employment Outcomes in the Childhood Cancer Survivor Study Cohort. Society for Behavioral Medicine, April 2011, oral presentation.

A1001 Clanton NR, Morris B, Pan Z, Mulrooney D, Jain N, Srivastava DK, Zeltzer L, Stovall M, Robison LL, Krull KR. Fatigue, vitality, sleep quality, and neurocognitive functioning in adult survivors of childhood cancer: A Report from the Childhood Cancer Survivor Study. International Neuropsychological Society, February 2010, platform presentation. International Society of Pediatric Oncology, October 2010, oral presentation.

A1002 Henderson TO, Whitton J, Leisenring W, Neglia J, Meadows A, Crotty C, Oeffinger KC, Diller L, Inskip P, Stovall M, Armstrong G, Robison LL, Nathan PC. Gastrointestinal Malignancies as a Second Malignant Neoplasm in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer & American Society of Clinical Oncology Annual Meeting, June 2010, platform presentations.

A1003 Kirchhoff AC, Krull KR, Ness KK, Park ER; Friedman DL, Armstrong GT, Stovall M, Oeffinger KC, Hudson M, Robison LL, Leisenring W. Occupational status of adult survivors of childhood cancer: A report from the Childhood Cancer Survivors Study. American Society of Preventive Oncology, March 2010, poster presentation.

A1004 Meacham LR, Ford J, Ritenour C, Wasilewski-Masker K, Shnorhavorian M, Leisenring W, Whitton J, Armstrong G, Stovall M, Sklar C, Robison L, Mertens A. Male health and perceptions of risk for testicular/sexual dysfunction: A report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010, poster presentation.

A1005 Termuhlen A, Tersak J, Liu Q, Yasui Y, Stovall M, Deutsch M, Sklar CA, Robison LL, Green DM. Twenty-five year follow-up among survivors of childhood Wilms Tumor: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting and International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010, platform presentations.

A1006 Armstrong GT, Liu W, Hammond S, Bhatia S, Neglia J, Stovall M, Leisenring W, Yasui Y, Srivastava D, Robison LL. Multiple Subsequent Neoplasms in the Childhood Cancer Survivor Study (CCSS) Cohort. American Society of Clinical Oncology Annual Meeting and International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010, platform presentations.

A1007 Vrooman LM, Najita J, Goodman P, Armstrong G, Hudson M, Kenney L, Laverdière C, Leisenring W, Mody R, Nathan P, Oeffinger K, Sklar C, Diller L. Long-Term outcomes after cancer in infancy: A report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010 platform presentation.

A1008 Ford J, Kawashima T, Whitton J, Leisenring W, Laverdière C, Stovall M, Zeltzer L, Randolph-Frye M, Robison L, Sklar C. Psychosexual functioning among women in the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010, poster presentation.

A1009 Green DM, Nolan VG, Kawashima T, Stovall M, Donaldson SS, Sklar CA, Robison LL. Hypothalamic/Pituitary radiation exposure in low doses may result in decreased fertility in female Childhood Cancer Survivor Study (CCSS) participants. American Society of Clinical Oncology Annual Meeting, June 2010, poster presentation.

A1010 Green DM, Zhu L, Stovall M, Nolan V, Ness K, Donaldson SS, Cox C, Oeffinger K, Meacham LR, Sklar CA, Krull K, Armstrong GT, Robison LL. Antidepressant use is associated with obesity among Childhood Cancer Survivor Study (CCSS) participants. International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010, poster presentation.

A1011 Kunin-Batson A, Kadan-Lottick N, Zhu L, Bordes V, Srivastava DK, Zeltzer L, Robison LL, Krull KR. Predictors of independent living status in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting June 2010, poster presentation.

A1012 Bhatti P, Veiga LHS, Ronckers CM, Sigurdson AJ, Stovall M, Smith SA, Weathers R, Leisenring W, Mertens AC, Hammond S, Friedman DL, Neglia JP, Meadows AT, Donaldson SS, Sklar CA, Robison LL, Inskip PD. Radiotherapy for childhood cancer and risk of thyroid cancer in a large cohort study. Submitted to SER, June 2010.

A1013 Goldsby R, Chen Y, Yasui Y, Raber S, Li L, Diefenbach K, Shnorhavorian M, Kaden-Lottick N, Kastrinos F, Stovall M, Oeffinger K, Diller L, Armstrong G, Robison L, Sklar C. Late gastrointestinal sequelae in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. International Society of Pediatric Oncology, October 2010, oral presentation.

A1014 Brackett J, Krull K, Scheurer M, Liu W, Srivastava K, Stovall M, Merchant T, Packer R, Robison L, Ocku MF. Antioxidant enzyme polymorphisms and neuropsychological outcomes in Medulloblastoma survivors: A report from the Childhood Cancer Survivor Study. International Society of Pediatric Oncology, October 2010, poster presentation.

A1015 Kunin-Batson A, Kadan-Lottick N, Zhu L, Cox C, Border V, Srivastava DK, Zeltzer L, Robison LL, Krull KR. Predictors of independent living after childhood cancer: A report from the Childhood Cancer Survivor Study. International Society of Pediatric Oncology, October 2010, oral presentation.

A1016 Best T, Skol AD, Gamazon E, Onel K. A functional analysis of variants associated with therapy-induced second malignancies after Hodgkin lymphoma identified by genome-wide scan 52nd American Society of Hematology Annual Meeting and Exposition, December 2010, poster.

A1017 Cozen W, Li D, Best T, Van Den Berg D, Skol AD, Cortessis VK, Mack TM, Glaser SL, Schumacher G, Weiss LM, Nathwani BN, Edlund CK, Hwang A, Bhatia S, Strong LC, Robison LL, Conti DV, Onel K. A Meta-Analysis of Nodular Sclerosis Hodgkin Lymphoma Identifies Risk Loci at 6p21.32. 52nd American Society of Hematology Annual Meeting and Exposition, December 2010, poster.

A1018 Cozen W, Li D, Best T, Van Den Berg D, Skol AD, Cortessis VK, Mack TM, Glaser SL, Schumacher G, Weiss LM, Nathwani BN, Edlund CK, Hwang A, Bhatia S, Strong LC, Robison LL, Conti DV, Onel K. A Meta-Analysis of Nodular Sclerosis Hodgkin Lymphoma Identifies Risk Loci at 6p21. 32 International Lymphoma Epidemiology Consortium, April 2010, oral presentation.

2009

A0901 Nathan PC, Ness KK, Hudson MM, Mahoney M, Ford JS, Landier W, Armstrong G, Henderson T, Robison LL, Oeffinger KC. Cancer screening in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, Orlando, FL, June 2009, platform presentation.

A0902 Boukheris H, Neglia JP, Stovall M, Hammond S, Mertens AC, Meadows AT, Donaldson SS, Armstrong G, Stratton KL, Robison LL, Inskip PD. Risk of salivary gland carcinoma among childhood cancer survivors: Role of treatment and cigarette smoking. ISS Conference, May 2009.

A0903 Bornstein MH, Haynes OM, Leisenring W, Hayashi R, Armstrong G, Robison L, Zeltzer L. Mental retardation and learning disability in survivors of childhood cancer diagnosed in infancy: A Report from the Childhood Cancer Survivor Study. Society for Research in Child Development, 2009.

A0904 Stuber M, Meeske K, Zebrack B, Krull K, Stratton K, Leisenring W, Robison L, Zeltzer L. Prevalence and predictors of Posttraumatic Stress Disorder in adult survivors of childhood cancer: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, 2009, platform presentation.

A0905 Krull KR, Huang S, Hudson MM, Gurney JG, Srivastava DK, Klosky J, Ness KK, Leisenring W, Termuhlen A, Robison LL. Adolescent psychopathology and adult health behaviors in long-term survivors of childhood cancer: Findings from the Childhood Cancer Survivors Study. American Society of Clinical Oncology, 2009.

A0906 Kirchhoff AC, Leisenring W, Ness KK, Park ER, Friedman DL, Oeffinger KC, Armstrong GT, Krull KR, Robison LL, Wickizer T. Health-related unemployment among survivors and siblings in the Childhood Cancer Survivor Study (CCSS). National Research Service Award trainees meeting at Academy Health, June 2009, oral presentation.

A0801 Mulrooney DA, Yeazel M, Mitby P, Kawashima T, Leisenring WM, Stovall M, Green DM, Sklar CA, Robison LL, Mertens AC. Cardiovascular disease in adult survivors of childhood and adolescent cancer: a report from the CCSS. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008; American Society of Clinical Oncology Annual Meeting, Chicago, IL, June 2008, oral presentation.

A0802 Armstrong GT, Ness KK, Whitton J, Leisenring W, Yasui Y, Zeltzer L, Donaldson SS, Hudson M, Robison LL, Packer R. Long-term outcomes among survivors of childhood central nervous system tumors: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, Chicago, June, 2008, oral presentation; International Symposium on Pediatric Neuro-Oncology, Chicago, IL, June 2008; Child Neurology Society, 2008.

A0803 Armstrong GT, Whitton J, Chow E, Leisenring W, Gajjar A, Kun L, Robison LL, Sklar C. Abnormal timing of menarche in survivors of childhood central nervous system tumors. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008; ISPNO 13th Annual Meeting, Chicago, IL, June 2008.

A0804 Ellenberg L, Gioia G, Liu Q, Yasui Y, Packer R, Mertens A, Donaldson S, Kaden-Lottick N, Armstrong G, Robison LL, Zeltzer LK. Executive functioning in long-term survivors of childhood brain tumors: a report from the Childhood Cancer Survivor Study (CCSS). International Neuropsychosocial Society Annual Meeting, February 2008.

A0805 Laverdière C, Liu Q, Yasui Y, Nathan P C, Gurney JG, Stovall M, Diller LR, Cheung NK, Wolden S, Robison LL, Sklar CA. Long-term outcomes in survivors of neuroblastoma: a report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0806 Lown EA, Goldsby R, Mertens AC, Greenfield T, Bond J, Whitton J, Korcha R, Robison LL, Zeltzer LK. Alcohol consumption patterns and risk factors among childhood cancer survivors compared to siblings and general population peers. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0807 Bluhm E, Oeffinger K, Sklar CA, Meadows A, Hayashi R, Mertens AC, Kawashima T, Donaldson S, Meacham L, Stovall M, Robison LL, Inskip P. Risk factors for common health conditions occurring five years after NHL: a report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0808 Ginsberg JP, Ness K, Goodman P, Leisenring W, Robison LL, Oeffinger KC. Long-term follow-up among survivors of childhood Ewing's sarcoma: a report of the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0809 Ness KK, Leisenring WM, Huang S, Hudson MM, Gurney JG, Whelan K, Hobbie WL, Lanctot JQ, Armstrong GT, Robison LL, Oeffinger KC. Physical activity – patterns and predictors of sedentary lifestyle among adult survivors of childhood cancer. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0810 Meacham LR, Chow EJ, Kamdar KY, Ness KK, Chen Y, Yasui Y, Oeffinger KC, Sklar CA, Robison LL, Mertens AC. Cardiovascular risk factor cluster in adult survivors of pediatric cancer: a report of the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0811 Oeffinger KC, Ford JS, Moskowitz CS, Diller L, Hudson MM, Chou JF, Smith S, Mertens AC, Robison LL. Mammogram practices of women at risk for breast cancer following chest radiation for a pediatric cancer: a report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0812 Smith S, Ford JS, Rakowski W, Moskowitz CS, Robison LL, Oeffinger KC. Decisional balance, stages of adoption, and screening mammography among women at risk of breast cancer following a pediatric malignancy: a report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0813 Mertens A, Leisenring W, Mitby P, Hammond S, Perkins J, Robison LL, Hudson M, Meadows A. Sun sensitivity, sun exposure and risk of skin cancer in a cohort of adult survivors of childhood and adolescent cancer. A report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008; 4th Biennial Cancer Survivorship Research Conference, Atlanta, GA, June 2008.

A0814 Bornstein MC, Haynes M, Hayashi R, Leisenring W, Armstrong G, Robison L, Zeltzer L. Mental retardation and learning disability in survivors of childhood cancer diagnosed in infancy: a report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008.

A0815 Henderson T, Rajaraman P, Stovall M, Olive A, Smith S, Mertens A, Meadows A, Neglia J, Whitton J, Inskip P, Robison L, Diller L. New primary sarcomas in survivors of childhood cancer: a detailed analysis of the effects of treatment: a report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008; American Society of Clinical Oncology, Chicago, IL, June 2008, oral presentation.

A0816 Lown EA, Goldsby R, Mertens AC, Korcha R, Greenfield T, Bond J, Whitton J, Robison LL, Zeltzer LK. Adult siblings of childhood cancer survivors are heavy drinkers: which siblings are at risk? a report from the Childhood Cancer Survivor Study. American Public Health Association, San Diego, October 2008, poster presentation.

A0817 Lu Q, Tsao JCI, Leisenring W, Armstrong G, Robison L, Zeltzer LK. Posttraumatic stress symptoms, pain and related impairment among adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). 4th Biennial Cancer Survivorship Research Conference, Atlanta, GA, June 2008.

A0818 Castellino SM, Tooze J, Geiger A, Leisenring W, Goodman P, Mertens A, Stovall M, Robison L, Hudson M. Risks of mortality in 5 year survivors of Hodgkin's lymphoma in the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting, Chicago, IL, June 2008, oral presentation.

A0819 Green DM, Kawashima T, Leisenring W, Stovall M, Donaldson S, Sklar CA, Byrne J, Robison LL. Fertility of females after treatment for childhood cancer: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting, Chicago, IL, June 2008, oral presentation.

A0820 Cox CL, Montgomery M, Oeffinger K, Leisenring W, Zeltzer L, Whitton J, Mertens A, Hudson MM, Robison L. Childhood cancer survivors: Patient and provider influences on physical activity participation. 4th Biannual Cancer Survivorship Research Conference, Atlanta, GA, June 2008.

A0821 Cox CL, Hudson M, Oeffinger K, Whitton J, Montgomery M, Mertens A, Robison L. Determinants of participation in recommended medical screening by at-risk adult survivors of childhood cancer. American Public Health Association Meeting & Exposition, San Diego, CA, October 2008, oral presentation.

A0822 Mertens AC, Leisenring W, Mitby P, Meadows A, Robison L, Hudson M. Sun protection behavior in a cohort of adult survivors of childhood and adolescent cancer. A report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, CANADA, June 2008, platform presentation.

A0823 Klesges LM, Ness KK, Lanctot JQ, Lown A, Whalen K, Huang S, Leisenring W, Stovall M, Oeffinger K, Robison L, Hudson M. Prevalence and clustering of multiple behavioural risk factors in adult survivors of childhood cancer. 4th Biennial Cancer Survivorship Research Conference: Mapping the New Challenges, Atlanta, GA, June 2008, poster presentation.

A0824 Goldsby R, Nathan P, Bowers D, Yeaton-Massey A, Raber S, Hill D, Robison L, Liu Q, Yutaka Y, Zeltzer L, Armstrong G, Packer R. Long-term neurologic outcomes in adult survivors of childhood acute lymphoblastic leukemia: results from the Childhood Cancer Survivor Study (CCSS). Child Neurology Society, 2008.

A0825 Cox CL, Mertens A, Hudson M, Whitton J, Montgomery M, Robison L. Determinants of mammography screening participation in adult female survivors of childhood cancer. 2008 ASCO Breast Cancer Symposium, Washington, D.C., September, 2008, poster presentation.

2007

A0701 Green DM, Kawashima T, Leisenring W, Stovall M, Donaldson SS, Sklar CA, Byrne J, Robison LL. Fecundity of males after treatment for childhood cancer. A report from the Childhood Cancer Survivor Study (CCSS). ASCO Annual Meeting, Chicago, IL., 2007.

A0702 Green DM, Kawashima T, Leisenring W, Stovall M, Donaldson SS, Sklar CA, Byrne J, Robison LL. Fertility of males after treatment for childhood cancer. A report from the Childhood Cancer Survivor Study (CCSS). SIOP 2007.

A0703 Lown EA, Goldsby R, Mertens AC, Greenfield T, Bond J, Whitton J, Korcha R, Robison LL, Zeltzer LK. Alcohol Consumption Patterns and Risk Factors among Childhood Cancer Survivors Compared to Siblings and General Population Peers. American Psychosocial Oncology Society, 2007.

A0704 Nathan PC, Greenberg ML, Ness KK, Mahoney MC, Gurney JG, Hudson MM, Donaldson SS, Leisenring WM, Robison LL, Oeffinger KC. Risk-based care in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). ASCO Annual Meeting, Chicago, IL., Sunday, June 03, 2007.

A0705 Wasilewski-Masker K, Leisenring W, Meacham LR, Hammond S, Meadows AT, Robison LL, Mertens AC. Late recurrence in survivors of childhood and adolescent cancer: a report from the Childhood Cancer Survivor Study (CCSS). ASCO Annual Meeting, Chicago, IL., 2007

A0706 Kaste SC, Baker S, Goodman P, Leisenring W, Stovall M, Hayashi R, Yeazel M, Hudson MM, Sklar C, Robison LL. Dental health of long-term survivors of childhood cancer: The childhood cancer survivor study (CCSS). ASCO Annual Meeting, Chicago, IL., 2007

A0707 Garney EG, Liu Q, Sklar CA, Meacham LR, Stovall M, Yasui Y, Robison LL, Oeffinger KC. Obesity in adult survivors of childhood acute lymphoblastic leukemia: A follow-up report from the childhood cancer survivor study. ASCO Annual Meeting, Chicago, IL., 2007.

A0708 Laverdiere C, Liu Q, Yasui Y, Nathan PC, Gurney J, Stovall M, Diller L, Cheung NK, Wolden S, Robison LL, Sklar CA. Long-term complications of neuroblastoma: A report from the childhood cancer survivor study. ASCO Annual Meeting, Chicago, IL, 2007.

A0709 Bluhm EC, Ronckers C, Hayashi RJ, Neglia JP, Mertens AC, Meadows AT, Mitby PA, Stovall M, Robison LL, Inskip PD. Cause-specific mortality and second cancer incidence after non-Hodgkin lymphoma: a report from the Childhood Cancer Survivor Study. ASH Annual Meeting, Atlanta, GA, 2007.

2006

A0601 Baker SK, Leisenring W, Hayashi R, Mertens A, Stovall M, Donaldson S, Robison L, Sklar C. Impact of Hematopoietic Cell Transplantation with Total Body Irradiation on the Health Status of Childhood Leukemia Survivors: A Report for the CCSS. American Society of Hematology, 2006.

A0602 Casillas J, Brooks S, Mertens A, Hudson M, Robison L, Oeffinger K. The Impact of Psychosocial Factors on Access to Care in Adult Minority Survivors: A Childhood Cancer Survivor Study. Western Society for Pediatric Research, 2006, platform presentation.

A0603 Henderson T, Whitton J, Hammond S, Stovall M, Meadows A, Mertens A, Neglia J, Robison L, Diller L. Sarcoma as a Subsequent Malignancy in Survivors of Childhood Malignancy: A Report from the CCSS. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer, 2006, poster presentation.

A0604 Lansdale M, Marina N, Castellino S, Goodman P, Hudson MM, Mertens AC, Sklar CA, Leisenring W, Robison LL, Oeffinger KC. Screening for Hepatitis C Virus (HCV) Infection in Long-Term Pediatric Cancer Survivors: A Report from the Childhood Cancer Survivor Study (CCSS). Third biennial NCI Cancer Survivorship Conference, 2006, poster presentation.

A0605 Laverdiere C, Liu Q, Yasui Y, Nathan PC, Gurney J, Stovall M, Diller L, Cheung N, Wolden S, Robison LL, Sklar CA. Long-term complications in survivors of neuroblastoma: a report from the Childhood Cancer Survivor Study. ASCO 2006.

A0606 Lu Q, Tsao JCI, Leisenring W, Robison L, Zeltzer LK. Pain Prevalence among Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). Third biennial NCI Cancer Survivorship Conference, 2006, poster presentation.

A0607 Mertens AC, Schultz KA, Ness KK, Whitton J, Recklitis C, Zebrack B, Zeltzer L, Robison LL. Social Adjustment in Survivors of Childhood Cancer: A Report from the CCSS. American Psychosocial Oncology Society, 2006, poster presentation.

A0608 Mertens AC, Steele JR, Goodman P, Oeffinger KC, Robison LL, Hudson MM. Follow-Up Care in Cancer Survivors: Newsletters Can't Do It Alone - A Report from the Childhood Cancer Survivor Study. American Psychosocial Oncology Society, 2006, platform presentation.

A0609 Mitby PA, Mertens AC, Hudson MM, Eshelman DE, Jacox C, Jones JK, Kamani S, Allam RK, Oeffinger KC. Does a Cognitive-Based Intervention Increase the Likelihood of Screening for Serious Late Effects in Adult Survivors of Childhood Cancer? Project Vision: A Report from CCSS. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer, 2006, platform presentation.

A0610 Mulrooney DA, Dover DC, Yasui Y, Ness K, Mertens AC, Neglia JP, Sklar CA, Robison LL, Davies SM. Twenty Years of Follow-Up Among Survivors of Childhood and Young Adult Acute Myeloid Leukemia (AML): A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Hematology, 2006, media platform presentation.

A0611 Ness K, Mertens AC, Zeltzer L, Gurney J, Leisenring W, Robison LL. Physical performance and health related quality of life in adult survivors of childhood cancer. Psychosocial and Neurocognitive Consequences of Childhood Cancer, 2006, platform presentation.

A0612 Schultz KAP, Ness KK, Whitton J, Recklitis C, Zebrack B, Robison L, Zeltzer L, Mertens AC. Social Adjustment of Adolescent Survivors in the Childhood Cancer Survivor Study. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer, 2006, platform presentation.

A0613 Whelan KF, Kawashima T, Mitby P, Blatt J, Waterbor J, Castleberry R, Sande J, Packer R, Sklar C, Robison L, Mertens A. Auditory and Speech Complications on Childhood Cancer Survivors: A Report from CCSS. American Society of Clinical Oncology, 2006, platform presentation.

A0614 Whelan K, Mertens A, Castleberry R, Mitby P, Kawashima T, Sklar C, Packer R, Waterbor J, Blatt J, Robison L. Visual complications in childhood cancer survivors: a Childhood Cancer Survivor Study report. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer, 2006, platform presentation.

2005

A0501 Owen JE, Kawashima T, Myers CD, Lu Q, Zebrack B, Mertens A, Robison L, Zeltzer LK. Pain prevalence and retrospective incidence in childhood cancer survivors: A report from the Childhood Cancer Survivor Study. American Society of Psychosocial Oncology, January, 2005, platform presentation.

A0502 Nagarajan R, Clohisey DR, Neglia JP, Sklar C, Robison, LL. Amputation in pediatric lower extremity bone sarcoma survivors: Predictors of function and quality of life. American Society of Pediatric Hematology-Oncology meeting May, 2005, poster presentation.

A0503 Ness KK, Mertens AC, Hudson MM, Wall MM, Leisenring WM, Oeffinger KC, Sklar CA, Robison LL, Gurney JG. Physical performance limitations and participation restrictions among long-term childhood cancer survivors: The Childhood Cancer Survivor Study. American Society of Pediatric Hematology-Oncology, May, 2005, poster presentation.

A0504 Gurney JG, O'Leary M, Ness KK, Shalamar SD, Baker KS. Metabolic syndrome and growth hormone deficiency in adult survivors of childhood leukemia. Submitted to the American Society of Pediatric Hematology-Oncology, May, 2005.

A0505 Oeffinger K, Mertens A, Sklar C, Kawashima T, Hudson M, Meadows A, Marina N, Kadan-Lottick N, Leisenring L, Robison L. Prevalence and severity of chronic diseases in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, May, 2005, platform presentation, plenary session.

A0506 Mertens A, Yasui Y, Liu Y, Neglia J, Robison L. Late cause-specific mortality in long-term survivors of childhood and adolescent cancer: An update from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, May, 2005, poster presentation.

A0507 Henderson T, Whitton J, Hammond S, Stovall M, Meadows A, Mertens A, Neglia J, Robison L, Cook F, Diller L. Sarcomas as a subsequent malignancy in survivors of pediatric malignancy: The Childhood Cancer Survivor Study. American Society of Clinical Oncology, May, 2005, platform presentation.

A0508 Bowers DC, McNeil DE, Liu Y, Leisenring W, Gurney J, Stovall M, Donaldson SS, Packer RJ, Robison LL, Oeffinger KC. Risk of stroke among >5 year survivors of childhood leukemia and brain tumors: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, May, 2005, platform presentation.

A0509 Casillas J, Castellino DM, Hudson MM, Mertens AC, Whitton J, Brooks SL, Zeltzer LK, Ablin A, Robison LL, Oeffinger KC. The effect of insurance and ethnicity on healthcare access and health behaviors: The Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, May, 2005, poster presentation.

A0510 Mertens AC, Neglia JP, Hammond S, Perkins JL, Liu Y, Robison LL. Incidence rates of keratinocyte carcinoma (KC) in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS). Society of Investigative Dermatology, May, 2005, platform presentation, plenary session.

A0511 Ergun-Longmire B, Mertens AC, Mitby P, Quin J, Heller G, Yasui Y, Robison LL, Sklar CA. Risk of second neoplasms in survivors of childhood cancer treated with growth hormone: An updated report from the Childhood Cancer Survivor Study. Endocrine Society, 2005, platform presentation.

A0512 Chemaitilly W, Mertens AC, Mitby P, Whitton J, Stovall M, Yasui Y, Robison LL, Sklar CA. Acute ovarian failure in survivors of childhood and adolescent cancer: Data from the Childhood Cancer Survivor Study. Endocrine Society, 2005, poster presentation.

A0401 Sigurdson A, Ronckers C., Mertens A, Sklar C, Stovall M, Smith S, Liu Y, Hammond S, Berkow R, Neglia J, Meadows A, Robison L, Inskip P. Second primary thyroid cancer after a first childhood malignancy: A report from the Childhood Cancer Survivor Study. American Association for Cancer Research, oral presentation.

A0402 Lu Q, Myers CD, Owen J, Zebrack BJ, Zevon MA, Mertens A, Robison LL, and Zeltzer LK. Pain prevalence among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Pain Society, poster presentation.

A0403 Recklitis CJ, Hudson MM, Zebrack BJ, Mertens AC, Mitby PA, Nagarajan R, Robison LL, Zeltzer L. Psychosocial functioning in a large-scale cohort of childhood cancer survivors: A report from the Childhood Cancer Survivor Study. American Psychosocial Oncology Society, 1st annual conference, oral presentation.

A0404 Bassal M, Kadan-Lottick NS, Neglia J, Taylor L, Yasui Y, Friedman DL, Mertens AC, Robison LL, Meadows AT. Risk of rare adult-type carcinomas as a subsequent neoplasm in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), poster presentation.

A0405 Bowers DC, McNeil DE, Liu Y, Yasui Y, Stovall M, Gurney JG, Hudson MM, Robison LL, Oeffinger KC. Stroke following therapy for Hodgkin Disease (HD): A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0406 Friedman DL, Whitton J, Yasui Y, Mertens AC, Hammond S, Stovall M, Donaldson SS, Meadows AT, Robison LL, Neglia JP. Risk of second malignant neoplasms (SMN) 20 years after childhood cancer: The updated experience of the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation.

A0407 Friedman DL, Whitton J, Yasui Y, Mertens AC, Hammond S, Stovall M, Donaldson SS, Meadows AT, Robison LL, Neglia JP. Second malignant neoplasms in five-year survivors of childhood cancer: An update from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0408 Termuhlen A, Tersak J, Hudson M, Mertens A, Gimpel N, Bleyer W, Yasui Y, Robison L, Oeffinger K. Health status, medical care, preventive screening, and risk behaviors in adult survivors of cancer diagnosed during adolescence: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), poster presentation.

A0409 Meacham LR, Gurney JG, Mertens AC, Ness KK, Sklar CA, Robison LL, Oeffinger KC. Body mass index (BMI) and final height in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Research, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0410 Meacham LR, Gimpel N, Overa R, Whitton JA, Sklar CA, Robison LL, Oeffinger KC. Diabetes mellitus in long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Research, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), poster presentation.

A0411 Sklar C, Mertens A, Mitby P, Whitton J, Stovall M, Mulder J, Green D, Nicholson S, Yasui Y, Robison L. Premature menopause in survivors of childhood and adolescent cancer: Data from the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Research, oral presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0412 Castellino SM, Hudson MM, Mertens AC, Yeazel M, Whitton J, Brooks S, Ablin A, Castleberry RP, Hobbie WL, Kaste S, Robison LL, Oeffinger KC. Comparison of long-term outcomes, health care utilization, and health behaviors in young adult African-American (AA) survivors of childhood cancer with white, non-Hispanic (WNH) survivors: A Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), poster presentation.

A0413 Perkins JL, Liu Y, Mitby PA, Neglia JP, Hammond S, Stovall M, Meadows AT, Hutchinson R, Dreyer Z, Robison LL, Mertens AC. Nonmelanoma skin cancer (NMSC) in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0414 Mulrooney DA, Mertens AC, Neglia JP, Green DM, Zeltzer L, Robison LL. Fatigue and sleep in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), poster presentation.

A0415 Owen JE, Myers CD, Lu Q, Zebrack B, Zevon M, Mertens AC, Robison LL, Zeltzer LK. Pain prevalence in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), poster presentation.

A0416 Mertens A, Riley A, Patenaude A, Bursch B, Robison L, Zeltzer L. Health and Well-Being in Adolescent Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Cancer Survivorship: Pathways to Health After Treatment Symposium, Washington DC, 2004, poster presentation.

2003

A0301 Neglia J, Inskip P, Liu Y, Yasui Y, Hammond S, Stovall M, Packer R, Meadows A, Mertens A, Robison L. Subsequent neoplasms (SNs) of the central nervous system (CNS) in survivors of childhood cancer: A case/control study from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation.

A0302 Brownstein C, Mertens A, Mitby P, Stovall M, Qin J, Heller G, Robison L, Sklar C. Factors that affect final height and change in height SDS in survivors of childhood cancer treated with growth hormone (GH): A report from the Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies' Annual Meeting, poster presentation.

A0303 Yeazel M, Oeffinger K, Gurney J, Mertens A, Hudson M, Emmons K, Chen H, Robison L. The cancer screening practices of long-term childhood cancer survivors. American Association for Cancer Research, poster presentation.

A0304 Perkins J, Yasui Y, Liu Y, Hammond S, Stovall M, Neglia J, Meadows A, Robison L, Mertens A. Nonmelanoma skin cancer (NMSC) in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation.

A0305 Mertens A, Mitby P, Radloss G, Perentesis J, Kiffmeyer W, Neglia J, Meadows A, Jones I, Potter J, Friedman D, Yasui Y, Robison L, Davies S. XRCC1 and glutathione s-transferase polymorphism and susceptibility to therapy-related cancer in Hodgkin's Disease survivors: A report from the Childhood Cancer Survivor Study. American Association for Cancer Research, oral presentation.

A0306 Mulrooney D, Mertens A, Neglia J, Green D, Zeltzer L, Robison L. Fatigue and sleep disturbance in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, poster presentation.

2002

A0201 The Investigators of the Childhood Cancer Survivor Study (CCSS): Long-Term Outcomes Among 5-Year Survivors of Childhood and Adolescent Cancers. American Society of Pediatric Hematology/Oncology, oral presentation.

A0202 Nagarajan R, Clohisey D, Greenberg M, Neglia JP, Sklar C, Yasui Y, Zeltzer L, Robison LL: Limb Function and Quality of Life (QOL) of Survivors of Pediatric Lower Limb Bone Tumors: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, poster presentation.

A0203 Mitby PA, Robison LL, Whitton JA, Zevon MA, Gibbs IC, Tersak JM, Meadows AT, Stovall M, Zeltzer LK, Mertens AC: Utilization of Special Education (SE) Services and Educational Attainment (EA) Among Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, poster presentation.

A0204 Hudson MM, Oeffinger K, Mertens A, Hobbie W, Chen H, Gurney J, Yeazel M, Robison L: General Health Status of Long-Term Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation.

A0205 Kadan-Lottick N, Robison L, Gurney J, Neglia J, Yasui Y, Hayashi R, Hudson M, Greenberg M, Mertens A: What Do Childhood Cancer Survivors Know About Their Past Diagnosis and Treatment? A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, poster presentation.

A0206 Oeffinger KC, Mertens A, Sklar C, Yasui Y, Fears T, Stovall M, Robison L: Obesity in Adult Survivors of Childhood Acute Leukemia: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, poster presentation.

A0207 Mertens A, Yasui Y, Liu Y, Stovall M, Hutchinson R, Sklar C, Robison L: Pulmonary Complications in Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, poster presentation.

A0208 Nagarajan R, Clohisy DR, Greenberg M, Neglia JP, Sklar C, Zeltzer L, Yasui Y, Robison LL: Limb Function and Quality of Life (QOL) of Survivors of Pediatric Lower Extremity Bone Tumors: A Report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0209 Kenney LB, Diller L, Friedman D, Neglia J, Yasui Y, Mertens A, Inskip P, Meadows A, Robison L: Risk Factors for Breast Cancer (BC) in Women from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0210 Oeffinger K, Mertens A, Hudson M, Castillo J, Gurney J, Yeazel M, Chen H, Robison L: Health Care Utilization of Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0211 Oeffinger K, Mertens A, Sklar C, Yasui Y, Fears T, Stovall M, Vik T, Robison L: Acute Lymphoblastic Leukemia and Obesity: A Report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0212 Pang JWY, Friedman DL, Whitton J, Weiss NS, Mertens A, Robison L: Employment Status of Adult Survivors of Pediatric Cancers: A Report from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0213 Mertens A, Yasui Y, Liu Y, Stovall M, Hutchinson R, Sklar C, Robison L: Pulmonary Complications in Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0214 Yasui Y, Liu Y, Neglia J, Friedman D, Bhatia S, Meadows A, Mertens A, Whitton J, Robison L: A Cautionary Note on the Methodology for the Analysis of Second Malignant Neoplasm (SMN) Risk in Childhood Cancer Survivors: Breast SMN After Hodgkin Disease as an Example. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0215 Mitby P, Robison L, Whitton J, Zevon M, Gibbs I, Tersak J, Meadows A, Stovall M, Zeltzer L, Mertens A. Utilization of special education services and educational attainment among long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0216 Gurney JG, Punyko J, Neglia J, Packer R, Sklar C, Kadan-Lottick N, Nicholson HS, Wolden S, McNeil DE, Mertens A., Robison L. Non-neurological late effects among childhood brain tumor survivors: an analysis from the childhood cancer survivors study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

A0217 Kadan-Lottick N, Robison L, Gurney J, Neglia J, Yasui Y, Hayashi R, Hudson M, Greenberg M, Mertens A. What do childhood cancer survivors know about their past diagnosis and treatment?: A report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), oral presentation.

2001

A0101 Sklar C, Mertens A, Mitby P, Qin J, Heller G, Yasui Y, Robison L: Risk of Disease Recurrence and Second Neoplasms (SN) in Survivors of Childhood Cancer Treated With Growth Hormone (GH): Data from the Childhood Cancer Survivor Study (CCSS). Pediatric Endocrine Society, oral presentation.

A0102 Green D, Whitton J, Stovall M, Mertens A, Donaldson S, Ruymann F, Pendergrass T, Robison L: Pregnancy Outcome of Partners of Male Survivors of Childhood Cancer. A Report from the Childhood Cancer Survivor Study (CCSS). American Association of Cancer Research, poster presentation.

A0103 Kadan N, Friedman D, Mertens A, Yasui Y, Whitton J, Robison L, Strong L: Clarification of Self-Reported Family History Data by Telephone Interview: A Report from the Childhood Cancer Survivor Study (CCSS). American Association of Cancer Research, poster presentation.

A0104 Friedman D, Kadan-Lottick N, Liu Y, Mertens A, Robison L, Strong L: History of Cancer Among First-Degree Relatives of Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, poster presentation.

A0105 Neglia J, Yasui Y, Mertens A, Friedman D, Hammond S, Donaldson S, Stovall M, Meadows A, Robison L: Second Primary Neoplasms (SPNs) of the Central Nervous System (CNS) in Five Year Survivors of Childhood Cancer — A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation.

A0106 Gurney JG, Packer R, Punyko J, Sklar C, Kadan-Lottick N, Neglia J, Nicholson S, Wolden S, McNeil E, Mertens A, Robison L: Non-neurological Late Effects Among Childhood Brain Tumor Survivors: A Preliminary Analysis from the Childhood Cancer Survivor Study. Society for Neuro-Oncology, oral presentation.

A0107 The Investigators of the Childhood Cancer Survivor Study (CCSS). Long-Term Outcomes Among Survivors of Cancer During Childhood and Adolescence. Society for Epidemiologic Research, poster presentation.

A0108 Mulvihill JJ, Strong LC, Robison LL: Genetic Disease in Offspring of Survivors of Childhood and Adolescent Cancer. American Society of Human Genetics, poster presentation.

A0109 Hammond S, Neglia J, Qualman S, Mertens A, Yasui Y, Meadows A, Robison L. Tissue archive of second malignant neoplasms (SMN) in the Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies, poster presentation.

2000

A0001 Packer RJ, Gurney J, Zeltzer L, Mertens A, Robison L: Long-Term Neurologic and Neurocognitive Status of Childhood Brain Tumors: A Childhood Cancer Survivor Study (CCSS) Report. Society for Neuro-Oncology, oral presentation.

A0002 Neglia J, Yasui Y, Mertens A, Friedman D, Hammond S, Donaldson S, Stovall M, Meadows A, Robison L: Second Primary Neoplasms (SPNs) of the Central Nervous System (CNS) in Five Year Survivors of Childhood Cancer--A Report from the Childhood Cancer Survivor Study (CCSS). International Pediatric Neuro-Oncology Symposium, oral presentation.

1999

A9901 Sklar C, Whitton J, Mertens A, Stovall M, Green D, Marina N, Greffe B, Wolden S, Robison L: Thyroid Dysfunction in Survivors of Hodgkin's Disease (HD): Data from the Childhood Cancer Survivor Study (CCSS). American Pediatric Society and Society for Pediatric Research, oral presentation.

A9902 Mertens A, Neglia J, Yasui Y, Potter J, Nesbit M, Ruccione K, Smithson A, Robison L: Mortality Rates and Causes of Death in 5-Year Survivors of Childhood and Adolescent Cancer. American Society of Clinical Oncology, oral presentation.

A9903 Neglia J, Mertens A, Yasui Y, Hammond S, Friedman D, Donaldson S, Meadows A, Robison L: Risk of Second Primary Neoplasms (SPNs) in Survivors of Childhood Cancer--Initial Analysis of the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, oral presentation.

A9904 Neglia J, Mertens A, Yasui Y, Hammond S, Friedman D, Donaldson S, Meadows A, Robison L: Risk Factors For Second Primary Neoplasms (SPNs) in Long-Term Survivors of Childhood Cancer--Initial Analysis of the Childhood Cancer Survivor Study (CCSS). International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting, oral presentation.

A9905 Mertens A, Neglia J, Yasui Y, Potter J, Nesbit M, Ruccione K, Smithson A, Robison L: Mortality in Five-Year Survivors of Childhood and Adolescent Cancer — Preliminary Analysis of the Childhood Cancer Survivor Study (CCSS). International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting, poster presentation.

A9906 Green DM, Whitton J, Stovall M, Mertens A, Ruymann F, Pendergrass T, Robison L: Pregnancy Outcome After Treatment for Cancer During Childhood or Adolescence. A Report from the Childhood Cancer Survivor Study (CCSS). International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting, oral presentation.

1998

A9801 Hammond S, Qualman S, Neglia J, Meadows A, Robison L. Mucoepidermoid carcinoma (MEC) of the salivary gland occurring as a second malignant neoplasm (SMN) in the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Pathology, oral presentation.

1997

A9701 Hammond S, Qualman S, Neglia J, Meadows A, Robison L. Assessment and validation of second neoplasms in the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Pathology, oral presentation.

CCSS Trainee List as of 5/2012

Trainee/Mentee	Training Experience	Current Position	CCSS Publications
Nina Kadan-Lottick, MD, MSPH	Post-doctoral Fellowship	Associate Professor Division of Pediatric Hematology-Oncology Yale University New Haven CT	JAMA 2002; Epidemiology 2003
Brad Zebrack, PhD	Post-doctoral Fellowship	Associate Professor School of Public Health University of Michigan Ann Arbor, MI	Pediatr 2002; J Clin Oncol 2004
Pauline Mitby, MPH	Graduate Training	Clinical Research Associate Division of Pediatric Hematology-Oncology Children's Hospital of Minnesota Minneapolis, MN	Cancer 2003
Rajaram Nagarajan, MD, MS	Post-doctoral Fellowship and Graduate Training	Assistant Professor Division of Pediatric Hematology-Oncology Cincinnati Children's Hospital Cincinnati, OH	Cancer 2003; Br J Cancer 2004
Carrie M. Brownstein, MD	Post-doctoral Fellowship	Senior Clinical Scientist and Sr. Associate Clinical Director Roche Pharmaceuticals Assistant Clinical Professor Department of Pediatric Hematology-Oncology New York-Presbyterian/Columbia New York, NY	J Clin Endocrinol Metab 2004
Lisa Kenney, MD, MPH	Post-doctoral Fellowship	Instructor Department of Pediatrics Harvard Medical School Pediatric Oncology Dana-Farber Cancer Institute Boston MA	Ann Intern Med 2004
Elyse Park, PhD	Graduate Training	Assistant Professor Harvard Medical School Department of Psychiatry Massachusetts General Hospital Boston MA	J Clin Oncol 2005
Sharon Castellino, MD, MS	Graduate Training	Associate Professor Department of Pediatrics Wake Forest University Winston-Salem, NC	J Clin Oncol 2005
Joanna Perkins, MD, MS	Post-doctoral Fellowship and Graduate Training	Hematology-Oncology Children's Hospital of Minnesota Minneapolis, MN	J Clin Oncol 2005
Judy Punyko, PhD	Graduate Training	State Maternal and Child Health Epidemiologist Minnesota Department of Health St Paul, MN	Pediatr Blood Cancer 2005
Wassim Chemaitilly, MD	Post-doctoral Fellowship	Assistant Member Endocrinology St. Jude Children's Research Hospital Memphis, TN	J Clin Endocrinol Metab 2006
Mylene Bassal, MD	Post-doctoral Fellowship	Assistant Member Department of Pediatrics University of Ottawa Ottawa, Canada	J Clin Oncol 2006
Berrin Ergun-Longmire, MD	Post-doctoral Fellowship	Assistant Professor Division of Pediatric Endocrinology Robert Wood Johnson Medical School New Brunswick, NJ	J Clin Endocrinol Metab 2006

Trainee/Mentee	Training Experience	Current Position	CCSS Publications
Cecile Ronckers, PhD	Post-doctoral Fellowship	Epidemiologist Emma Children's Hospital Amsterdam, Netherlands	Radiat Res 2006
Tara Henderson, MD, MPH	Fellowship and Graduate Training	Assistant Professor Department of Pediatrics University of Chicago Chicago, IL	JNCI 2007
Eric Chow, MD, MPH	Fellowship and Graduate Training	Medical Director Pediatric Cancer Long Term Follow-up Program Seattle Children's Hospital Seattle, WA	J Pediatr 2007; Pediatr Blood Cancer 2009
Todd Florin, MD	Medical Student	Pediatric Emergency Fellow Children's Hospital of Philadelphia Philadelphia, PA	Cancer Epi Biomarker Prev 2007
Kris Ann Schultz, MD, MS	Fellowship and Graduate Training	Hematology-Oncology Children's Hospital of Minnesota Minneapolis, MN	J Clin Oncol 2007
Jenny Pang, MD, MPH	Fellowship and Graduate Training	Clinical Assistant Professor School of Public Health University of Washington Seattle, WA	Pediatr Blood Cancer 2008
Irina Dinu, PhD	Post-doctoral Fellowship	Assistant Professor Department of Public Health Sciences University of Alberta Edmonton, Alberta	Pediatr Blood Cancer 2008
Daniel Mulrooney, MD, MS	Fellowship and Graduate Training	Assistant Professor Department of Pediatrics University of Minnesota Minneapolis, MN	Sleep 2008 Br Med J 2009
Elizabeth Bluhm, MD, MPH	Post-doctoral Fellowship	Department of Internal Medicine Washington Hospital Medical Center Washington, DC	Blood 2008
Anne Lown, DrPH	Post-doctoral Fellowship	Assistant Clinical Professor Dept. of Family Health Care Nursing UCSF San Francisco, CA	Addiction 2008
Edward Garmey, MD	Post-doctoral Fellowship	Associate Director for Clinical Development GPC-Biotech Princeton, NJ	J Clin Oncol 2008
Natasha Buchanan, PhD	Post-doctoral Fellowship	Behavioral Scientist Centers for Disease Control Atlanta, GA	Cancer 2009
Meagan Lansdale, MD	Medical Student	Anesthesiology Resident Stanford University Palo Alto, CA	Cancer 2009
Caroline Laverdiere, MD	Fellowship Training	Assistant Professor Department of Pediatrics University of Montreal Montreal, QC	JNCI 2009
Christopher Janson, MD	Medical Student	Pediatric Resident Boston Children's Hospital Boston MA	Cancer Epi Biomarker Prev 2009
Karen Wasilewski-Masker, MD, M.Sc.	Fellowship Training	Assistant Professor Department of Pediatrics Emory University School of Medicine Atlanta, GA	JNCI 2009
Lisa Kahalley, PhD	Post-doctoral Fellowship	Assistant Professor Department of Pediatrics Baylor College of Medicine Houston, TX	Nicotine Tob Res 2010 PBC 2012 PBC 2011

Trainee/Mentee	Training Experience	Current Position	CCSS Publications
Beth Kurt, MD, MS	Fellowship and Graduate training	Pediatric Oncologist Helen DeVos Children's Hospital Grand Rapids, MI	PBC 2011
Timothy Best, PhD candidate	Graduate degree (PhD)	PhD Candidate University of Chicago Chicago, IL	Nat Med 2011
Anne Kirchhoff, PhD	Post-doctoral Fellowship	Assistant Professor University of Utah Salt Lake City, UT	CEBP 2011 Cancer 2011 Med Care 2010
Sharon Castellino, MD, MPH	Graduate degree (MPH)	Assistant Professor Wake Forest University Winston-Salem, NC	Blood 2011
Michele Montgomery, PhD	Graduate degree (PhD)	Assistant Professor University of Alabama Tuscaloosa, AL	J Cancer Surv 2011
Nancy Clanton, PhD	Post-doctoral training	Instructor University of Alabama Birmingham, AL	Cancer 2011
Kerri Nottage, MD	Fellowship training	Assistant Member St. Jude Children's Research Hospital Memphis, TN	Blood 2011
Neyssa Marina, MD, MS	Graduate degree (MS)	Professor Associate Chief of Clinical Affairs Stanford University School of Medicine Palo Alto, CA	Manuscript submitted



The Childhood Cancer Survivor Study



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A BRIEF UPDATE

From the Long-Term Follow-Up Study

April 2012

<http://ltfu.stjude.org>

Topic:

FATIGUE, SLEEP, & MENTAL FUNCTIONING

Why we studied sleep and fatigue issues:

- Fatigue and reduced sleep quality are commonly reported by childhood cancer survivors. About 45 percent of the general population have symptoms of fatigue. Rates as high as 90 percent have been reported in certain groups of cancer survivors.
- Survivors are also at increased risk of experiencing problems with mental functioning that can affect their well-being and quality of life. We wanted to learn more about the associations between fatigue and poor sleep quality and mental functioning among adult survivors.

Who we studied:

Over 1500 survivors and siblings of survivors

- 48 percent Male
- 52 percent Female

What we studied:

The effects of day-time sleepiness, fatigue, poor sleep quality, and low vitality (energy levels) on mental skills, including:

- **Task efficiency:** The ability to complete everyday tasks at work, home, or school
- **Emotional regulation:** The ability to control one's emotional responses
- **Organization:** The ability to organize one's environment
- **Memory:** The ability to remember information over time (short-term and long-term)

The information for this study came from responses to study questionnaires. To assess mental functioning survivors and siblings responded to statements such as "I have problems completing my work," "I get frustrated easily," and "My desk/workspace is a mess."

We found that . . .

- Problems with mental functioning were reported by more than 20 percent of survivors in this study.
- Survivors of brain tumors had the highest rates of problems with mental functioning. Survivors of leukemia and Hodgkin lymphoma also had increased problems with task efficiency.
- Those with fatigue and sleep disturbance were approximately 2 to 3 times more likely to experience reduced mental function.
- Fatigue, sleepiness, poor sleep quality, and low vitality had a negative impact on survivors' mental functioning that was independent of the effects of radiation, steroids, or antimetabolite chemotherapy drugs (drugs such as methotrexate that destroy cancer cells by interfering with cell division.) This means that fatigue and sleep problems were associated with mental functioning difficulties even in survivors who did not receive these treatments.

Sleep problems and fatigue have a direct effect on mental functioning that is independent of the effects of treatment.

In summary:

- Mental functioning in long-term survivors of childhood cancer appears particularly vulnerable to the effects of fatigue and sleep disruption.
- Health care providers should inform survivors about health habits they can practice to improve sleep quantity and quality.
- Improving sleep quality may lead to improved mental functioning and a better quality of life for survivors.

Reference

Clanton NR, Klosky JL, Li C, Jain N, Srivastava DK, Mulrooney D, Zeltzer L, Stovall M, Robison LL, Krull KR. Fatigue, vitality, sleep, and neurocognitive functioning in adult survivors of childhood Cancer: A report from the childhood cancer survivor study. *Cancer* 2011;2559-67.

Improve Your Sleep, Improve Your Life

by practicing good sleep hygiene

Poor sleep and fatigue can have serious consequences – they can contribute to emotional problems such as depression, increase the likelihood of serious accidents, and affect personal productivity on the job and at home. Improving sleep quality and learning to achieve natural sleep can help prevent these negative effects.

Practicing good **sleep hygiene** can help ensure you get the sleep you need. According to the National Sleep Foundation (web link below) sleep hygiene simply refers to the “variety of different practices that are necessary to have normal, quality night-time sleep and full day-time alertness.” When these practices become habits, sleep usually improves.

Sleep-promoting habits

- Try not to nap during the day.
- Spend time outdoors in the sunlight every morning and avoid bright light late at night.
- Go to bed at the same time every night and get up at the same time every morning, even on weekends.
- Avoid alcohol and caffeine 4-6 hours before going to bed.
- Stop watching television and turn off your computer at least an hour before bedtime.
- Exercise regularly but not right before bed.
- Do something relaxing before you go to bed, such as listening to soft music or meditating.
- Keep your bedroom dark, and comfortably cool.
- Use your bedroom only for sleeping and avoid falling asleep on the couch or anywhere outside of your bedroom.

It's best to keep the TV out of your sleeping area!



Other factors that can affect sleep

- Some physical conditions, such as acid reflux or snoring, can make sleep more difficult.
- Stress and anxiety interfere with sleep quality.
- Depression can cause excessive sleepiness.
- Many medications can cause sleeplessness as a side effect.

See your doctor if . . .

- You have any of the conditions listed above.
- You have tried practicing the sleep hygiene suggestions above and you still have trouble falling or staying asleep at night.

Your doctor may recommend dietary changes or environmental changes or prescribe supplements or short-term sleep medications. The goal is to help your body learn to sleep naturally!

Web Links

St. Jude Children's Research Hospital offers a number of “handouts” on our website on the subjects of mental functioning and healthy sleep:
<http://www.stjude.org/sjlife/handouts>

The National Sleep Foundation provides a variety of sleep hygiene resources:
<http://www.sleepfoundation.org>

Physical fitness promotes healthy mental functioning, improved quality of life, and a good night's sleep. Check here for fitness tips:
<http://www.health.gov>

A BRIEF UPDATE

From the Long-Term Follow-Up Study

April 2011

<http://ltfu.stjude.org>

Topic: HEALTH LINKS

What:

- Screening and care guidelines for managing late effects of childhood cancer treatment
- Health Links are part of the Children's Oncology Group Survivorship Guidelines
- Information provided by LTFU study participants has been crucial to the development of the guidelines. Thank you, participants!

Who provides the Health Links?

Children's Oncology Group (COG)

- An international clinical trials cooperative group supported by the US National Cancer Institute
- Does research on childhood cancer treatments
- LTFU Study member institutions take part in COG.

Where:

On the Web at:

<http://www.survivorshipguidelines.org>

For healthcare providers:

The following links at the website are geared toward healthcare professionals:

- Long-Term Follow-Up Guidelines
- Long-Term Follow-Up Guidelines Appendix I (Materials for Clinical Application of the LTFU Guidelines)
- Patient-Specific Guideline Identification Tool
- Radiation Reference Guide
- Long-Term Follow-Up Guidelines Appendix II (Complete indexed set of Health Links)

For survivors:

Survivors can click on individual Health Links topics.

Available Health Links

- Introduction to Long-Term Follow-Up
- Introduction to Long-Term Follow-Up (Spanish)
- Emotional Issues
- Emotional Issues (Spanish)
- Educational Issues
- Finding and Paying for Healthcare
- Finding and Paying for Healthcare (Spanish)
- Diet and Physical Activity
- Diet and Physical Activity (Spanish)
- Eye Health
- Cataracts
- Hearing Loss
- Growth Hormone Deficiency
- Central Adrenal Insufficiency
- Hyperprolactinemia
- Hypopituitarism
- Dental Health
- Osteoradionecrosis
- Thyroid Problems
- Heart Health
- Pulmonary Health
- Bleomycin Alert
- Gastrointestinal Health
- Liver Health
- Hepatitis
- Splenic Precautions
- Kidney Health
- Single Kidney Health
- Bladder Health
- Cystectomy
- Neurogenic Bladder
- Female Health Issues
- Male Health Issues
- Precocious Puberty
- Bone Health
- Osteonecrosis
- Amputation
- Limb Sparing Procedures
- Scoliosis and Kyphosis
- Peripheral Neuropathy
- Raynaud's Phenomenon
- Chronic Pain
- Skin Health
- Breast Cancer
- Colorectal Cancer
- Reducing the Risk of Second Cancers
- Reducing the Risk of Second Cancers (Spanish)

Children's Oncology Group Health Links

<http://www.survivorshipguidelines.org>



How to use the Survivorship Guidelines and Health Links

- The Health Links are part of the COG Survivorship Guidelines (see website address above.) They are written in lay language and are addressed to survivors themselves. However, please review them with your doctor.
- Other parts of the guidelines are written in scientific language and are addressed to healthcare professionals.
- Share the site with your primary care doctor, your dentist, and your other regular healthcare providers; ask them to review it with you.
- To view individual Health Links topics, scroll down the page to the instruction that reads:

Click below to download individual Health Links

Clicking on a topic will open the pdf file of the topic in a new window or tab.

More about the Survivorship Guidelines

(Adapted from the survivorship guidelines website) COG's Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers were created for healthcare providers. The purpose is to provide recommendations for screening and management of health problems that can develop after treatment for childhood cancers.

The guidelines can be useful for survivors themselves, but at this time the only version available is meant for healthcare providers. Because of this, survivors are strongly encouraged to use the guidelines only with the assistance of a healthcare professional who is knowledgeable about long-term follow-up care for survivors of childhood, adolescent, and young adult cancers. This is important so that survivors can be sure of getting a complete picture of their health status and any risks they face can be put in the correct perspective.

COG does not provide individualized treatment advice to patients or their families, and strongly recommends discussing this information with a qualified medical professional.

Make sure you receive your newsletter and other Study materials. Update your contact information anytime it changes.

Go to <http://ltfu.stjude.org/newsletters> and click the link on the right side of the page labeled "Update Your Info."

You can update your name, address, telephone number, and email address. You can also leave a comment.

Thank you!

A BRIEF UPDATE

From the Long-Term Follow-Up Study

January 2011

<http://ltfu.stjude.org>

Topic: DENTAL HEALTH

Why did we study participants' dental health?

Treatments including radiation and chemotherapy in children can result in problems with oral health.

Who participated in this study?

11,353 Long-Term Follow-Up Study participants (8522 Survivors and 2831 Siblings)

- 50 percent females and 50 percent males
- 87 percent white non-Hispanic
- Between 15 and 34 years old

What we studied:

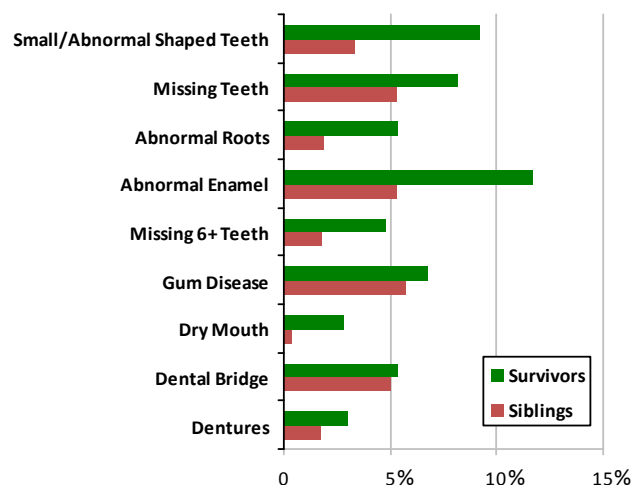
Dental abnormalities reported by study participants and experiences that predict having dental problems. The dental abnormalities we studied included missing teeth, decreased enamel on the surface of teeth, abnormally shaped or small teeth, gum disease, having five or more cavities, wearing a dental bridge or dentures, and having a severely dry mouth (xerostomia).

We found that . . .

72 percent of survivors reported that they had visited a dentist in the past year.

When compared to siblings, survivors were:

- 3 times more likely to have small or abnormally shaped teeth
- 3 times more likely to have abnormal roots
- 2½ times more likely to have decreased enamel on their teeth
- 2½ times more likely to have lost 6 or more teeth
- 10 times more likely to have a severely dry mouth



Percent of Survivors and Siblings with Dental Problems

At increased risk were . . .

- People younger than age 5 at the time of their cancer treatment
- Those who had higher doses of radiation to the teeth
- Those who had high exposure to the alkylating agent cyclophosphamide

In summary:

Survivors of childhood cancer who received radiation to the jaw or alkylating agent chemotherapy, such as cyclophosphamide, before the age of 5 years should be checked regularly for dental problems. All survivors of childhood cancer should practice good dental health (more on other side).

Reference

Kaste SC, Goodman P, Leisenring W, Stovall M, Hayashi RJ, Yeazel M, Beiraghi S, Hudson MM, Sklar CA, Robison LL, Baker KS. Impact of Radiation and Chemotherapy on Risk of Dental Abnormalities. *Cancer* 2009; 115(24):5817-27.

Dental Health Following Childhood Cancer Treatment

Adapted from the Children's Oncology Group Health Link

<http://www.survivorshipguidelines.org>

What are the risk factors for dental problems after childhood cancer treatment?

- Treatment with chemotherapy before your permanent teeth were fully formed, especially before the age of 5
- Radiation that included the mouth and/or salivary glands
- Treatment with azathioprine (after a bone marrow transplant)
- Chronic graft-versus-host disease (after a bone marrow transplant)

What should you do to keep your teeth and mouth as healthy as possible?

- See your dentist at least every six months. Make sure your dentist knows about the treatment you received. **(Ask your oncologist for a summary of your treatment.)** Be sure that your visit includes an oral cancer screening.
- Tell your dentist immediately if you have any signs of infection in your mouth or gums, such as redness, tenderness, excessive bleeding of gums, painful teeth, or areas of increased sensitivity.
- Always practice good oral health habits: brush your teeth and tongue twice a day, floss at least once a day, and follow all of your dentist's recommendations.
- Remember that your diet and other health habits affect your oral health, too!
 - Limit sweets and carbohydrate-rich foods.
 - Don't use tobacco products.
 - Drink alcohol only in moderation (since alcohol may also increase other problems following childhood cancer treatment).

What does your dentist need to know about your health?

Always let your dentist know if you have or had any of the following:

- Shunt (tube to drain fluid from the brain)
- Limb salvage procedure (replacement of bone with a metal rod or bone graft)
- Leaky or scarred heart valve (this sometimes happens after radiation to the chest)
- Splenectomy (surgical removal of the spleen)
- Radiation dose to the spleen of 40 Gray (Gy) or more. This dose is sometimes written as 4000 centigray (cGy) or 4000 rads.
- Currently active chronic graft-versus-host disease following stem cell transplant

What do you and your dentist need to know about the risk of osteoradionecrosis?

- Osteoradionecrosis (**ORN**) is a problem with bone healing that sometimes happens in people who received high doses of radiation, especially to the jaw. Symptoms can include mouth pain, jaw swelling, and difficulty opening the mouth fully. It is important to know that risk of **ORN** does not decrease with the passage time after radiation treatment.
- **ORN** is uncommon but it can occur when a survivor undergoes a dental procedure like pulling a tooth, or other surgery that involves the jawbone. If you need this type of dental work, there are special treatments that can be done to lessen the risk of **ORN**. For example, oxygen that is under pressure can be given before dental procedures to help with healing.
- If you received radiation to the jaw you should:
 - Tell your dentist so he or she can get details about the treatment before doing any procedures that could lead to **ORN**.
 - Have regular dental care and take good care of your teeth and gums because the risk of cavities is higher for people who received large doses of radiation.

For more information about dental health issues following childhood cancer treatment:

American Dental Association website (click on "Oral Health Topics")

www.ada.org

The American College of Oral and Maxillofacial Surgeons

www.acoms.org

Patient Centers website (click on "Head and Neck")

<http://www.patientcenters.com/survivors/news/reading/html>

LTFU

Long-Term Follow-Up Study

Stay linked to the LTFU Study:

email: ltfu@stjude.org

phone: 1.800.775.2167

Update your contact information at:

<http://ltfu.stjude.org>



*For a list of participating centers,
please see our website*

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Surviving childhood cancer is a major life accomplishment. It took courage and determination to survive, and it takes courage and determination to live as a survivor. Congratulations, participants! Accomplishments can come with costs, however, and for some survivors those costs involve limitations on their ability to live independently in adulthood. In this issue, we present information about a recently published study of independent living status among LTFU Study participants.

Independence has a personal meaning for each individual. For some people, independence may mean living on one's own. For others it may mean having a voice in decisions that are made about one's living situation. However, everyone needs to feel that they can control aspects of their lives and participate in community life. On page 2 we offer information on some resources to help individuals realize their personal goals relating to independent living.

Courage of a survivor. Katie Sonnichsen has faced limitations brought on by side effects of cancer treatment with courage and humor. Read her story on page 4.



Thank you. As always, we want to thank you, our participants, for being our partners in research. We hope you are enjoying your Summer!

New Study of Women's Health

The EMPOWER Study is an exciting new LTFU study focused on women's health. If you are a woman between the ages of 25 and 49 who was treated with chest radiation for a childhood cancer, you may be contacted for this study.



If you'd like additional information about the EMPOWER study, please call the LTFU Study toll-free telephone line: 1-800-775-2167.

Would you like to receive the LTFU Study newsletter by email?

Let us know where to send it!

1. Go to <http://ltfu.stjude.org>
2. Click on "Update Your Info" in the menu bar at the top of the screen.
3. Type in your contact information, including your email address.
4. Enter a Comment to let us know you want us to email your newsletter to you.

Study Update

Independent Living Status of Adult Survivors of Childhood Cancer

Living independently, and caring for and being responsible for oneself are important goals for most adults, and most adult survivors of childhood cancer are successful in achieving these goals. Some survivors face challenges in this area, though, and we wanted to learn more about which groups might be most at risk.

What we learned. Most survivors in this study—more than 82 percent!—reported that they are living independently. However, survivors were more than twice as likely as the siblings in the comparison group to be living with parents or other relatives or to rely on nursing or caregiver support.

Survivors were most likely to be in a dependent living situation if they:

- ❑ Had received whole brain (cranial) radiation to treat their childhood illness
- ❑ Had a diagnosis of leukemia, non-Hodgkin's lymphoma or brain tumor (compared to solid tumor or bone cancer)
- ❑ Were younger at diagnosis: People who were diagnosed and treated before age 6 were only half as likely to report that they are living on their own as those who were at least 12 years old at diagnosis.
- ❑ Were depressed.

Dr. Alicia Kunin-Batson, the author of this study, says, “While some of these things can't be changed, others can be managed and assistance is available. If you are experiencing depression or you have difficulties in thinking,



Dr. Alicia Kunin-Batson

attention, learning, or remembering it is important to talk to your doctor about these potential barriers to independence.”

Why results are important.

The results of this study tell us about which groups of survivors might need help in achieving their goals in the area of independent living. They also provide information that can be used to plan

interventions to reduce the impact of barriers to independence.

About the study. More than 6000 adult survivors and more than 2000 siblings who were at least 25 years old provided the answers to the surveys that were analyzed for this study. We used the siblings as our comparison group because they shared in the experiences that the survivors had with illness and treatment.

Alicia Kunin-Batson, PhD, is an assistant professor in the Department of Pediatrics at the University of Minnesota. Details of this study were published earlier this year in the journal *Pediatric Blood & Cancer*.



LIFT-OFF!

Resources to Reach Your Goals

Resources are available for survivors who are living with one or more disabilities who want help achieving their independent living goals:

Centers for Independent Living are private non-profit agencies that operate within a local community and provide many independent living services. Independent living centers (ILCs) exist in each state. They are funded by grants from the US Rehabilitation Services Administration. The idea behind ILCs is that people with disabilities are the best experts on their own needs. At least 51 percent of staff of ILCs are individuals with disabilities. ILCs are not places where people live. Rather, they provide the following types of services to people with disabilities:

- ❑ Information and referral
- ❑ Independent living skills training
- ❑ Individual and systems advocacy
- ❑ Peer counseling

Specific services provided by ILCs vary but can include such things as support groups, social and recreational activities, financial and budget counseling, assistive technology exchange and recycle programs, installation of wheelchair ramps and other home modifications, and many others.

Supported employment means work in a setting where both disabled and non-disabled people work together and where people with disabilities receive comparable wages to people who are not disabled. Often, even people with severe disabilities are able to work in supported jobs. In supported employment, a person has a job coach who stays involved long-term or permanently. Other help that may be provided includes transportation, assistive technology and individually tailored supervision. State Vocational Rehabilitation offices can help to arrange supported employment opportunities.

Please see the Web Links on page 4 for additional information.

Employment and Young Adult Survivors

Long-Term Follow-Up Study researchers often partner with colleagues from other centers to study issues that are important to survivors of childhood cancer and similar illnesses. One such partner, Dr. David R. Strauser, is a psychologist at the University of Illinois at Urbana-Champaign, where he is on the faculty of the Department of

“Very few young adult cancer survivors take advantage of the services offered by state Vocational Rehabilitation offices The majority of survivors in our study who received vocational rehabilitation services became successfully employed.”

—Dr. David Strauser

Kinesiology and Community Health. Dr. Strauser works in the area of occupational development and employment of young adults with disabilities. In the last few years, he has focused more and more of his attention on cancer survivors.

In a recent study he conducted, Dr. Strauser found that very few young adult cancer survivors take advantage of the services offered by state Vocational Rehabilitation offices. These offices offer a wide range of services to individuals who qualify for help. Services may include career counseling, job placement, assistance with job accommodations and adaptive technologies, even help with buying clothes that are appropriate for the work place.

The majority of survivors in the study who received vocational rehabilitation services became successfully employed. In fact, the study showed that those who received job search assistance and on-the-job support were four times more likely to be employed after receiving such services.

“Applying for vocational services through state offices

is an important step survivors can take if they’re seeking employment,” says Dr. Strauser. “State Vocational Rehabilitation offices are sometimes unfamiliar with the specific needs of cancer survivors. Still, it is definitely worth applying. Your pediatric oncologist or other health care provider can provide information to help with the application process,” he says.

Dr. Strauser is also starting work on a project to learn if individualized support can help young adult brain tumor survivors develop job-related skills and achieve successful employment.

The preliminary results from a small group of individuals suggest that brain tumor survivors who were diagnosed before age six and those who were diagnosed at age 12 or older are able to develop the personal skills needed to hold down a job better than those who were diagnosed when they were between the ages of 6 and 12. These skills include understanding how to fit in to the work place environment and work well with others, being on time for work, staying focused on the task at hand, and similar capabilities.

“These are preliminary results from a small group,” say Dr. Strauser, “but, they show the importance of research in designing programs that can target the needs of individuals who most need help.”



Dr. David Strauser

Comments by Dr. David R. Strauser: “There are many levels of independence.”

Editor’s note: We asked Dr. Strauser to comment on the research highlighted in the Study Update on page 2. Below are his remarks.

By the time they are in their late teens or early 20s, most people make the transition from living in an environment where they are dependent on others to living independently and being responsible for their own care. For young adult survivors of childhood cancer this transition may present unique challenges. This research from the LTFU Study presents valuable insights about specific risk factors that may make it challenging for survivors to live independently in adulthood.

In seeking to help survivors achieve an optimal degree of independence, healthcare providers must assess how a person’s social environment, personal relationships, employment status and potential, access to medical care, and ability to manage late effects may affect their ability to live independently. Independent living is not an all or nothing affair; however. There are many levels of independence and each represents a significant achievement. Helping individuals attain their desired level of independence should be a primary goal of psychosocial treatment.

Notes from Participants

Katie's Story: Coping with Late Effects of Treatment

To a 4-year old, childhood cancer might not look so bad. But today, 31-year-old Katie Sonnichsen, of Sioux Falls, South Dakota, is still dealing with delayed effects of treatment. Even so, she believes that looking back on 27 years as a cancer survivor is cause for celebration. “As a result of my treatments and the love and support of my family and friends, I am here 27 years later to share my story,” she says.



Katie and her mom during treatment

Katie was diagnosed with Acute Lymphocytic Leukemia (ALL) in June, 1984. Her parents signed her up for a clinical trial which determined her treatment protocol. She received an aggressive treatment of various chemotherapy drugs, as well as whole brain (cranial) radiation. The radiation was given to Katie as part of the clinical trial research. “We were concerned about that because we knew there might be residual side effects,” recalls her mom, Pam, “but Katie never had a relapse after treatment. The cranial radiation may have helped.”

As a young adult, Katie has had to deal with many challenges caused by treatment side effects. “I have a learning disability that makes reading comprehension difficult,” she explains, “but I was able to persevere through high school and college.” Katie received accommodations in college to help her deal with her learning disability. “I was allowed extra time to finish tests,” she says, “and I had assistance with note-taking so that I might be able to focus on the professor’s lecture for the day.” Treatment also left Katie with cataracts in both eyes and affected her growth—at 31 years old, she stands 4 feet 10 inches tall.

Social relationships have also been difficult for Katie. “I have had some of the most meaningful friendships a person could ask for, yet sometimes I have not felt as though I fit in,” she says.

“I can be a persistent person . . . I will do what I can to finish a job or task no matter how long it might take me.”

fear that I might say or do something wrong or even be rejected. It seems kind of silly when I consider the chances and risks my parents took when it came to my treatments.”

Despite all these challenges, Katie graduated from Augustana College with a bachelor’s degree in social work. She also holds a diploma in culinary arts from Mitchell Technical Institute. “Over the last few years I have become more assertive,” Katie says. “I am willing to stand up for what I believe in—I can be a persistent person in that I will do what I can to finish a job or task no matter how long it might take me.”

Today, Katie is successfully supporting herself and living independently. She is working at a restaurant in Sioux Falls and at a local grocery store. “I’m still in pursuit of the perfect job,” she admits, “and have no idea what I want to be ‘when I grow up.’”

Surrounded by two loving parents, four siblings, and friends, Katie celebrates her cancer-free life by advocating for research. “Do not be afraid of the word ‘research,’” she says to others. “Through being part of a study, you are doing your part to help someone else. The treatments that I’ve undergone will aid the doctors, nurses and scientists in finding answers to what may cause these cancers, how we can prevent them and, most importantly, how we can cure them.”

Editor's note: Katie's story originally appeared in the Children's Cancer Research Fund's Butterfly newsletter. It is reproduced here with permission in a modified form.



Katie Sonnichsen

Web Links

For more information about supported employment, see this page from the U.S. Department of Labor:

<http://www.dol.gov/odep/archives/fact/supportd.htm>

The Social Security website lists contact information for the Office of Vocational Rehabilitation of each state. It also includes information about Centers for Independent Living, listed by state:

<https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate>