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Children's Hospital Colorado Denver, CO

Children's Hospital of Los Angeles Los Angeles, CA

Children's Hospital of Orange County Orange, CA

Children's Hospital of Philadelphia Philadelphia, PA

Children's Hospital of Pittsburgh Pittsburgh, PA

Children's Hospitals and Clinics of Minnesota Minneapolis-St. Paul, MN

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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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

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Toronto Hospital for Sick Children Toronto, ON

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University of Michigan - Mott Children's Hospital Ann Arbor, MI

University of Minnesota

 $Minneapolis,\,MN$

UT-Southwestern Medical Center Dallas, TX

U.T.M.D. Anderson Cancer Center Houston, TX CCSS Annual Investigators' Meeting Memphis, TN June 12 – 13, 2013

Childhood Cancer Survivor Study

An NCI-funded resource for outcome and intervention research

1124 CA55727

http://ccss.stjude.org

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2013 CCSS Investigator Meeting At-A-Glance The Peabody Hotel

Memphis, TN

<u>Day/Time</u>	<u>Meeting</u>	<u>Attendees</u>	<u>Room</u>
Tuesday, June 11			
5:00 – 8:00pm	CCSS Executive Committee	Executive Committee	Ben Hollander
Wednesday, June 12	Mezzanine Level		
8:00 – 10:00am	CCSS Steering Committee (continental breakfast 7a – 8a)	Steering Committee + Executive Committee	Salon D/E
10:00am – 1:00pm	CCSS Principal Investigator (working lunch)	Steering Committee + Executive Committee + Institutional PI's	Salon D/E
2:00 – 7:00pm	Plenary Session*	All Attendees	Continental Ballroom
7:00 – 8:00pm	Reception	All Attendees	Skyway/Roof
Thursday, June 13	Mezzanine Level		
7:00 – 8:00am	Continental Breakfast	All Attendees	Continental Ballroom
8:00am – 12:00pm	Plenary Session*	All Attendees	Continental Ballroom
12:00 – 1:00pm	Box Lunch Break-Out Sessions*	All Attendees	Cont. Ballroom; Brinkley; Cockrell; Hollander; DeSoto; Louis XVI
1:00pm	Adjourn		

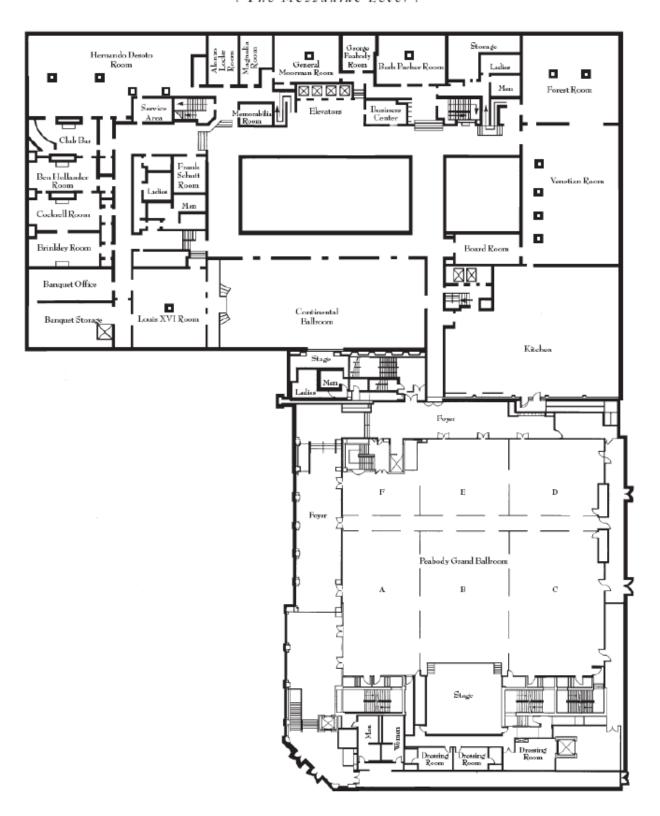
^{*}See the Plenary Session Agenda on the following page for details

CCSS Investigator Meeting Plenary Session Agenda

			_
<u>Day/Time</u>	Topic	<u>Presenter</u>	Room
Wednesday, June 12			
2:00 - 3:40pm	<u>Update Reports</u>		Continental
	Principal Investigator	L. Robison	Ballroom
	Coordinating Center	G. Armstrong	
	Data and Statistics Center	W. Leisenring	
	Radiation Physics Center	M. Stovall	
	Biorepository and Biopathology Centers	L. Robison	
	Research and Publications Committee	D. Green	
	Education Committee	M. Hudson	
3:40 – 4:00pm	Break		
4:00 – 7:00pm	Research Presentations		Continental
	Standard Risk ALL Outcomes	P. Nathan	Ballroom
	Infertility Treatment and Pregnancy	L. Diller	
	Efficacy of COG Guidelines for Heart Failure	L. Wong	
	Calculating Cumulative Total Incidence	Y. Yasui	
	Telomere Length and SMN	M. Gramatages	
	Update on Genome-Wide Analysis	L. Morton	
Thursday, June 13			
8:00 – 9:30am	Ancillary Intervention Studies		Continental
	Reducing Skin Cancer Risk	A. Geller	Ballroom
	EMPOWER	K. Oeffinger	
	ECHOS	C. Cox/M. Hudson	
9:30 – 10:20am	Working Group Reports		Continental
	Biostatistics/Epidemiology	Leisenring/Mertens	Ballroom
	Genetics	S. Bhatia	
10:20 – 10:40am	Break		
10:40a – 12:00p	Working Group Reports		Continental
	Chronic Disease	C. Sklar	Ballroom
	Second Neoplasms	J. Neglia	
	Psychology	K. Krull	
	Cancer Control	K. Oeffinger	
12:00 – 1:00pm	Working Group Breakout Sessions (Box Lunch)		To be
	Genetics (S. Bhatia)		announced
	Chronic Disease (C. Sklar)		
	Second Neoplasm (J. Neglia)		
	Cancer Control (K. Oeffinger)		
	Psychology (K. Krull)		
	Biostat/Epidemiology (Leisenring/Mertens)		

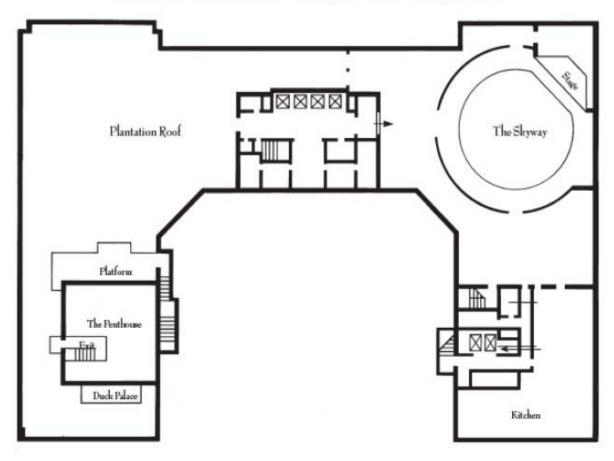
Conference Center Floor Plan

. The Mezzanine Level .



Reception Floor Plan

. The Plantation Roof & The Skyway .



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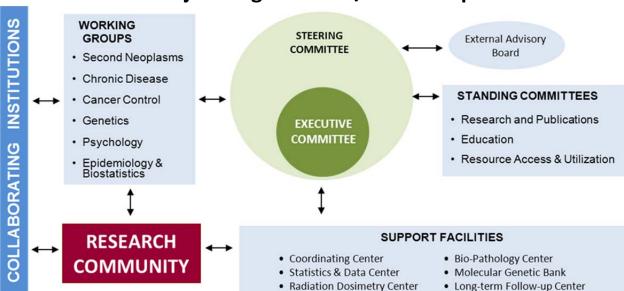
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Registered as of 5/21/2013

COSS Cohort Surveys

Baseline 10/29/92 – 12/10/02

Follow-up 1 02/1/00 – 12/10/02

Follow-up 2 11/06/02 – 04/25/05

Follow-up 3 04/09/05 – 11/15/06

Follow-up 4 07/13/07 - 11/1/09

Follow-up 5

1998 2000 2002 2004 2006 2008 2010 2012 2013

Family History Survey 08/01/95 – 12/01/04

Women's Health Survey 06/27/01 – 01/23/03

Men's Health Survey 02/08 – 11/01/09

Breast Cancer Surveys 2/9/12 – 4/1/13

Healthcare Barriers Survey Sleep/Fatigue Survey 11/06/02 – 02/10/04 Needs Assessment Survey 5/7/10 – 1/17/12

02/01/01 - 10/10/01

Mammography Survey 06/06/05 - 08/24/06

Participation Feasibility Survey 7/27/10 – 4/25/11

Teen Survey 12/10/01 – 02/27/03

Health Information Survey 11/05 – 08/06

Health Insurance Survey

Bone Tumor Survey 11/08/00 – 07/05/02

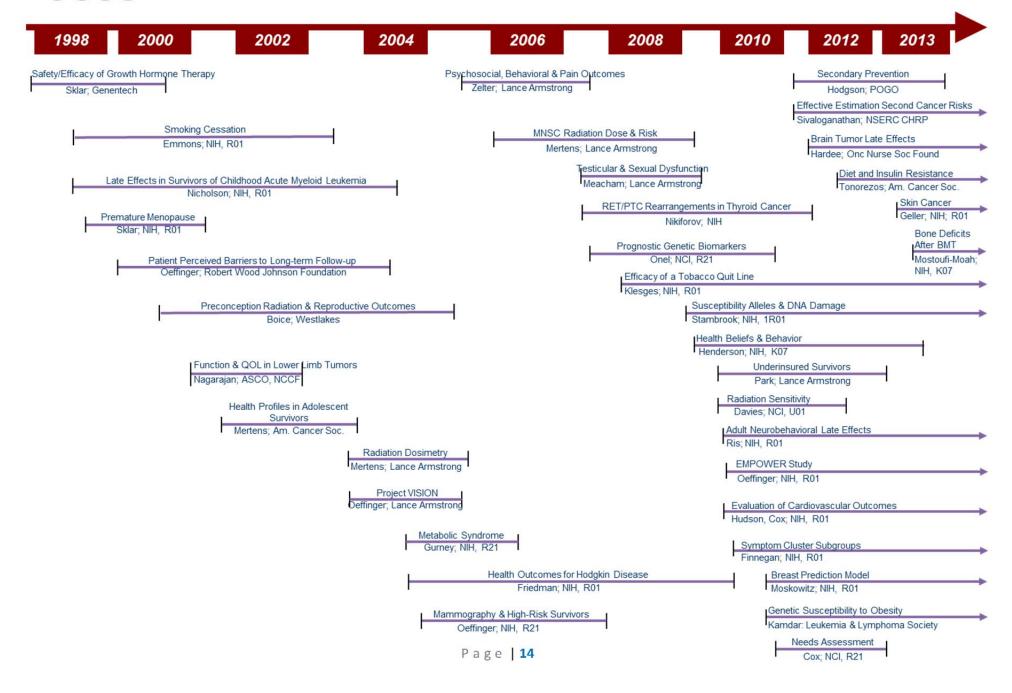
5/6/11 – 4/27/12

Project Vision Survey 1/1/03-12/31/05

Stroke Recurrence Survey 4/27/11 – 11/5/12

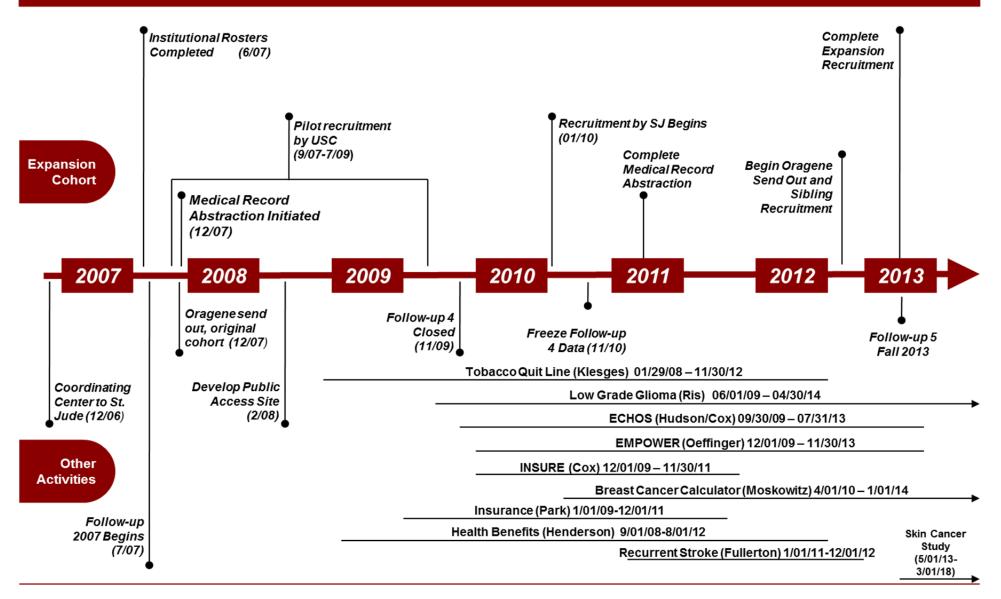
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Externally-Funded Ancillary Studies





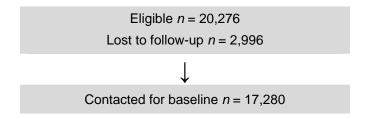
Childhood Cancer Survivor Study (U24 CA55727) Coordinating Center Timeline



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

Characteristic	Survivors i	n=14,357	Siblings n=3,899		
- Maradio Hotio	No.	%	No.	%	
Age at entry into the cohort (years) <9 10-14 15-19 20-24 25-29 30-34 35-39 40+	175 1933 3126 3118 2770 1977 926 332	1.2 13.5 21.8 21.7 19.3 13.8 6.4 2.3	76 355 656 671 709 655 461 316	2.0 9.1 16.8 17.2 18.2 16.8 11.8 8.1	
Sex Male Female	7713 6644	53.7 46.3	1875 2024	48.1 51.9	
Race/ethnicity White non-Hispanic Black non-Hispanic American Indian/Alaska Native Asian or Pacific Islander Hispanic Other Unknown	11942 668 88 167 397 1045	83.2 4.7 0.6 1.2 2.8 7.3 0.3	3414 102 15 41 60 130 137	87.6 2.6 0.4 1.1 1.5 3.3 3.5	
Age at cancer diagnosis (years) 0-4 5-9 10-14 15-20	5754 3200 2912 2491	40.1 22.3 20.3 17.4			
Diagnosis Acute lymphoblastic leukemia Acute myeloid leukemia Other leukemia Astrocytoma Medulloblastoma, PNET Other CNS malignancies Hodgkin lymphoma Non-Hodgkin lymphoma Kidney cancer Neuroblastoma Soft tissue sarcoma Ewings sarcoma Osteosarcoma Other bone malignancy	4151 356 320 1184 381 315 1927 1083 1258 951 1243 403 733 52	28.9 2.5 2.2 8.2 2.7 2.2 13.4 7.5 8.8 6.6 8.7 2.8 5.1			
Vital status at cohort entry Alive Dead	13182 1175	91.8 8.2			
Treatment Chemo + RT + surgery Chemo + RT Chemo + surgery Chemo only RT + surgery RT only Surgery only Medical records not available	5550 1459 2274 816 1497 33 910 1818	38.7 10.2 15.8 5.7 10.4 0.2 6.3 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 (1992 – 2002)	20	n = 17,280*	83%	0%	17% [†]	0%	0%
Follow-Up 1 (2000 – 2002)	16	n = 12,884	81%	6%	2%	4%	7%
Follow-Up 2 (2002 – 2005)	24	n = 11,859	78%	8%	3%	5%	6%
Follow-Up 3 (2005 – 2006)	4	n = 11,393	78%	5%	1%	3%	13%
Follow-Up 4 (2007 – 2009)	28	n = 10,143 (9,769 sent)**	79%***	8.7%	2.4%	1.6%	5.1%

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

^{*}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 4 not sent)

^{***}Follow-Up 4 participation rate was:

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	246	88%
2	Children's Hospital Colorado	816	625	29	596	594	99%
3	Children's Hospital of Pittsburgh	1,070	874	110	764	753	99%
4	Children's Hospital at Stanford University	677	479	108	371	358	96%
5	Dana-Farber Cancer Institute	932	932	27	905	905	100%
6	Emory University	1,240	938	221	717	703	98%
7	Children's National Medical Center	576	443	132	311	280	90%
8	U.T.M.D. Anderson Cancer Center	762	654	47	607	593	98%
9	Memorial Sloan-Kettering Cancer Center	1,626	748	97	651	650	99%
11	University of California at San Francisco	796	663	264	399	246	62%+
12	Seattle Children's Hospital	1,161	854	25	829	791	95%
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	159	2,144	1,674	78%
16	Nationwide Children's Hospital	687	506	5	501	499	99%
17	Roswell Park Cancer Institute	317	284	43	241	240	99%
19	Minneapolis Children's Medical Center	761	592	10	582	582	100%
20	Children's Hospital of Philadelphia	1,505	1,128	119	1,009	992	98%
21	St. Louis Children's Hospital	618	473	52	421	421	100%
22	Children's Hospital of Los Angeles	1,184	762	18	744	731	98%
23	UCLA Medical Center	133	95	28	67	67	100%
24	Riley Hospital for Children, Indiana Univ.	1,253	972	124	848	722	85%
25	UAB/Children's Hospital of Alabama	572	422	57	365	349	96%
26	Univ. of MI/Mott Children's Hospital	932	736	70	666	641	96%
27	UT Southwestern Medical Center	977	750	108	642	642	100%
28	Texas Children's Hospital	1,174	863	249	614	608	99%
29	City of Hope National Medical Center	285	227	95	132	130	99%
-	Totals	25,086	19,403	2,715	16,688	15,700	
	New Centers						
30	Children's Hospital of Orange County	690	593	34	559	267	48%
31	University of Chicago	464	459	107	352	352	100%
32	Lurie Children's Hospital of Chicago	1,176	1,114	2	1,112	244	22%
33	Cook Children's Hospital	620	551	21	530	467	88%
	Totals	2,950	2,717	138	2,579	1,490	

^{*}MRAF = Medical Record Abstraction Form; submitted online as of 3/28/13

^{+ =} MRAFs for non-participants completed, but are held at primary institution

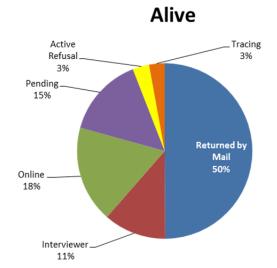
Expansion Cohort: Recruitment Status by Institution as of 5/14/2013

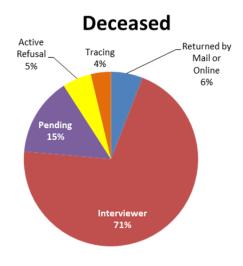
Nome	Eligible	HIPAA	% of Elig	Baseline Completed	0/ of Flic
Name St. Jude Children's Research Hospital	2,144	Returned 1,913	89.2%	1,728	% of Elig 80.6%
-					
Children's Hospital Colorado	596	500	83.9%	414	69.5%
Minneapolis Children's Medical Center	582	468	80.4%	366	62.9%
St. Louis Children's Hospital	421	337	80.0%	274	65.1%
Riley Hospital for Children, Indiana Univ.	848	672	79.2%	509	60.0%
University of Minnesota	279	221	79.2%	167	59.9%
Children's Hospital at Stanford University	371	293	79.0%	232	62.5%
Univ of MI - Mott Children's Hospital	666	525	78.8%	434	65.2%
Emory University	717	564	78.7%	421	58.7%
Children's Hospital of Philadelphia	1,009	783	77.6%	634	62.8%
U.T.M.D. Anderson Cancer Center	607	469	77.3%	337	55.5%
Nationwide Children's Hospital	501	384	76.6%	320	63.9%
Children's Hospital of Pittsburgh	764	581	76.0%	461	60.3%
Children's Hospital of Los Angeles	744	551	74.1%	393	52.8%
Seattle Children's Hospital	829	601	72.5%	457	55.1%
Roswell Park Cancer Institute	241	171	71.0%	132	54.8%
University of California at San Francisco	399	280	70.2%	213	53.4%
Memorial Sloan-Kettering Cancer Center	651	450	69.1%	372	57.1%
Dana-Farber Cancer Institute	905	620	68.5%	428	47.3%
Sub-Total for Initial Data Freeze	13,274	10,383	78.2%	8,292	62.5%
UT Southwestern Medical Center	642	426	66.4%	279	43.5%
UAB/Children's Hospital of Alabama	365	241	66.0%	184	50.4%
City of Hope	132	86	65.2%	61	46.2%
UCLA Mattel Children's Hospital	67	42	62.7%	35	52.2%
Children's National Medical Center	311	117	37.6%	83	26.7%
Texas Children's Hospital	614	213	34.7%	168	27.4%
Sub-Total for non-Data Freeze Sites	2,131	1,125	52.8%	810	38.0%
Total	15,405	11,508	74.7%	9,102	59.1%

Expansion Baseline Survey as of 5/14/2013

		Survivor	S
HIPAA's Received	11,508		
Questionnaires Sent	11,508		
Questionnaires Returned	9,102	79.1%	_
Alive	n	% of Sent	% of Completed
Number Sent	10,729		,
Number Completed	8,507	79.3%	
Returned by Mail	5,354	49.9%	62.9%
Completed by Interviewers	1,238	11.5%	14.6%
Completed Online	1,915	17.8%	22.5%
Pending Return	1,588	14.8%	
Active Refusal	327	3.0%	
In Tracing	307	2.9%	_
Deceased	n	% of Sent	% of Completed
Number Eligible	779		
Completed	595	76.4%	
Completed by Interviewers	549	70.5%	92.3%
Returned by Mail or Online	46	5.9%	7.7%
Notation by Mail of Offiline		0.070	1.1 /0
Pending Return	113	14.5%	_
Active Refusal	42	5.4%	-
In Tracing	29	3.7%	-

Survey Period: 5/08 - Present





Oragene DNA Kit Summary: Original Cohort

Kits Sent	Cases (n = 8,334)		Siblin	gs (n = 2,710)*
	n	% of Sent	n	% of Sent
Returned	4,305	51.7%	737	27.2%
Refused	786	9.4%	96	3.5%
Pending	2,617	31.4%	1672	61.7%
In Tracing	486	5.8%	201	7.4%
Deceased	140	1.7%	4	0.1%

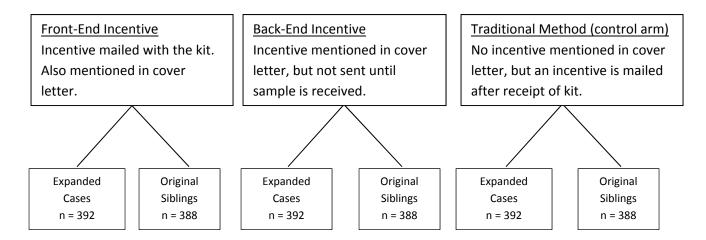
Methodology Summary

- 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.
- Resend kit upon participant request.
- Mass resend to all non-responders occurred in January 2010.
- Second mass resend to original cohort cases (survivors) occured February 2012.
- Pilot mailing to examine use of incentives (\$25 gift card) sent to selected original cohort siblings and expanded cohort occurred October November 2012 (see following page).
- *Sibling response rates are prior to the incentive pilot study.

Report Date 5/2013

Oragene DNA Kit Incentive Pilot Study Return Rates

Methodology Summary (Incentive = \$25 Target Gift Card)



Return Rate Summary at 6 Month Follow-Up

Expanded Cohort Survivors

Method	Number Sent	Mailing Date	Response Rate (6 mos.)	P value
Front-End	392	10/19/2012	204 (52.0%)	<0.001
Back-End	392	11/9/2012	162 (41.3%)	0.047
Traditional (control)	392	11/30/2012	134* (34.2%)	

^{*5.5} months from the initial mailing date

Original Cohort Siblings (previous passive non-responders)

Method	Number	Mailing Date	Response Rate (6 mos.)	P value
	Sent			
Front-End	388	10/12/2012	111 (28.6%)	<0.001
Back-End	388	10/25/2012	65 (16.7%)	0.696
Traditional (control)	388	11/6/2012	60 (15.5%)	

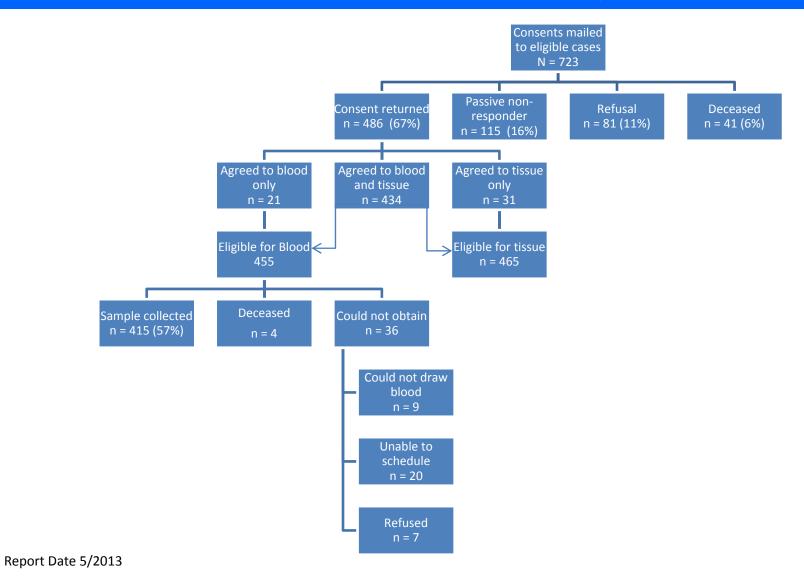
Report Date 5/2013

Subsequent Neoplasms by Primary Cancer Diagnosis as of 5/2013

				Primar	y Cancer D	iagnosis			
Subsequent Neoplasm*	Leukemia	CNS	HD	NHL	Kidney	Neuro- blastoma	Soft tissue sarcoma	Bone cancer	Total
Breast	30	5	223	13	11	3	20	40	345
Meningioma	125	83	3	8		1	7	2	229
Other CNS	45	24	9	4	1	1	6	2	92
Thyroid	37	18	52	11	3	11	9	13	154
Soft tissue sarcoma	7	10	24	4	7	5	22	7	86
Leukemia	12	3	17	5	2	4	4	6	53
Bone	6	5	6	7	6		13	10	53
Melanoma	9	8	15	2	2		9	7	52
Lymphoma	10	4	20	4	_	2	5	1	46
Renal carcinoma	3	2	5	3	1	9	2	3	28
Other carcinoma	31	10	40	11	8	5	16	18	139
NMSC	582	209	876	124	45	9	55	47	1,947
All others	14	7	29	10	2	4	9	8	83
Total	911	388	1,319	206	88	54	177	164	3,307

^{*}Includes in-situ breast cancer and non-invasive melanoma

Blood and Tissue Collection for Cases with a Confirmed SMN (Original and Expansion Cohorts)



RT Data/Analyses Summary as of May 2013

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

Study Title	Study PI	Number exposed to RT	Dosimetry required	Dosimetry status
Cohort studies (conti	nued)			
Osteoporosis and avascular necrosis	Kadan-Lottick	~8500	Dose to gonads and pituitary and maximum brain dose	Complete Dec 2005
Fertility among survivors	Green	5624	Dose to gonads and pituitary	Complete Oct 2005, Jan 2006, Sept 2007
Bone Marrow Transplant	Baker/ Chow	379	Dose to cranium	Complete Mar 2006
Dental Outcomes	Kaste	5632	Total average dose to the teeth	Complete Nov 2006
Thyroid exposure /ALL patients	Chow	2389	Dose to thyroid and pituitary	Complete Feb 2007
Stillbirth and neonatal death	Boice / Signorello	2805	Dose to ovaries, uterus, testes, pituitary	Complete Jun 2006
Menarche timing	Armstrong	299	Dose to ovaries and pituitary	Complete Feb 2007
Hodgkin Disease Outcomes	Castellino	1551	Dose range to body regions	Complete Jun 2007
Carotid Artery Dose	Ness/Gurney	50	Dose to the carotid artery	Complete Jul 2007
Thyroid exposure /entire cohort	Bhatti / Sigurdson	8494	Dose to thyroid	Complete Nov 2007
BRIEF neuro-psych outcomes	Ness	~8500	Dose to 4 brain regions	Complete Nov 2007
Cardiac outcomes	Mulrooney	~8500	Average dose to heart	Complete Feb 2008
Cataract cohort	Chodick / Inskip	~8500	Dose to lens	Complete Feb 2008
Visual complications	Mertens / Whelan	~8500	Dose to eye and brain	Complete Feb 2008
Breast screening	Oeffinger	3913	Yes/No and body region treated	Complete Feb 2008
Pain	Ness	~8300	Body sites, dose to 4 brain regions	Complete Apr 2008
Salivary gland tumors	Inskip	~8500	Dose to salivary glands or sites of treatment	Complete May 2008
Psychosexual outcomes/ females	Sklar	1412	Dose to ovaries and pituitary	Complete Feb 2009
Wilms Tumor long term follow-up	Termuhlen	717	Dose to heart and kidneys	Complete Oct 2009
TBI/BMT Leukemia Cohort	Baker and Chow	2722	Dose to thyroid, gonads, brain, spine	Complete Jan 2010
Obesity	Green	5632	Pituitary	Complete Jan 2010

Study Title	Study PI	Number exposed to RT	Dosimetry required	Dosimetry status
Cohort studies (conti	nued)			
Fertility	Green	4023	Ovaries and pituitary	Complete Jan 2010
GI second cancers	Henderson	46	SMN site in/near/out tx field	Complete Jan 2010
ECHOS	Cox / Hudson	883	Treatment dose and body region	Complete Jun 2010
Pregnancies during treatment	Mulvihill	16	Therapy records	Complete Sept 2010
GU complications	Shnorhavorian / Sklar	8507	Dose to kidneys, ureters, bladder	Complete Dec 2010
Stroke – first and recurrent	Fullerton / Mueller	8633	Maximum dose to brain – existing dosimetry CNS, HD, Leukemia	Complete Dec 2010
Functional Outcomes	Ness / Marina	1094	Max dose to limb, pelvis, chest	Complete Feb 2011
Pulmonary complications	Huang	1876	Average dose to heart and lungs for CNS patients	Complete Apr 2011
Cranial Radiation	Brinkman	6875	Maximum TD by brain region	Complete May 2011
Oocyte radiosensitivity	Hamish	4324	Dose to ovaries	Complete Mar 2011
CNS Long. Patterns of Late Effects	Hardie	923	Maximum TD by brain region	Complete Oct 2011
Longitudinal Changes in Health Status	Hudson / Oeffinger	8507	Used existing maximum TD by region	Complete Feb 2011
Male Infertility	Seidel	7717	Dose to testes and pituitary	Complete Mar 2011
Obesity among ALL survivors	Kamdar	1215	Maximum TD to spine and brain regions	Complete Nov 2011
Cardiac Outcomes – Risk model	Chow	8507	Maximum TD to chest and abdomen, heart average	Complete Jan 2012
BCC SMN – Genetic Risk	Davies	1282	Maximum TD by body region and brain region	Complete Nov 2012
NCI-GWA SMN risk	Morton	8507	Maximum TD by body region and brain region	In Progress
Lifestyle factors and pregnancy outcomes	Gawade	3567	Females. Ovary, uterus and pituitary dose previous run.	Complete Oct 2012
HL-Health Status	Effinger	1675	Maximum TD by body region- update	Complete Nov2012

Radiation Therapy Record Status as of May 2013: Original (diagnosed 1970-1986) & Expanded Cohorts (diagnosed 1987-1999)*

INSTITUTION	Records	received	Records p	processed ¹	Stat	us
Cohort:	Original	Expanded	Original	Expanded	Original	Expanded
Children's Hospital at Stanford University	386	132	386	0	Complete	Ongoing
Nationwide Children's Hospital	391	161	391	110	Complete	Ongoing
Children's Hospital of Los Angeles	279	135	279	18	Complete	Ongoing
Children's Hospital of Philadelphia	493	332	493	7	Complete	Ongoing
Children's Hospital of Pittsburgh	387	185	387	107	Complete	Ongoing
Children's National Medical Center	113	9	113	0	Complete	Ongoing
City of Hope	-	46	-	29	-	Ongoing
Dana-Farber Cancer Institute	427	182	427	38	Complete	Ongoing
Emory University	68	173	68	106	Complete	Ongoing
Mayo Clinic	299	-	299	-	Complete	Ongoing
Memorial Sloan-Kettering Cancer Center	377	207	377	179	Complete	Ongoing
Minneapolis Children's Medical Center	145	175	145	138	Complete	Ongoing
Riley Hospital for Children, Indiana University	209	175	209	112	Complete	Ongoing
Roswell Park Cancer Institute	221	95	221	74	Complete	Ongoing
Seattle Children's Hospital	274	252	274	76	Complete	Ongoing
St. Jude Children's Research Hospital	977	675	977	271	Complete	Ongoing
St. Louis Children's Hospital	228	125	228	63	Complete	Ongoing
Texas Children's (Baylor)	220	32	220	15	Complete	Ongoing
Children's Hospital Colorado	377	57	377	16	Complete	Ongoing
Toronto Hospital for Sick Children	697	0	697	0	Complete	Ongoing
U.T.M.D. Anderson Cancer Center	408	175	408	94	Complete	Ongoing
UAB/The Children's Hospital of Alabama	97	61	97	17	Complete	Ongoing
UCLA Mattel Children's Hospital	250	17	250	7	Complete	Ongoing
University of California at San Francisco	236	56	236	49	Complete	Ongoing
University of Michigan - Mott Children's Hospital	431	187	431	127	Complete	Ongoing
University of Minnesota	370	80	370	50	Complete	Ongoing
UT - Southwestern Medical Center	147	122	147	88	Complete	Ongoing
Total by cohort	8,507	3,846	8,507	1,791	Complete	Ongoing
Combined Total	12,3	153	10,2	.98		

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

^{[1] &}quot;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 CON	ITROL					
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 CCSS	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
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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CANCER CON	ITROL (continued)					
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/Sloan Kettering	Chronic Disease	03.29.11	Approved	Pending
03.16.11	Risk reduction strategies to prevent of 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 Psychology	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
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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CANCER CON	TROL (continued)					
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 Psychology	01.04.12	Approved	Approved
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	Withdrawn	
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
06.07.12	Receipt of a Treatment Summary and its relationship to morbidities and premature mortality	Ford/MSKCC		07.16.12	Approved	Pending
06.07.12	Association of Surgical Procedure to Health Status in Sarcoma Survivors	Avedian/Stanford	Chronic Disease	07.16.12	Approved	Pending
06.16.12	Morbidity and Mortality Associated with the Diagnosis of Subsequent Meningiomas – Is it Necessary to Screen Adult Survivors of Childhood Cancer Survivors for Meningiomas?	Bowers/ UT Southwestern	SMN	07.16.12	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CANCER CON	TROL (continued)					
06.20.12	The Consequences of Childhood Cancer on Employer-Sponsored Health Insurance and Social Security Benefits	Kirchhoff/Utah		07.16.12	Approved	Approved
07.11.12	Survival Burden in Childhood Cancer Survivors	Henderson/Univ. of Chicago	Chronic Disease SMN	08.28.12	Approved	Pending
09.11.12	Longitudinal Evaluation of Chronic Disease and Health Perceptions in Soft Tissue Sarcoma Survivors	Mueller/Univ. of Michigan	Chronic Disease Psychology	09.18.12	Approved	Approved
09.17.12	The Socio-economic Outcomes of Siblings of Childhood Cancer Survivors	Henderson/ Univ. of Chicago		10.05.12	Approved	Pending
10.24.12	Cancer Screening in Childhood Cancer Survivors: Grounded Theory and Discourse Analysis	Tripp/MD Anderson		11.20.12	Approved	Pending
11.01.12	Evaluating socioeconomic and health-related pathways that predict smoking in survivors of childhood cancer	Erinosho/UNC	Psychology	11.20.12	Approved	Pending
11.19.12	Health Beliefs and Behaviors: Cohort Studies in Childhood Cancer Survivors	Henderson/University of Chicago	SMN	01.10.13	Approved	Pending
05.21.13	Comparison of baseline characteristics of the CCSS original and expanded cohorts	Nathan/Sick Kids				
CHRONIC DIS	EASE					
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
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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CHRONIC DIS	EASE (continued)					
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
07.14.09	Renal Outcomes	Nottage/SJCRH			Withdrawn due to overlap	

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CHRONIC DIS	EASE (continued)					
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	Approved
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	6.17.10	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	Not Approved
04.22.11	Changes in BMI Among Adult Survivors of Childhood CNS Tumors	Chang/MD Anderson	Psychology	05.03.11	Approved	Approved
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			

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
CHRONIC DIS	EASE (continued)					
05.06.12	Chronic Medical Conditions Among Long-term Survivors of Pediatric Non-Hodgkin Lymphoma	Bluhm/Washington Hospital	Epi/Biostats Psychology			
06.07.12	Longitudinal Pulmonary Complications in Survivors of Childhood Cancer	Dietz/UCSD	Epi/Biostats	07.16.12	Approved	Pending
06.07.12	Using the Cumulative Illness Rating Scale to characterize the burden of chronic conditions among childhood cancer survivors	Ness/SJCRH Epi/Biostats		07.16.12	Approved	Pending
06.07.12	Increasing risk of chronic endocrine disorders in aging survivors of childhood cancer	Mostoufi-Moab	Mostoufi-Moab		Approved	Pending
06.15.12	Medical and Psychosocial Outcomes of Survivors of AYA Cancer	Henderson/U. of Chicago	Cancer Control Psychology	07.16.12	Approved	Pending
08.20.12	Long-term Risk of Small Bowel Obstruction in Pediatric Patients with Primary Abdominal Tumors	Diller/Harvard	Epi/Biostats	08.28.12	Approved	Approved
05.21.13	The impact of chronic disease on health care utilization in the CCSS cohort	Nathan/Sick Kids				
EPIDEMIOLOG	GY / 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	Hold
02.12.09	Predicting Late Effects of Individual Cancer Survivors: A Pilot Methodological Study	Yasui/Edmonton Alberta		03.16.09	Approved	Ancillary Study Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
EPIDEMIOLOG	GY / BIOSTATISTICS (continued)					
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
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	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	Not Approved
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	Approved
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	Approved
05.15.12	Predicting the risk of SMN among childhood cancer survivors with NMSC as a second malignancy	Ojha/SJCRH	SMN	06.13.12	Withdrawn	

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
EPIDEMIOLOG	SY / BIOSTATISTICS (continued)					
07.16.12	Access to Health Information Technology and Health Information Seeking in Adult Survivors of Childhood Cancer	Mertens/SJCRH	Cancer Control	08.28.12	Approved	Approved
12.12.12	Estimation of risk ratios in the presence of statistical interactions	Satagopan/MSKCC		01.10.13	Approved	Approved
GENETICS						
05.02.08	Characterization of Genomic Alterations in Yang/NCI SMN 06.02.08 Radiation-Related Breast Cancer Using ArrayCGH (Comparative Genomic Hybridization)		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 Kadan-Lottick/Yale Neurocognitive and Psychological Functioning among Survivors of Childhood Leukemia and Lymphoma		Psychology	03.16.09	Approved	Pending
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	DuBois/UCSF 12.18.08 Appro		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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
GENETICS (co	ntinued)					
07.28.10	Detecting Germ Cell Mutation by Family DNA Sequencing	Mulvihill/OU				Pending
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	Withdrawn
04.04.11	Genome-Wide Association Study of Subsequent	Morton/NCI	SMN	04.21.11	Approved	Approved
	Malignancies		Epi/Biostats			
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
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	
10.18.12	Epigenomic Profiling of Metabolic Outcomes in Childhood Leukemia Survivors	Lupo/Baylor	Cancer Control	11.20.12	Approved	Pending
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
		Warwick/Medical College of Wisconsin	Chronic Disease	07.11.08	Withdrawn	

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PSYCHOLOGY	(continued)					
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	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
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	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
PSYCHOLOG	(continued)					
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	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	e/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	of Florida Epi/Biostats 08.16.11		Approved	Approved
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	Approved
03.27.12	Chronic alcohol consumption and neurocognitive function in adult survivors of childhood cancer	Brinkman/SJCRH	Cancer Control	04.26.12	Approved	Pending
04.25.12	Psychosocial and physical factors influencing fatigue in survivors of childhood Hodgkin Lymphoma	Crabtree/SJCRH	Epi/Biostats	05.15.12	Approved	Approved
05.07.12	Identifying Longitudinal Predictors of Quality of Life in Adolescent Survivors of Pediatric Cancer	Stern/VCU		06.13.12	Approved	Approved
05.08 12	Fatigue reported by childhood cancer survivors and its relationship to health outcomes	Lai/Northwestern University	Epi/Biostats	06.13.12	Approved	Pending
10.03.12	Locus of Control and Survivorship Care	Mays/Georgetown		11.20.12	Approved	Withdrawn
10.06.12	Psychosocial Outcomes of Pediatric Cancer Survivors	Nellen/University of Virginia		10.26.12	Withdrawn	
10.12.12	The Impact of Vision Loss Among Childhood Survivors of Central Nervous System Astroglial Tumors	De Blank/Rainbow Babies	Chronic Disease	10.26.12	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
PSYCHOLOGY	(continued)					
10.16.12	A Pilot Study to Investigate Stimulants to Improve Neurocognitive Impairment in Adult Survivors of Childhood Cancer	Balsamo/ Yale		10.26.12	Approved	Pending
10.17.12	Posttraumatic stress and growth in survivors of recurrent pediatric blood cancers	Hoffman/University of Iowa		10.26.12	Withdrawn	
10.24.12	Neurocognitive and Psychosocial Difficulties in Survivors of Rhabdomyosarcomas	Schapiro/Washington University		11.20.12	Approved	Pending
10.29.12	Sleep and Fatigue in Survivors of Pediatric CNS tumors	Manley/Dana-Farber	Chronic Disease	11.20.12	Approved	Pending
10.30.12	Eating Disorder Behaviors in Survivors of Childhood Caner	Neale/UCSF	/UCSF 11.20.1		Approved	Pending
05.01.13	Social and behavioral phenotypes of adolescent survivors of childhood cancer	Brinkman/SCJRH				
05.08.13	Exploring latent clusters of survivors using the BSI-18	D'Agostino/Princess Margaret Cancer Centre				
SECOND MAL	IGNANT 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		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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
SECOND MAL	IGNANT NEOPLASMS (continued)					
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
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	Not Approved
08.31.11	Lymphoma as SMN	Suh/University of Chicago		09.21.11	Approved	Not Approved
04.03.12	Late Second Neoplasms in Long-Term Survivors of Childhood Cancer	Turcotte/University of Minnesota	Epi/Biostats	04.26.12	Approved	Pending
06.07.12	Second Malignant Neoplasm in Down syndrome survivors of childhood cancer	Xavier/MUSC	Genetics	07.16.12	Approved	Pending
07.03.12	Pooled International Study of Radiation Related Intracranial Tumors	Inskip/NCI		07.16.12	Approved	Approved
09.18.12	Exposure-specific absolute risks of second primary cancer and cardiovascular disease for five-year survivors of childhood Hodgkin's lymphoma	Kovalchik//NCI	Cancer Control Chronic Disease	10.05.12	Approved	Pending
11.02.12	Radiation Dose Reconstruction Methods for Intensity Modulated Radiation Therapy (IMRT)	Howell/MD Anderson	Epi/Biostats Chronic Disease	11.20.12	Approved	Pending
11.27.12	Subsequent Neoplasms in Survivors of Medulloblastoma at St. Jude Children's Research Hospital	Tsui/SJCRH	Chronic Disease	01.10.13	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
SECOND MAL	IGNANT NEOPLASMS (continued)					
01.08.13	Beyond radiation: Understanding thyroid cancer risk in childhood cancer	Turcotte/University of Minnesota	Epi/Biostats	04.02.13	Approved	Pending
04.14.13	Comparison of radiation dose reconstruction methods for subsequent neoplasm studies	Morton/NCI	Epi/Biostats Genetics	5.15.13	Approved	Pending

INSTITUTION KEY

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

Statistical Center Current Project List

Concept	Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Submitted	l & Draft Manuscripts				
11-04	Infertility and the use of fertility treatments in female survivors	Sara Barton/ Lisa Diller	Wendy/Pam	Julie Najita (Harvard)	Accepted - Lancet Oncology
09-13	Cardiovascular risk factor clusters and outcomes	Greg Armstrong	Yan Chen	Yutaka	Accepted - JCO
10-7	Scoring alkylating agent exposure: evaluation of the CED	Dan Green	Wendy	Vikki	Revised/Resubmitted - PBC
09-14	Cost effectiveness of cardiac guidelines	Lennie Wong	Kayla/Wendy	Lennie Wong (COH)	Submitted - JCO
10-24	Male infertility - Male Health Questionnaire	Wasilewski/Meacham	Kristy	Wendy	Submitted - Human Reproduction
Ancillary	COG L9704 / CCSS Collaboration - AML Downs' Syndrome	Joe Neglia / Kris Ann Schulz	Toana	COG Statistician	To be Resubmitted
05-11	Randomized trial identifies predictors of appropriate screening	Jeanne Steele/Ann Mertens	Toana	Melanie Wall (Columbia)	Accepted - J Cancer Survivorship
10-16	Incidence of Breast Cancer after Chest radiation	Kevin Oeffinger	Wendy	Chaya Moskowitz (MSKCC)	Submitted - NEJM
10-14	Health Behaviors and Mortality	Cheryl Cox	Wendy	Vikki Nolan	Submitted - JAMA Internal Med
10-23	Longitudinal Chronic Health conditions	Greg Armstrong/ Kevin Oeffinger	Kayla/Toana	Wendy	Submitted - JCO
11-07	Longitudinal Patterns of Psychological Distress in Adult Survivors of Childhood Cancer	Tara Brinkman/ Kevin Krull	Liang Zhu	Kumar	Manuscript submitted to JCO
10-19	Infectious Complications	Joanna Perkins	Yan Chen	Yutaka	Manuscript in Preparation
10-22	Longitudinal Health care	Jackie Casillas	Qi Liu	Yutaka	Manuscript in Preparation
Ancillary	Psychosexual functioning	Jennifer Ford / Chuck Sklar	Toana	Wendy/John	Manuscript in preparation

Concept	Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Submitted	d & Draft Manuscripts (continued)				
Internal	Missing data imputation (methodology)	Leah Martin/Qi Liu	Yutaka	Wendy	Manuscript in Preparation
04-06	Relationship between PTSS and PTG	James Klosky/Kevin Krull	Toana	Wendy	Manuscript in preparation
07-08	Health outcomes for infant cancer survivors	Lynda Vrooman/ Lisa Diller	Pam/Wendy	Julie Najita (Harvard)	Manuscript in preparation
10-15	Telomere length case/control study	Monica Gramatages	Qi Liu	Yutaka	Submitted – Clin Cancer Res
10-08	Conditional Survival: A Comparison of CCSS and SEER Data	Ann Mertens	Erin Kreiter/Jiang Yong	Yutaka	Manuscript in Preparation
11-13	Risk of Breast Cancer Following Spinal Irradiation for a Pediatric Malignancy	Chaya Moskowitz	Wendy	Chaya Moskowitz (MSKCC)	Manuscript in Preparation
05-09	Regional Access	Dierdre Caplin/ Kevin Oeffinger	Kiri	Dierdre Caplan	Manuscript in Preparation
10-09	Pulmonary outcomes among CNS survivors	Tseng Huang/ Kiri Ness	Yan Chen	Yutaka	Manuscript in Preparation
10-02	Predictors of quality of life in adolescent survivors of childhood cancer	Vikki Nolan	Vikki Nolan	Kiri	Manuscript in Preparation
10-17	Growth Hormone and subsequent CNS Neoplasms	Briana Patterson	Yan Chen	Yutaka	Manuscript in Preparation
11-09	Inverse probability censored weighting (IPCW) to adjust for selection bias and drop out	Chonghzi Di	Toana / Kayla	Wendy	Manuscript in Preparation
11-10	Neurologic/neurosensory sequelae in CNS survivors	Elizabeth Wells	Kristy	Wendy	Manuscript in Preparation
11-03	Morbidity in Survivors of Childhood Leukemia with Down Syndrome	Shannon Raber/ Rob Goldsby	Kayla	Wendy	Manuscript in Preparation
11-15	A longitudinal assessment of physical activity	Carmen Wilson	Kayla	Wendy	Manuscript in Preparation

Concept	Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status
Submitted	& Draft Manuscripts (continued)				
11-18	Physical Activity and Psychological Functioning Among Teenage Survivors	Katie Devine/ Kevin Krull	John	Wendy	Manuscript in Preparation
10-04	Predicting cardiovascular disease; creation of a risk score model Paper 1	Eric Chow	Yan Chen	Yutaka	Manuscript in Preparation
12-02	Association between lifestyle factors, psychological status and adverse pregnancy outcomes	Prasad Gawade	Kiri	Wendy	Manuscript in Preparation
12-05	Psychological and neurocognitive outcomes in adolescents and young adults	Pinki Prasad	Nan Zhang	Kumar	Manuscript in Preparation
12-07	Estimation of the burden of recurrent events I the presence of competing risk	Huiru Dong/Yutaka/Wendy/Les	Yutaka		Manuscript in Preparation
09-16	Recurrent Stroke in childhood cancer survivors	Sabine Mueller/Heather Fullerton	Kayla	Wendy	Manuscript in Preparation
08-12	Characterization of genomic alterations in radiation-related breast cancer using array-CGH (comparative genomic hybridization).	Rose Yang	Kayla	NCI group	Manuscript submitted – in revision
Analyses C	Ongoing				
Ancillary	MDM2 risk factor for BC	Stella Davies	John	Wendy	Analyses completed
Ancillary	ARL111 risk for multiple SMN	Stella Davies	Kayla	John / Wendy	Analyses completed
04-15	Psychosocial sequelea after cancer in infancy vs. after infancy	Marc Bornstein (Axia)	John / Wendy	NCI Statistician	Analyses Ongoing
04-12	BCC risks due to sun exposure and radiation	Ann Mertens	Wendy	Wendy	Analyses Ongoing
09-01	Impact of Chronic disease on NCQ and psychosocial functions	Kevin Krull (was Neelam Jain)	Chenghong Li	Kumar	Analyses Ongoing
Ancillary	Breast cancer risk calculator after chest radiation	Chaya Moskowitz	Wendy	Chaya (MSKCC)	Analyses Ongoing
09-15	GU outcomes	Margarett Shnoorhavian	Pam	Wendy	Analyses Ongoing

Concept	Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status	
Analyses Ongoing (continued)						
07-01	Incidence of cataract in relation of radiation dose	Gabriel Chodick	Yan Chen /Yutaka	Gabriel / Peter Inskip	Data sent	
11-11	Longitudinal Patterns of Late Effects in Adult Survivors of Childhood Brain Tumors	Thomas Hardie	Kristy	Penn Statistician	Data sent	
Ancillary	MSK Retinoblastoma survivor study w/sibling data from CCSS	Ira Dunkel	Kayla	Yuelin Li (MSKCC)	Partial Data sent, pending additional data	
11-02	Non-Surgical Premature Menopause in CCSS Update	Levine/ Sklar	John	Wendy	Analyses Initiated and data review underway.	
10-05	Outcomes of Pregnancies Exposed to Cancer Therapy	John Mulvihill	John	Wendy	Data sent.	
11-01	Longitudinal Health Status	Melissa Hudson	Kiri	Wendy/Kiri	Analyses Ongoing	
10-04	Predicting cardiovascular disease; creation of a risk score model, Paper 2	Eric Chow	Yan Chen	Yutaka	Analyses Ongoing	
11-23	Health behaviors and mammogram utilization	Shoshana Rosenberg	Wendy	Chaya Moskowitz (MSKCC)	Data Sent.	
11-22	Chronic Health Conditions and Employment Status Transitions	Anne Kirchhoff	Wendy	Anne K.	Analyses Ongoing	
11-19	Breast Cancer in Survivors Not Exposed to Chest Radiation	Tara Henderson	Wendy	Chaya Moskowitz (MSKCC)	Initiating data preparation	
11-12	Direct and indirect effects of anthracycline exposure on cardiac outcomes	Blythe Ryerson	Wendy/Kayla	Blythe Ryerson	Data sent.	
11-16	Joint effects of treatment and host factors on second primary breast cancers	Peter Inskip	Wendy	Chaya/John	Data planning with MSKCC/NCI/MDA	
Ancillary	Thyroid cancer SNP study	Yuri Nikiforov / Smita Bhatia	John	Wendy	Case / Control selection, data sent.	
Ancillary	Genetic susceptibility to Obesity After Treatment for Childhood Cancer	Kala Kamdar	Kristy	Local Statistician	Subjects selected, data sent.	

Concept	Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status	
Analyses Ongoing (continued)						
11-20	Solid Organ transplant after Childhood Cancer	Drew Dietz	Kristy	Wendy	Analyses Initiated / Linkage with UNOS	
11-24	Male sexual health	Chad Ritenour/ Lillian Meacham	Kristy	Wendy	Analyses Ongoing	
12-03	GWAS of Subsequent Neoplasms in CCSS	Lindsey Morton	Wendy	NCI group	Data sent.	
09-08	Participation Feasibility Study	Dan Green/Ann Mertens	Wei Liu	Kumar	Analysis ongoing	
12-01	Measurement invariance in health-related quality of life between survivors and siblings	I-Chang Huang	Wendy		Data sent.	
12-06	Predictors of Colorectal Cancer Screening Practices	Connie Kohler/Casey Daniel	Kayla	Wendy	Analyses Ongoing	
12-10	Health Status Outcomes in HL survivors	Karen Effinger	Wendy/John	Alice Whittemore (Stanford)	Data sent. Analyses underway.	
12-12	Access to Health Information technology and Health Information Seeking	Mechelle Claridy	Wendy	Ann Mertens	Data set in Preparation	
12-07	Long term outcomes among standard risk ALL patients	Stefan Essig	Qiaozhi Li/Yan Chen	Yutaka	Analysis ongoing	
Ancillary	Breast Cancer after HL collaboration with Dutch group	Smita Bhatia	John	Wendy	Provided data.	
12-17	Longitudinal predictors of QOL in Adolescent survivors	Claire Russell/Kevin Krull	Zhenghong/Kiri	Claire/ Local Statistician	Provided Data for dissertation.	
12-11	Health and Functional Status of Adult Medulloblastoma Survivors	Allison King	Wendy/Chongzhi	Kristy	Analysis ongoing	
12-19	Health-related locus of control in childhood cancer survivors	Cara Kimberg	Nan Zhang	Kumar	Analysis ongoing	
13-09	Health outcomes among survivors of adolescent and young adult cancer	Eugene Suh	Wendy	Kayla	Analyses intiated	
12-18	Second neoplasms in 5th and 6th decades of life	Lucie Turcotte/Joe Neglia	Wendy / John		Analyses initiated	

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Analyses Ongoing (continued)						
13-02	Subsequent Neoplasms in Survivors of Centeral Nervous System Tumors	Karen Tsui	Chenghong Li	Kumar	Analyses ongoing.	
12-09	Longitudinal Evaluation chronic Health Conditions in Ewings Sarcoma survivors	Neyssa Marina	Yan Chen	Yutaka	Analyses initiated	
13-07	Risk factors for intestinal obstruction requiring surgical intervention among patients with primary abdominal tumors	Arin Madenci	Stacey Fisher/Qi Liu	Yutaka	Analyses initiated	
13-05	Breast Cancer in Childhood Cancer Survivors: The impact of screening on morbidity	Tara Henderson	Chaya			
Approved	Concepts in Queue					
12-16	Perceptions of risk for Male Health Problems	Jordan Gilleland	Wendy/Kristy			
13-01	Pooled International Study of Radiation related Tumors of the Brain and Nervous System	Peter Inskip	NCI statisticians		Data needed?	
13-04	Longitudinal Eval of Chronic Disease and Health Status in Soft Tissue Sarcoma Survivors	Emily Mueller	Wendy/Local Statistician		Data needed?	
13-08	Psychosocial and physcial factors influencing fatigue in survivors of childhood HL	Amanda Rach	Wendy			
13-10	Body Mass Index trajectories among adult survivors of childhood central nervous system tumors	Maria Chang	Wendy		Data needed	
Proposals Under Development						
11-17	Prevalence and Predictors of Smoking Initiation and Cessation in Childhood Cancer Survivors	Bob Klesges	Kumar			

Concept	Project	Investigator	Stat Center Contact	Secondary or Senior Statistician	Status	
Proposals Under Development (continued)						
	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			
	Longitudinal changes in health risk factor clusters	Nobuko Hijiya	Wendy/Kiri			
	Second malignant neoplasm in Down syndrome survivors of childhood cancer	Ana Xavier	Wendy			
12-14	Cost Effectiveness of Breast Cancer Screening Guidelines for Female Survivors	Lennie Wong	Wendy			
12-15	BMI and physical activity in relation to risk of SMN	Stephanie George	Wendy			
	Predictors of healthy aging in childhood cancer survivors	Kiri	Wendy/Yutaka			
	Frailty and chronic conditions among childhood cancer survivors	Kiri	Kiri			
	Morbidity and Mortality Associated with Meningiomas following Cranial Radiation Exposure	Daniel Bowers	Chaya / Wendy			
	Comparison of radiation dose reconstruction methods for subsequent neoplasm studies	Lindsey Morton				
13-11	Longitudinal Analysis of Pulmonary Complications	Andrew Dietz	Wendy			
	Predictors of receipt of a treatment summary, and its relationship to receipt of risk-based health care, incidence of morbidities and premature mortality.	Jennifer Ford/Tara Henderson	Chaya / Wendy			

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Ancillary S	Study Grant Proposals				
	ECHOS (Cardiovascular risk factor monitoring)	Hudson	Wendy		Funded
	Insure (Needs Assessment)	Сох	Wendy		Complete – 1 st manuscript draft prepared
	Projecting breast cancer risk	Moskowitz/Oeffinger			Funded
Data Mana	gement				
	Cleaning of Elyse Park RO1 Insurance Study Data	Elyse Park	John Whitton/Chris Vukadinovich	Wendy	Underway
	Creation of Frozen data sets for baseline expansion	John Whitton	John Whitton/Sandrine Moutou	Wendy	Underway
	Creation of Frozen data set for expansion MRAF	John Whitton	John /Kayla	Wendy	Underway
	Audit and freeze of current SMN Data	John Whitton	Joe/Lucie	Wendy	Completed Dec. 2012
	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
	"Toolbox" variable creation	John Whitton	John	Pam/Kayla/Toana	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 and siblings complete
	Creation of frozen data set for DNA samples	Stella Davies	Sue Huang/Zhenghong Li	Kiri	Data Frozen May, 2010

Publications and Manuscripts

Peer-reviewed Manuscripts and Reviews

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- 13. Gurney JG, Kadan-Lottick NS, Packer RJ, Neglia JP, Sklar CA, Punyko JA, Stovall M, Yasui Y, Nicholson HS, Wolden S, McNeil DE, Mertens AC, Robison LL. Endocrine and cardiovascular late effects among adult survivors of childhood brain tumors: Childhood Cancer Survivor Study. *Cancer*, 2003; 97(3): 663-73.
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Manuscripts Submitted for Publication

- Armstrong GT, Kawashima T, Leisenring W, Stratton K, Stovall M, Hudson MM, Sklar CA, Robison LL, Oeffinger KC. Aging and Risk of Severe, Disabling, Life-threatening and Fatal Events in the Childhood Cancer Survivor Study. Submitted
- Brinkman TM, Zhang N, Recklitis CJ, Kimberg C, Zeltzer LK, Muriel AC, Stovall M, Srivastava DK, Sklar CA, Robison LL, Krull KR. Suicide Ideation and Associated Mortality in Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- Brinkman TM, Zhu L, Zeltzer LK, Recklitis CJ, Kimberg C, Zhang N, Muriel AC, Stovall M, Srivastava DK, Robison LL, Krull KR. Longitudinal Patterns of Psychological Distress in Aging Adult Survivors of Childhood Cancer. Submitted
- 4. Cox CL, Nolan VG, Leisenring W, Yasui Y, Ogg SW, Mertens AC, Neglia JP, Ness K, Armstrong GT, Robison LL. New Risk Factors for Late Mortality: The Childhood Cancer Survivor Study. Submitted
- Dagnali CL, Morton LM, Hicks BD, Zhou W, Jacobs KB, Deng Z, Hutchinson AA, Escobar H, Blake S, Sanderson BW, Kingham BF, Nicolet CM, Sampson JN, Robison LL, Armstrong GT, Bhatia S, Radloff GA, Davies SM, Teshome K, Chowdhury S, Lashley KS, Cook MB, Tucker MA, Yeager M, Chanock SJ. Evaluation of Whole Genome Amplified DNA and Reduced Genomic DNA for High Performance of Commercial SNP Microarrays. Submitted
- 6. Gramatges MM, Liu Q, Yasui Y, Okcu MF, Meadow AT, Neglia JP, Strong LC, Armstrong GT, Robison LL, Bhatia S. Relative Telomere Length and Risk of Second Malignant Neoplasm in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- 7. Green DM, Nolan VG, Gooman PJ, Whitton JA, Srivastava DK, Leisenring WM, Neglia JP, Sklar CA, Kaste SC, Hudson MM, Diller LR, Stovall M, Donaldson SS, Robison LL. The Cyclophosphamide Equivalent Dose as an Approach for Quantifying Alkylating Agent Exposure: A Report from the Childhood Cancer Survivor Study. Reviewed, Revised manuscript submitted
- 8. Klosky JL, Foster RH, Li Z, Peasant C, Howell C, Mertens AC, Robison LL, Ness KK. Risky Sexual Behavior in Adolescent Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- Klosky JL, Krull KR, Kawashima T, Leisenring W, Randolph-Frye M, Zebrack BJ, Stuber ML, Robison LL, Phipps S. Relations between Posttraumatic Stress and Posttraumatic Growth in Long-term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- Moskowitz CS, Chou JF, Wolden SL, Bernstein JL, Malhotra J, Friedman DN, Mubdi NZ, Leisenring WM, Stovall M, Hammond S, Smith SA, Hudson MM, Diller LR, Bhatia S, Kenney L, Neglia JP, Begg CB, Robison LL, Oeffinger KC. Breast Cancer after Chest Radiation Therapy for a Childhood Cancer. Submitted
- Wasilewski-Masker K, Seidel KD, Leisenring W, Mertens A, Shnorhavorian M, Ritenour CW, 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. Submitted
- 12. Wong LF, Bhatia S, Landier W, Francisco L, Leisenring W, Hudson MM, Armstrong GT, Mertens A, Stovall M, Robison LL, Lyman GH, Lipshultz SE, Armenian S. Efficacy and Cost-effectiveness of the Children's Oncology Group Longterm Follow-up Guidelines in Reducing the Risk of Congestive Heart Failure in Childhood Cancer Survivors. Submitted
- 13. Yang X, Killian K, Hammond S, Burke L, Wang Y, Davis S, Strong L, Neglia J, Stovall M, Robison L, Mabuchi K, Inskip P, Meltzer P. Characterization of Genomic Alterations in Radiation-related Breast Cancer Among Childhood Cancer Survivors using Comparative Genomic Hybridization Arrays. Submitted

Investigator-Initiated, Ancillary Studies for External-Funding That Utilize the CCSS Resource as of 5/2013

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

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 does 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.

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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 (Career Development Award)

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: Active (continued)

Principal Investigator: Sogol Mostoufi-Moah (University of Pennsylvania)

Title: Bone Deficits and Excess Adiposity after Pediatric Bone Marrow Transplantation

Dates of Funding: 4/13 - 3/18

Funding Source: National Institutes of Health (K07 CA166177)

Award: \$50,000

Study Aims: Among survivors of HSCT to characterize changes in bone density and structure, body composition and fat

distribution, and associated risk factors and outcomes.

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 Funding: 5/13 – 4/18

Funding Source: National Institutes of Health (R01 CA175231)

Award: \$4,117,427 (proposed)

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.

Ancillary Studies: Proposed

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

Title: Neurofibromin and response to genotoxins

Proposed Funding Source: National Institutes of Health (R01)

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.

Principal Investigator: Richard Sposto (Children's Hospital Los Angeles) **Title**: Personalized Therapeutic Decision-making for Childhood Cancer

Proposed Funding Source: Patient-Centered Outcomes Research Institute (PCORI)

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.

Principal Investigator: Jaya Satagopan (Memorial Sloan-Kettering Cancer Center)

Title: Evaluation of Statistical Interactions in Cancer Epidemiology Studies

Proposed Funding Source: National Institutes of Health (R01)

Study Aims: To expand upon previous work and develop novel methods for evaluating interactions through investigating parametric link functions, shrinkage methods, and removable interactions, with subsequent software development.

Principal Investigator: Javier Blanco (University of Buffalo)

Title: Characterization of Cardiac Mitochondrial DNA in Donors with Down Syndrome

Proposed Funding Source: National Institutes of Health (K03)

Study Aims: To understand the specific alterations in cardiac mitochondrial DNA among individuals with and without Down Syndrome to inform future avenues of research to identify those factors associated with cardiotoxicity.

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.

Ancillary Studies: Unfunded (continued)

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.

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.

Principal Investigator: Whitney Witt (University of Wisconsin)

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

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.

Childhood Cancer Survivor Study (CCSS) Presented Abstracts 1997 – 2013

Year	Number	
2013	14	
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	

2013

<u>A1301</u> Kirchhoff AC, Leisenring W, Oeffinger K, Armstrong GT, Robison LL. Labor Force Transitions in the Childhood Cancer Survivor Study. 34th Annual Meeting & Scientific Sessions of the Society of Behavior Medicine, March 2013, poster presentation.

<u>A1302</u> Kirchhoff AC, Kuhlthau K, Leisenring W, Warner EL, Armstrong GT, Oeffinger K, Robison LL, Park ER. Childhood Cancer Survivors and Social Security Benefit Coverage: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Preventive Oncology, March 2013, poster presentation.

<u>A1303</u> Daniel CL, Kohler C, Nathan P, Oeffinger K, Stratton K, Leisenring W, Whelan K, Waterbor J, Henderson T, Armstrong G, Krull K, Robison LL. Predictors of Colorectal Cancer Screening among High-Risk Survivors of Childhood Cancer. American Society of Preventive Oncology, March 2013, oral presentation.

<u>A1304</u> Prasad PK, Hardy KK, Zhang N, Srivastava DK, Edelstein K, Zeltzer L, Stovall M, Leisenring W, Seibel NL, Armstrong GT, Robison LL, Krull KK. Psychological and Neurocognitive outcomes in survivors diagnosed with cancer as adolescents and young adults: A Report from the Childhood Cancer Survivor Study. American Society of Pediatric Hematology-Oncology, April 2013, poster presentation.

<u>A1305</u> Park ER, Kirchhoff AC, Perez-Lougee G, Leisenring W, Weissman JS, Donelan K, Mertens AC, Reschovsky J, Armstrong GT, Robison LL, Diller LR, Recklitis CJ, Kuhlthau KA. Childhood cancer survivor familiarity with the Affordable Care Act. New England Cancer Survivorship Research Conference, May 2013, poster presentation.

<u>A1306</u> Wilson CL, Leisenring WL, Nathan P, Oeffinger K, Wasilewski K, Hudson MM, Castellino S, Stovall M, Armstrong GT, Brinkman TM, Robison LL, Ness KK. Predictors of declining levels of physical activity among adult survivors of childhood cancer. American Society of Clinical Oncology Annual Meeting, June 2013, poster presentation, 13th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, poster presentation.

A1307 Essig S, Qiaozhi L, Chen Y, Hitzler J, Leisenring W, Greenberg M, Sklar C, Hudson MM, Armstrong GT, Krull K, Neglia JP, Oeffinger KC, Robison LL, Yasui Y, Nathan PC. Estimated long-term outcomes in children newly diagnosed with standard risk acute lymphoblastic leukemia (ALL) based on similarly treated members of the Childhood Cancer Survivor Study (CCSS) cohort. American Society of Clinical Oncology Annual Meeting, June 2013, poster presentation.

<u>A1308</u> Soriano S, Bashore L, Ross G, Proffitt-Leyva R, Armstrong GT, Robison LL, Bowman WP. Recruitment of an Ethnically Diverse Population of Childhood Cancer Survivors: A Single Institution Experience. 13th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, poster presentation.

<u>A1309</u> Gawade PL, Oeffinger KC, Sklar CA, Green DM, Krull KK, Chemaitilly W, Stovall M, Leisenring W, Robison LL, Ness KK. Prepregnancy Lifestyle Factors, Psychological Distress and Adverse Pregnancy Outcomes in Female Survivors of Childhood Cancer. 13th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, submitted.

A1310 Gramatges MM, Liu Q, Yasui Y, Okcu F, Neglia JP, Strong LC, Armstrong GT, Robison LL, Bhatia S. Telomere Length and Risk of Second Malignant Neoplasms (SMNs) in Survivors of Childhood Cancer: A Childhood Cancer Survivor Study (CCSS). 13th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, oral presentation.

A1311 Goldsby R, Raber S, Stratton K, Ablin A, Li L, Strong L, Leisenring W, Oeffinger K, Sklar C, Armstrong GT, Robison LL, Bhatia S. Long-term sequelae in survivors of childhood leukemia with Down Syndrome: A matched cohort study from the Childhood Cancer Survivor Study. Congress of the International Society for Pediatric Oncology (SIOP), September 2013, submitted.

A1312 Huang I-C, Kenzik K, Brinkman T, Armstrong GT, Robison LL, Krull KR. Long-term sequelae in survivors of childhood leukemia with Down Syndrome: A matched cohort study from the Childhood Cancer Survivor Study. International Psycho-Oncology Society (IPOS), November 2013, submitted.

<u>A1313</u> Mueller S, Fullerton HJ, Stratton K, Leisenring W, Armstrong GT, Weathers RE, Stovall M, Goldsby RE, Sklar CA, Robison LL, Krull KR. Recurrent Stroke Risk in Childhood Cancer Survivors. Society for Neuro-Oncology, November 2013, submitted.

A1314 Van den Berg A, Cozen W, Li D, Timofeeva M, Diepstra A, Hazelet, D, Delahaye M, Edlund, CK, Rostgaard K, Van Den Berg DJ, Glaser SL, Robison LL, Mack TM, Ghesquieres H, Bhatia S, Strong LC, Hwang AE, Nieters, A, Smedby K, de Sanjose S, Cortessis VK, Lightfoot T, Roman E, Becker N, Lenka F, Benavente Y, Maynadie M, Visser L, Veenstra RN, Staines A, Cocco PL, Boffetta P, Kiemeney L, Lake A, Montgomery D, Slager SL, Cerhan JR, Gallagher A, Taylor GM, Brennan P, Conti DV, Coetzee GA, Onel K, Jarrett RF, Hjalgrim H, McKay JD. TFC3/E2a (19p13.3) is a novel Hodgkin lymphoma susceptibility locus; a meta-GWAS study by the Interlymp Hodgkin lymphoma consortium. International Symposium on Hodgkin lymphoma, October 2013, submitted.

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.

<u>A1202</u> 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.

<u>A1203</u> 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.

<u>A1204</u> 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.

<u>A1208</u> 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.

<u>A1210</u> 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.

<u>A1212</u> 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.

<u>A1214</u> 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

<u>A1101</u> 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, Leigsnring 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.

<u>A1103</u> 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.

<u>A1104</u> 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.

<u>A1106</u> 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.

<u>A1107</u> 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.

<u>A1108</u> 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.

<u>A1110</u> 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.

<u>A1111</u> 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.

<u>A1112</u> 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.

<u>A1113</u> 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.

<u>A1114</u> 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.

2010

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.

<u>A1003</u> 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.

<u>A1008</u> 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.

<u>A1009</u> 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.

<u>A1011</u> 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.

<u>A1012</u> 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.

<u>A1014</u> 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.

<u>A1015</u> 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.

<u>A1017</u> 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.

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. 52nd American Society of Hematology Annual Meeting and Exposition, December 2010, poster.

A1019 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.

<u>A0902</u> 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.

2008

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.

<u>A0806</u> 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.

<u>A0814</u> 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.

<u>A0817</u> 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.

<u>A0703</u> 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

<u>A0601</u> 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.

<u>A0608</u> 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.

<u>A0614</u> 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, Clohisy 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.

<u>A0504</u> 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.

<u>A0511</u> 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.

2004

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.

<u>A0404</u> 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.

<u>A0406</u> 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.

<u>A0303</u> 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

<u>A0201</u> 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, Clohisy 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.

<u>A0204</u> 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.

<u>A0205</u> 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.

<u>A0206</u> 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.

<u>A0212</u> 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

<u>A0101</u> 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.

<u>A0107</u> 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

<u>A0001</u> 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

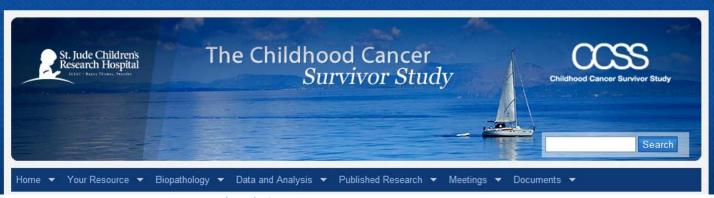
<u>A9701</u> Hammond S, Qualman S, Neglia J, Meadows A, Robison L. Assessment and validation of second neoplasms in the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Pathology, oral presentation.

CCSS Trainee List as of 5/2013

Trainee/Mentee	Training Experience	Current Position	CCSS Publications
Nina Kadan-Lottick, MD, MSPH	Post-doctoral Fellowship	Associate Professor	JAMA 2002;
		Division of Pediatric Hematology-Oncology	Epidemiology 2003
		Yale University	
		New Haven CT	
Brad Zebrack, PhD	Post-doctoral Fellowship	Associate Professor	Pediatr 2002;
		School of Public Health	J Clin Oncol 2004
		University of Michigan	
		Ann Arbor, MI	
Pauline Mitby, MPH	Graduate Training	Clinical Research Associate	Cancer 2003
		Division of Pediatric Hematology-Oncology	
		Children's Hospital of Minnesota	
		Minneapolis, MN	
Rajaram Nagarajan, MD, MS	Post-doctoral Fellowship	Assistant Professor	Cancer 2003;
	and Graduate Training	Division of Pediatric Hematology-Oncology	Br J Cancer 2004
		Cincinnati Children's Hospital	
		Cincinnati, OH	
Carrie M. Brownstein, MD	Post-doctoral Fellowship	Senior Clinical Scientist and Sr. Associate Clinical	J Clin Endocrinol Metab
		Director Roche Pharmaceuticals	2004
		Assistant Clinical Professor	
		Department of Pediatric Hematology-Oncology	
		New York-Presbyterian/Columbia	
		New York, NY	
Lisa Kenney, MD, MPH	Post-doctoral Fellowship	Instructor	Ann Intern Med 2004
		Department of Pediatrics	
		Harvard Medical School	
		Pediatric Oncology	
		Dana-Farber Cancer Institute	
		Boston MA	
Elyse Park, PhD	Graduate Training	Assistant Professor	J Clin Oncol 2005
		Harvard Medical School	
		Department of Psychiatry Massachusetts	
		General Hospital	
		Boston MA	
Sharon Castellino, MD, MS	Graduate Training	Associate Professor	J Clin Oncol 2005
· · · · · · · · · · · · · · · · · · ·	_	Department of Pediatrics	
		Wake Forest University	
		Winston-Salem, NC	
Joanna Perkins, MD, MS	Post-doctoral Fellowship	Hematology-Oncology	J Clin Oncol 2005
	and Graduate Training	Children's Hospital of Minnesota	-
	ŭ	Minneapolis, MN	
Judy Punyko, PhD	Graduate Training	State Maternal and Child Health Epidemiologist	Pediatr Blood Cancer 2005
344, 141, 145, 1112	· ·	Minnesota Department of Health	
		St Paul, MN	
Wassim Chemaitilly, MD	Post-doctoral Fellowship	Assistant Member	J Clin Endocrinol Metab
Wassiii Gilemakiiy, WB		Endocrinology	2006
		St. Jude Children's Research Hospital	
		Memphis, TN	
Mylene Bassal, MD	Post-doctoral Fellowship	Assistant Member	J Clin Oncol 2006
, .ee zassai, iiie	. see assessary enowship	Department of Pediatrics	5 5 5.1001 2000
		University of Ottawa	
		Ottawa, Canada	
Berrin Ergun-Longmire, MD	Post-doctoral Fellowship	Assistant Professor	J Clin Endocrinol Metab
berrin Ergun-Longillile, IVID	i ost-doctoral reliowship	Division of Pediatric Endocrinology	2006
		Robert Wood Johnson Medical School	2000
		New Brunswick, NJ	

Trainee/Mentee	Training Experience	Current Position	CCSS Publications
Cecile Ronckers, PhD	Post-doctoral Fellowship	Epidemiologist	Radiat Res 2006
		Emma Children's Hospital	
		Amsterdam, Netherlands	
Tara Henderson, MD, MPH	Fellowship and Graduate	Assistant Professor	JNCI 2007
	Training	Department of Pediatrics	
		University of Chicago	
		Chicago, IL	
Eric Chow, MD, MPH	Fellowship and Graduate	Medical Director	J Pediatr 2007
	Training	Pediatric Cancer Long Term Follow-up Program	Pediatr Blood Cancer 2009
		Seattle Children's Hospital	
		Seattle, WA	
Todd Florin, MD	Medical Student	Pediatric Emergency Fellow	Cancer Epi Biomarker Prev
		Children's Hospital of Philadelphia	2007
		Philadelphia, PA	
Kris Ann Schultz, MD, MS	Fellowship and Graduate	Hematology-Oncology	J Clin Oncol 2007
	Training	Children's Hospital of Minnesota	
	G	Minneapolis, MN	
Jenny Pang, MD, MPH	Fellowship and Graduate	Clinical Assistant Professor	Pediatr Blood Cancer 2008
	Training	School of Public Health	
		University of Washington	
		Seattle, WA	
Irina Dinu, PhD	Post-doctoral Fellowship	Assistant Professor	Pediatr Blood Cancer 2008
ilila billa, i ilb	1 Ost doctoral renowship	Department of Public Health Sciences	rediati biood cancer 2000
		University of Alberta	
		Edmonton, Alberta	
Daniel Mulaconou MAD MAC	Fallannahira arad Creadinaka	•	Class 2000
Daniel Mulrooney, MD, MS	Fellowship and Graduate	Assistant Member	Sleep 2008
	Training	St. Jude Children's Research Hospital	Br Med J 2009
		Memphis, TN	
Elizabeth Bluhm, MD, MPH	Post-doctoral Fellowship	Department of Internal Medicine	Blood 2008
		Washington Hospital Medical Center	
		Washington, DC	
Anne Lown, DrPH	Post-doctoral Fellowship	Assistant Clinical Professor	Addiction 2008
		Depart. of Family Health Care Nursing	
		UCSF	
		San Francisco, CA	
Edward Garmey, MD	Post-doctoral Fellowship	Associate Director for Clinical Development	J Clin Oncol 2008
		GPC-Biotech	
		Princeton, NJ	
Natasha Buchanan, PhD	Post-doctoral Fellowship	Behavioral Scientist	Cancer 2009
	·	Centers for Disease Control	
		Atlanta, GA	
Meagan Lansdale, MD	Medical Student	Anesthesiology Resident	Cancer 2009
		Stanford University	
		Palo Alto, CA	
Caroline Laverdiere, MD	Fellowship Training	Assistant Professor	JNCI 2009
caronne Laverdiere, IVID	Tellowship Training	Department of Pediatrics	JIVCI 2009
		University of Montreal	
		•	
Christophor Issaes MAD	Madical Student	Montreal, QC	Cancor Eni Biomandian Burn
Christopher Janson, MD	Medical Student	Pediatric Resident	Cancer Epi Biomarker Prev
		Boston Children's Hospital	2009
Managa Maratta - 11 AA - 1 - 2 - 2	estlement et i	Boston MA	INC. 2000
Karen Wasilewski-Masker, MD,	Fellowship Training	Assistant Professor	JNCI 2009
M.Sc.		Department of Pediatrics	
		Emory University School of Medicine	
		Atlanta, GA	
Lisa Kahalley, PhD	Post-doctoral Fellowship	Assistant Professor	Nicotine Tob Res 2010
		Department of Pediatrics	PBC 2012
		Baylor College of Medicine	PBC 2011

Trainee/Mentee	Training Experience	Current Position	CCSS Publications
Beth Kurt, MD, MS	Fellowship and Graduate	Pediatric Oncologist	Pediatr Blood Cancer 2011
	Training	Helen DeVos Children's Hospital	
		Grand Rapids, MI	
Timothy Best, PhD	Graduate degree (PhD)	Postdoctoral Scholar	Nat Med 2011
		University of Chicago	
		Chicago, IL	
Anne Kirchhoff, PhD	Post-doctoral Fellowship	Assistant Professor	CEBP 2011
		University of Utah	Cancer 2011
		Salt Lake City, UT	Med Care 2010
Sharon Castellino, MD, MPH	Graduate degree (MPH)	Assistant Professor	Blood 2011
		Wake Forest University	
		Winston-Salem, NC	
Michele Montgomery, PhD	Graduate degree (PhD)	Assistant Professor	J Cancer Surv 2011
<i>5 n</i>	G , ,	University of Alabama	
		Tuscaloosa, AL	
Nancy Clanton, PhD	Post-doctoral training	Assistant Professor	Cancer 2011
,	J	University of Tennessee	
		Memphis, TN	
Kerri Nottage, MD	Fellowship training	Assistant Member	Blood 2011
,		St. Jude Children' Research Hospital	
		Memphis, TN	
Carmen Wilson, PhD	Post-doctoral Fellowship	Post-doctoral Fellow	Cancer 2012
,	,	St. Jude Children' Research Hospital	JNCI, In press
		Memphis, TN	, ,
Houda Boukheris, MD	Post-doctoral Fellowship		Int J Radiat Oncol Biol Phys
			2012
Tanya Watt, MD	Fellowship training	Assistant Professor	JNCI 2012
		UT Southwestern	
		Dallas, TN	
Julienne Brackett, MD	Fellowship training	Assistant Professor	Neuro Oncol 2012
		Texas Children's Hospital	
		Houston, TX	
Lucie Turcotte, MD, MPH	Fellowship training	Fellow	
		University of Minnesota	
		Minneapolis, MN	
Tien Huang, PhD	Post-doctoral Fellowship	Instructor	
5 .	•	University of Oklahoma	
		Norman, OK	
Casey Daniel, PhD	Graduate degree (PhD)	Post-doctoral Fellow	
,	0 ()	Wake Forest University	
		Winston-Salem, NC	
Prasad Gawade, PhD	Fellowship training	Post-doctoral Fellow	
,	, - 3	St. Jude Children's Research Hospital	
		Memphis, TN	



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LTFU

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http://ccss.stjude.org/about/sitemap



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Appendix

Samples—LTFU Participant Brief Updates; Newsletter

A BRIEF UPDATE

From the Long-Term Follow-Up Study

April 2013

http://ltfu.stjude.org

Topic: HEART HEALTH

Why we studied heart health:

Survivors of childhood and adolescent cancer are at increased risk for heart disease because of the treatments they received.

Who we studied: 18,257 LTFU Study participants

- 14,358 Survivors (7,713 male and 6,645 female)
- 3,899 Siblings (1,875 male and 2,024 female)

What we studied:

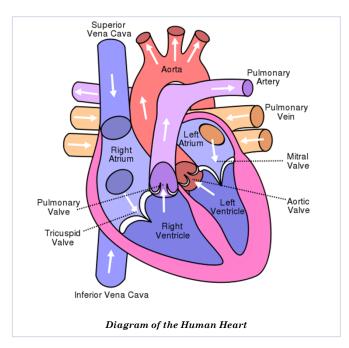
Heart disease reported on the LTFU study questionnaires by study participants

- Congestive heart failure (CHF) a condition in which the heart can no longer pump enough blood to supply the body's needs.
- Heart attack (myocardial infarction, MI) an interruption of the blood supply to part of the heart that causes heart cells to die. This is most commonly due to a blocked blood vessel.
- **Pericardial disease** problems caused by excess fluid build-up in the pericardium. The pericardium is a double-walled sac that surrounds and protects the heart. If too much fluid collects in the sac, it can cause problems by putting pressure on the heart.
- Problems with stiff or leaking heart valves

We found that . . .

- Overall, only 5 percent of the Survivors in this study reported having heart disease.
- Survivors who received 250 mg/m² or more of anthracyclines were at greater risk of heart problems
 than survivors who did not receive this treatment.

Those who received 1500 centigray or more of radiation to the heart were at greater risk of heart problems than those who received no heart radiation.



In summary:

- Most survivors, including those who were treated with anthracyclines or chest radiation, do not have any heart damage from their treatment.
- Those who received radiation to the chest or abdomen, or anthracycline chemotherapy, especially at a young age, should have a yearly check-up with special attention to any heart symptoms.
- All survivors of childhood cancer should practice good health habits that include maintaining a healthy weight, eating a balanced diet and engaging in regular physical exercise.
- Doctors and other health care providers need to be aware of the risk of heart disease faced by young adult survivors of childhood cancer.

<u>Reference</u>

• Mulrooney DA, Yeazel MW, Kawashima T, Mertens AC, Mitby P, Stovall M, Donaldson SS, Green DM, Sklar CA, Robison LL, Leisenring WM. Cardiac outcomes in a cohort of adult survivors of childhood and adolescent cancer: retrospective analysis of the Childhood Cancer Survivor Study cohort. British Medical Journal 2009; 339:b4606.

Take Care of Your Heart

Adapted from the Children's Oncology Group Health Link

Know your treatment history!

- Most survivors, including those who were treated with anthracyclines or chest radiation, do not have any heart damage from their treatment. However, certain types of cancer treatment given during childhood can sometimes result in heart problems. Also, survivors may experience problems with heart disease at younger ages than do people who did not undergo treatment for a serious childhood illness like cancer.
- Since heart problems may happen many years after cancer treatment, it is important for childhood cancer survivors to be aware of any treatments they received that might affect the heart. That way, they can take steps to keep their heart healthy, including regular medical check-ups and tests to monitor heart function. And, if a problem develops, it can be detected early. For complete information, please see the Health Link (web address at bottom of page.)

What types of treatments can cause heart problems?

Anthracycline chemotherapy may cause problems with heart muscle function (left ventricular dysfunction, cardiomyopathy) and abnormal heart rhythms (arrhythmias). Commonly used anthracyclines include:

- Doxorubicin (Adriamycin)
- Daunorubicin (daunomycin, Cerubidine)
- Idarubicin (Idamycin)
- Mitoxantrone (Novantrone)
- Epirubicin

Radiation therapy to certain areas may lead to scarring and stiffening of heart tissues, causing abnormal heart rhythms (arrhythmias) and problems with the heart muscle (cardiomyopathy), heart valves (valvular stenosis or valvular insufficiency), blood vessels (coronary artery disease), and the membrane around the heart (pericarditis or pericardial fibrosis). These areas Include:

- Chest or thorax (including mantle, mediastinal, and axillary treatment fields)
- Spine (chest or thoracic portion of the spine)
- Abdomen
- Total body irradiation (TBI)

In severe cases, these heart problems may result in a heart attack (myocardial infarction), a dangerous heart rhythm (arrhythmia), or an inability of the heart to pump blood properly (congestive heart failure).

Precautions for special situations

- To prevent a serious infection of the heart, survivors with leaky or scarred heart valves and those with active chronic graft-versus-host disease (cGVHD) following a bone marrow transplant may need to take an antibiotic before having dental work or other invasive medical procedures performed.
- Pregnancy and illnesses that produce a high fever can cause stress to the heart. Survivors whose cancer treatment included medicines that can affect heart function, should inform their healthcare providers so that steps can be taken to reduce stress on their heart in these situations.
- Some other medical problems, including obesity, high blood pressure, high cholesterol or triglyceride levels in the blood, and diabetes, may increase the risk of heart problems from cancer therapy. It is very important to practice good health habits to help minimize the risk from these conditions.
- Survivors treated with anthracyclines or chest radiation should check with their healthcare providers before beginning any exercise program. Aerobic exercise (brisk walking, running) is generally safe and actually healthy for the heart. Intensive isometric exercise, such as heavy weight lifting and wrestling, should generally be avoided.

For more information:

Children's Oncology Group Health Link – Heart Health http://www.survivorshipguidelines.org/pdf/HeartHealth.pdf
American Heart Association

http://www.americanheart.org

Physical activity and dietary guidelines from the U.S. Department of Health and Human Services http://www.health.gov

A BRIEF UPDATE

From the Long-Term Follow-Up Study

January 2013

http://ltfu.stjude.org

Topic: EMPLOYMENT

Why we studied employment issues:

Supporting oneself and adjusting successfully to the work-place are milestones on the path to an independent life. Since treatment for childhood cancer can affect every area of a person's life, it may influence the ability to reach these milestones. We wanted to learn more about the challenges survivors face in relation to employment in the work world.

What we studied:

Employment is such a central concern that we looked at several different aspects of this topic. In separate studies we examined:

1. Occupational Skill Level of Adult Childhood Cancer Survivors

We looked at three occupational categories for survivors and siblings 25 years of age or older:

- Managerial/professional occupations, for example, scientists, educators, healthcare providers
- Non-physical service or blue-collar occupations
- Physical service or blue-collar occupations
 Examples of physical and non-physical service
 or blue-collar occupations include construc tion, maintenance, or repair, food service,
 office and administrative support, etc.

2. Relationship between Physical/Mental Health and Employment

We looked at how physical and mental health problems as well as problems with learning, memory, and information processing can affect employment.

3. Unemployment among Adult Survivors

We compared survivors with nearest-age members of the sibling group in two areas:

- Being unemployed because of illness or disability
- Being unemployed but able to work and looking for work

What we found:

- Survivors who worked were less often in higherskilled occupations compared to siblings.
- Survivors' personal income was lower than siblings' incomes within each occupational skill level.
- Survivors in poor physical health were almost eight times more likely to be unemployed compared with adult survivors in good health.
 - Problems with memory, emotions, and similar mental health limitations were also linked to unemployment but the effects of these types of problems were not as great as the effect of poor physical health.
- Survivors were unemployed for health reasons more often than siblings. They were also more likely to report being unemployed but looking for work than siblings.
- Unemployed survivors had lower education and income and were more likely to rely on publicly funded health insurance.

The many benefits of work include . . .

- The financial means needed for independent living
- Employer-provided health insurance
- Opportunities for social interaction and friendships
- Feelings of competence and self-esteem

In summary:

- Adult survivors of childhood cancer are more likely to be unemployed and under-employed compared to siblings.
- Survivors may not know their employment rights.

 They may need help finding employment resources.
- Additional research is needed to identify survivors with health problems affecting their ability to work so they can receive the help they need to succeed in the workplace.

Employment Resources for Survivors

Adult survivors of childhood cancer may face barriers to employment. Health problems resulting from cancer and treatment make it hard for some survivors to work. Additionally, survivors sometimes face job discrimination because of employers' fears about cancer and the effects of treatment. Some resources to help overcome these and similar barriers follow.

Legal protections are provided by Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA).

- ADA, passed in 1990, prohibits job discrimination against people with disabilities. It requires employers to provide
 "reasonable accommodations" to disabled workers. Accommodations are agreed on between the employer and
 employee. They include such things as providing wheelchair access, adjusting scheduled work hours, or installing
 adaptive equipment such as a braille readers or large-button phones.
- FMLA, passed in 1993, requires covered employers to provide employees up to 12 weeks of job-protected, unpaid leave during any 12-month period for qualified medical and family reasons, such as caring for a family member during an illness or being unable to work because of a serious medical condition.

Survivorship clinics

The center where you received your treatment or a center in your community may have a survivorship clinic that can help you learn about the need for and availability of job accommodations, adaptive equipment, prostheses, etc., that can help survivors adjust successfully to the workplace.

Vocational rehabilitation

Each U.S. state has an office of vocational rehabilitation that provides a wide range of services for people with disabilities. Services include career counseling, job training and placement and help with arranging job accommodations. The Social Security website lists contact information for the Office of Vocational Rehabilitation of each state:

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

Research featured in a previous Long-Term Follow-Up Study newsletter showed that the majority of survivors who received vocational rehabilitation services became successfully employed:

http://ltfu.stjude.org/docs/ltfu/nwsltr-summer11.pdf

Survivorship Guidelines

The Children's Oncology Group Survivorship Guidelines recommend periodic screening of survivors for educational or occupational delays. Please see the recommendations and resources at the following links:

http://www.survivorshipguidelines.org/pdf/EducationalIssues.pdf

http://survivorshipguidelines.org/pdf/FindingPayingforHealthcare.pdf

References for the studies discussed in this Update:

Kirchhoff AC et al. Occupational outcomes of adult childhood cancer survivors: A report from the Childhood Cancer Survivor Study. *Cancer* 2011: 3033-44.

Kirchhoff AC et al. Physical, mental, and neurocognitive status and employment outcomes in the childhood cancer survivor study cohort. *Cancer Epidemiol Biomarkers Prev.* 2011;20(9):1838-49.

Kirchhoff AC et al. Unemployment among adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Medical Care* 2010; 48(11): 1015-25.



SAVE THE DATE!

You're invited to participate in a live webcast of the

St. Jude Children's Research Hospital 14th Annual Survivors Day Conference

9 a.m., Saturday, October 27, 2012

Childhood cancer survivors and viewers nationwide will have an opportunity to submit questions during panel sessions with cancer survivors and thought leaders in childhood cancer and survivorship. Look for a mailing in the coming weeks with more information on conference highlights and webcast details.





Celebrating 50 years of finding cures and saving children

In this issue

Study Update: Fertility and offspring 2

Resources for Healing 3

Health Links: Fertility 4

tarting a family is a life goal for many, as being a parent is a significant source of meaning and happiness. Unfortunately, some survivors may be unable to get pregnant or to father a child because of their childhood illness and treatment. Others may worry about the possibility that treatments they received will have harmful effects on their children.

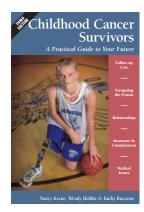
The good news is that children of survivors don't inherit a higher genetic risk for cancer from their parents, unless the person's cancer was caused by a known genetic mutation. However, it's unknown whether certain types of treatments might cause harm to the children of survivors who received those treatments. LTFU Study investigators recently published results of a project looking at possible effects of radiation therapy on the offspring of childhood cancer survivors. We report those results in this issue of the newsletter. We also report on two detailed studies of fertility among male and female survivors.

Thank you. As always, we want to thank you, our participants, for being our partners in research. Scientific findings such as those reported in this newsletter are a direct result of your continuing participation in the LTFU Study.

Just Released! Childhood Cancer Survivors, 3rd Edition

he third edition of *Childhood Cancer Survivors* provides state-of-the-art information for survivors on topics such as:

- Medical late effects from treatment
- Emotional aspects of surviving cancer
- Schedules for follow-up care
- Challenges in the heathcare system
- Lifestyle choices to maximize health
- Discrimination in employment or insurance



oven throughout the text are stories from more than 100 survivors and parents. Authors Keene, Hobbie, and Ruccione are experts in the field of childhood cancer. Keene is the mother of a survivor of childhood leukemia and the author of several books including *Childhood Leukemia*, *Childhood Cancer*, *Educating the Child with Cancer*, and *Chemo, Craziness & Comfort*. Hobbie is Associate Director of the Cancer Survivorship Program at Children's Hospital of Philadelphia. Ruccione is Co-Director of the HOPE (Hematology-Oncology Psychosocial and Education) Program in the Children's Center for Cancer and Blood Diseases at Children's Hospital Los Angeles. Available from online booksellers or at:

http://shop.oreilly.com/product/9781457118678.do

Study Update

Fertility and Offspring of Childhood Cancer Survivors

ince many survivors desire to have a child, issues related to fertility and offspring are highly important ones for the LTFU Study. We do know that some



Dr. Dan Green

treatments in childhood, including radiation and some types of chemotherapy, can cause people to be unable to have children. We wanted to learn more about this risk and about the specific treatments that lead to infertility. In addition, we wanted to find out if radiation treatment in childhood or adolescence could affect a person's offspring when they conceived or fathered a pregnancy as an adult.

Fertility of male and female survivors

r. Dan Green led a team that investigated fertility issues in separate studies of male and female survivors. The research team compared the fertility rates of the survivors to those of participants in the LTFU Study sibling comparison group. They also looked at specific treatment exposures. They found that:

- Overall, female survivors were 20 percent less likely to become pregnant than the female siblings.
- ☐ Male survivors who did not have any of the high-risk treatments were just as likely as the siblings to father a pregnancy.
- ☐ Radiation treatment to areas of the body that included the testicles in males or the ovaries and uterus in females led to a higher risk of infertility.
- ☐ Treatment with high doses of alkylating agent chemotherapy drugs increased the likelihood of infertility for both males and females.

Also at increased risk of infertility were:

- ☐ Men who were diagnosed at older ages (15-20 years) or who were treated with the alkylating agent procarbazine or with high doses of cyclophosphamide (Cytoxan).
- ☐ Women who were exposed to radiation doses of more than 30 Gray to the hypothalamic/pituitary area of the brain or who were treated with the specific chemotherapy agents lomustine (CCNU) or cyclophosphamide.

Why results are important. Knowing the effects of specific treatments can help survivors and their health care providers understand their reproductive consequences and fertility options. The results of this study may also be used to

counsel future patients about fertility problems that are linked to cancer treatments.

About the study. Participants in this study were between the ages of 15 and 44 years. The male study included 7,516 men (6,224 survivors and 1,292 siblings); the female study included 6,590 women (5,149 survivors and 1,441 siblings).

Alkylating agents . . .

... are a common type of chemotherapy drugs. They have been linked to damage to the gonads (ovaries and testicles). They are used to treat many different types of diseases, including leukemia, Hodgkin and Non-Hodgkin lymphoma, and solid tumors. Alkylating agents include drugs like:

- BCNU (Carmustine)
- Busulfan
- CCNU (Lomustine)
- Chlorambucil
- Cyclophosphamide (Cytoxan)
- Ifosfamide
- Mechlorethamine (Nitrogen Mustard)
- Melphalan
- Procarbazine
- Thiotepa

Effects of treatment on offspring

t is not known whether radiation treatment causes genetic damage to human germ cells (sperm cells and egg cells) that can harm a person's offspring. Scientific advances may soon make it possible to directly determine whether such damage occurs. In the meantime, LTFU Study investigators, led by Dr. Lisa Signorello, have come up with an indirect method to assess the possibility that radiation treatment damages germ cells. The investigators reasoned that genetic mutations in germ cells might lead to a higher rate of stillbirth or neonatal death. So studying the occurrence of stillbirth and neonatal deaths could be used as a way of finding out "by proxy" if radiation treatment is likely to cause genetic damage to germ cells.

The researchers wanted to find out if stillbirth or neonatal death occurred more often among children of survivors who had received radiation to the testicles or the ovaries and uterus or to the pituitary gland. Stillbirth is defined as a fetal death after 20 weeks of pregnancy. Neonatal death refers to

death immediately after birth or in the first four weeks of life. The pituitary gland is a pea-sized structure in the brain that regulates the production of the sex hormones, testosterone in boys and estrogen in girls.

The research team found that:

- Radiation exposure to the testicles in males did not
 - increase the risk of stillbirth or neonatal death among the children conceived after they received this treatment.
- ☐ Radiation exposure to the pituitary gland did not increase the risk of stillbirth or neonatal death among the children of males or females.
- □ Radiation exposure to the ovaries and uterus of females, however, did greatly increase the risk of stillbirth or neonatal death among the children conceived after treatment. Higher radiation doses led to greater risk.

In spite of the increased risk among female survivors, the research team concluded that this study did *not* provide evidence that radiation therapy causes mutations to either sperm or egg cells leading to genetic damage to the offspring of either men or women. Stillbirths and neonatal deaths did occur more often among the children of girls whose ovaries and uterus had been irradiated. However, the researchers believed this was because of radiation damage to the uterus and its blood vessels. This uterine damage likely led to the loss of offspring, rather than any genetic damage to the girls' egg cells.

This study found that treatment with alkylating agent chemotherapy did not increase the risk of stillbirth or neonatal death among children of male or female survivors, even at high doses.

Why results are important. The results of this study are reassuring for male survivors. There does not seem to be an increased risk of stillbirth or neonatal death among the offspring of men who received radiation to treat their child-hood illness. Women who received high-dose radiation to the ovaries and uterus, however, do face a higher risk. Knowledge of this finding can help health care providers deliver the best possible care to these survivors if they conceive a child.

About the study. The study analyzed information about 1,148 men and 1,647 women who had survived childhood cancer. Among the participants, there were 4,946 pregnancies.

References:

Green DM, Kawashima T, Stovall M, Leisenring W, Sklar CA, Mertens AC, Donaldson SS, Byrne J, Robison LL. Fertility of male survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Journal of Clinical Oncology. 2010 Jan 10;28(2):332-9.

Green DM, Kawashima T, Stovall M, Leisenring W, Sklar CA, Mertens

AC, Donaldson SS, Byrne J, Robison LL. Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. Journal of Clinical Oncology. 2009 Jun 1;27(16):2677-85.

Signorello LB, Mulvihill JJ, Green DM, Munro HM, Stovall M, Weathers RE, Mertens AC, Whitton JA, Robison LL, Boice JD Jr. Stillbirth and neonatal death in relation to radiation exposure before conception: a retrospective cohort study. Lancet. 2010 Aug 21;376(9741):624-30.

The study did not find evidence that radiation causes changes (mutations) in the sperm or eggs (germ cells) of survivors that could result in genetic damage to their offspring.

The higher rate of stillbirth and neonatal death among the children of girls treated with radiation was felt to result from damage to the uterus and its blood vessels rather than to mutations in the egg cells.

Resources for Healing

Resources are available to help with fertility issues and with grieving the loss of a child. If you're facing either of these situations, please investigate the assistance offered by the organizations listed below:

For help with infertility issues:

www.livestrong.com/fertility-information

A project of the Lance Armstrong Foundation (LAF), the LIVESTRONG site provides in-depth articles on many different aspects of fertility.

www.fertilehope.org

This site is another project of LAF. It offers calculators for infertility risk and for reproductive options based on risk, information for health care professionals, a searchable database of resources, including doctors, financial resources, legal assistance, and more.

www.resolve.org

The website of the National Infertility Association offers a newsletter, information sheets, and access to support groups.

www.fertileaction.org

Started by a cancer survivor, the mission of this organization is to eradicate the cost of fertility preservation for female cancer survivors.

If you are grieving the loss of a child:

www.nationalshare.org

This site offers resources for bereaved families as well as for health care professionals. It includes a network of support groups, organized by US State, that are often associated with local hospitals.

www.compassionatefriends.org

This national volunteer organization offers grief support after the death of a child and has chapters in most US states, as well as a presence on Facebook.

Fertility Issues after Childhood Cancer Treatment

(Adapted from the Children's Oncology Group Health Links)

In females

Childhood cancer treatment can lead to . . .

Estrogen deficiency. Estrogen deficiency occurs when the immature eggs (egg follicles) in the ovaries are depleted or damaged. It can be a result of alkylating agent chemotherapy, radiation therapy to the ovaries or the pituitary gland, or surgical removal of the ovaries. If this happens to a young girl, she will need hormones prescribed by a doctor to go into puberty. Estrogen is also needed to help maintain strong bones, a healthy heart, and overall well-being. Young women who are estrogen deficient should discuss the potential risks and benefits of hormone replacement therapy with their doctor.

Women with depleted egg follicles are at risk of . . .

Ovarian failure. This means that the ovaries completely stop making estrogen and that menstrual periods stop permanently. Ovarian failure occurs in women at menopause as part of normal aging. The average age of menopause is 51.

Premature menopause. This means that menstrual periods stop permanently before age 40. If a woman is currently having periods but received chemotherapy or radiation that can affect ovarian function, she may still be at risk of entering menopause at an early age.

Infertility (the inability to get pregnant). Infertility can be caused by depletion of or damage to egg follicles, and the reduced production of ovarian hormones. Radiation therapy may cause scarring that reduces blood flow to reproductive organs and affects their ability to sustain a pregnancy. There may also be other reasons for infertility that are unrelated to cancer therapy.

Pregnancy risks. Radiation therapy can lead to an increased risk of miscarriage, premature delivery, or problems during labor. Chemotherapy with anthracycline drugs (such as doxorubicin or daunorubicin) and radiation therapy to the upper abdomen or chest may lead to heart problems. If a woman has heart problems, pregnancy and labor can make them worse.

In males

Childhood cancer treatment can lead to . . .

Testosterone deficiency. This means that the testicles can't produce enough of the male hormone testosterone. It can be caused by alkylating agent chemotherapy, by radiation therapy to the testicles or the pituitary gland, or by surgical removal of both testicles. If this happens to a young boy, he will need hormones prescribed by a doctor to go into puberty. If it happens after puberty, a man will need testosterone therapy to maintain a healthy body composition of muscle, bone, and fat, as well as a healthy sex drive and the ability to have erections.

Infertility (the inability to father a pregnancy). Infertility can be caused by reduced testosterone, decreased, damaged, or absent sperm, damage to the duct system that transports the sperm, or to the nerves that control sexual function. There may also be other reasons for infertility that are unrelated to cancer therapy.

Is treatment-related infertility permanent?

Men who had both testicles surgically removed will not be able to make sperm and infertility will be permanent. The same is true for women who had both of their ovaries removed. Infertility following radiation is likely permanent.

Some men may recover sperm production months or years after the completion of chemotherapy. For others, the damage from chemotherapy may be permanent. This means you should use birth control if you don't want to make someone pregnant.

Women who were already menstruating will stop having monthly periods during their cancer therapy. In most cases, menstrual periods will start up again after treatment ends. It can sometimes take up to several years to restart menstruation. If you don't want to get pregnant, birth control should be used, even if you're not having monthly periods.

If a woman wants to have children but is at risk of premature menopause because of the treatment she received, it is best not to delay getting pregnant beyond the early thirties.

For complete information, please see the following Children's Oncology Group Health Links:

http://www.survivorshipguidelines.org/pdf/FemaleHealthIssues.pdf

http://www.survivorshipguidelines.org/pdf/MaleHealthIssues.pdf

http://www.survivorshipguidelines.org/pdf/HeartHealth.pdf