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Children's Hospital Colorado Aurora, 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, 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

Dana-Farber Cancer Institute/Children's Hospital Boston, MA

Mattel Children's Hospital at UCLA Los Angeles, CA

Mayo Clinic

Rochester, MN

Memorial Sloan-Kettering Cancer Center New York, NY

Miller Children's Hospital

Long Beach, CA

Nationwide Children's Hospital Columbus, OH

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Roswell Park Cancer Institute

Buffalo, NY

Seattle Children's Hospital Seattle, WA

St. Louis Children's Hospital St. Louis, MO

Texas Children's Hospital Houston, TX

Toronto Hospital for Sick Children

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UAB/The Children's Hospital of Alabama
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UT-Southwestern Medical Center Dallas, TX

U.T.M.D. Anderson Cancer Center Houston, TX

### CCSS Annual Investigator Meeting Atlanta, GA June 14 – 15, 2017

# Childhood Cancer Survivor Study

NCI-funded resource for outcome and intervention research

U24 CA55727

http://ccss.stjude.org

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# 2017 CCSS Investigator Meeting At-A-Glance

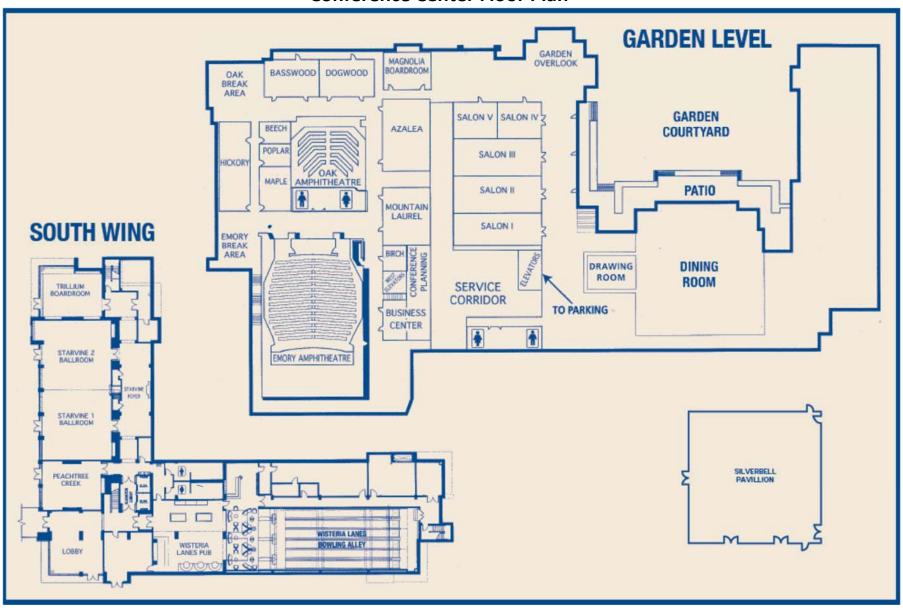
### Emory Conference Center Hotel Atlanta, GA

<u>Day/Time</u> Tuesday, June 13	<u>Meeting</u>	<u>Attendees</u>	<u>Room</u>
5:00 – 8:00 pm	CCSS Executive Committee	Executive Committee	Basswood Room
Wednesday, June 14			
7:00 – 8:00 am 8:00 – 10:00 am	Breakfast Buffet CCSS Executive Committee	Executive Committee	Conference Dining Room Salons 3-5
10:00 am – 1:00 pm	CCSS Steering Committee and Principal Investigators	Steering and Executive Committees, Institutional PIs	Salons 3-5
1:00 – 2:00 pm	Lunch	Steering and Executive Committees, Institutional PIs	Conference Dining Room
2:00 – 6:30 pm	Plenary Session*	All Attendees	Emory Amphitheatre
6:30 – 7:30 pm 6:30 – 9:00 pm	Founders Reception Dinner	All Attendees	Garden Courtyard Conference Dining Room
Thursday, June 15			
7:00 – 8:00 am	Breakfast Buffet	All Attendees	Conference Dining Room
8:00 am – 12:00 pm	Plenary Session*	All Attendees	Emory Amphitheatre
12:00 – 2:00 pm	Box Lunch Break-Out Sessions	All Attendees	See Plenary Session Agenda
2:00 pm	Adjourn		

<sup>\*</sup>See the Plenary Session Agenda on the following page for details

#### CCSS Investigator Meeting Plenary Session Agenda Day/Time Topic Presenter Room Wednesday, June 14 **Update Reports Emory Amphitheatre** G. Armstrong Principal Investigator 2:00 - 3:40 pm **Coordinating Center** T. Gibson **Data and Statistics Center** W. Leisenring **Radiation Physics Center** R. Howell **Biopathology Center** M. Arnold Biorepository/Molecular Genetic Bank S. Davies **Research and Publications Committee** D. Green **Education Committee** M. Hudson 3:40 - 4:00 pm Break 4:00 - 4:30 pm New CCSS mHealth Technology Center M. Pletcher **Emory Amphitheatre** 4:30 - 6:30 pm **Research Presentations Emory Amphitheatre** Temporal Trends in Medulloblastoma Outcomes R. Salloum Lack of Concern About Future Health in Survivors T. Gibson Utility-based Health-related Quality of Life J. Yeh Chronic Health Conditions and Cognitive Outcomes Y. Cheung Susceptibility Loci that Modify Radiation-Related L. Morton Risk for Breast Cancer and Update on Genotyping/Sequencing **Ancillary Intervention Studies** Thursday, June 15 **Emory Amphitheatre** ASK A. Geller 8:00 - 9:00 am **EQUAL** E. Tonorezos **CHIIP** E. Chow P. Nathan **CCSS Intervention Strategic Plan Emory Amphitheatre** 9:00 - 9:30 am 9:30 - 10:20 am **Working Group Reports Emory Amphitheatre** Chronic Disease K. Oeffinger **Cancer Control** P. Nathan 10:20 - 10:40 am **Break Emory Amphitheatre** 10:40 am - 12:00 pm **Working Group Reports** Psychology K. Krull Biostatistics/Epidemiology Y. Yasui S. Bhatia Genetics **Second Neoplasms** J. Neglia 12:00 - 2:00 pm **Working Group Breakout Sessions** Genetics (S. Bhatia) Peachtree Creek (South Wing) Chronic Disease (K. Oeffinger) Starvine 1 (South Wing) Second Neoplasms (J. Neglia) Starvine 2 (South Wing) Cancer Control and Intervention (P. Nathan) Hickory Room (Garden Level) Psychology (K. Krull) Maple Room (Garden Level) Biostatistics/Epidemiology (Y. Yasui) Oak Amphitheatre (Garden Level)

#### **Conference Center Floor Plan**



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Children's Hospital of Philadelphia, Philadelphia, PA Children's Hospital of Pittsburgh, Pittsburgh, PA

Children's National Medical Center, Washington, DC

Cincinnati Children's Hospital Medical Center, Cincinnati, OH

City of Hope Medical Center, Los Angeles, CA Cook Children's Medical Center, Ft. Worth, TX

Dana-Farber Cancer Institute/Children's Hospital, Boston, MA

Fred Hutchinson Cancer Research Center, Seattle, WA

Hospital for Sick Children, Toronto, ON

Mayo Clinic, Rochester, MN

Memorial Sloan-Kettering Cancer Center, New York, NY

Miller Children's Hospital, Long Beach, CA National Cancer Institute, Bethesda, MD

Nationwide Children's Hospital, Columbus, OH Riley Hospital for Children, Indianapolis, IN

Roswell Park Cancer Institute, Buffalo, NY St. Louis Children's Hospital, St. Louis, MO

Seattle Children's Hospital, Seattle, WA

Stanford University School of Medicine, Stanford, CA

Texas Children's Hospital, Houston, TX University of Alabama, Birmingham, AL University of California-Los Angeles, CA University of California-San Francisco, CA

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University of Michigan, Ann Arbor, MI
University of Minnesota, Minneapolis, MN
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Paul Nathan, MD\*‡

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Willam Timmer, PhD<sup>‡</sup>, Nita Seibel, MD<sup>‡</sup>, Julia Rowland, PhD<sup>‡</sup>,

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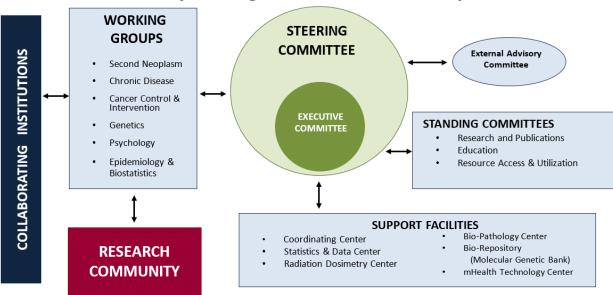
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Standing Committee Chairs Research and Publications Committee Education Committee Resource Access/Utilization Committee	Daniel Green, MD* Melissa Hudson, MD* Greg Armstrong, MD, MSCE*
Support Facilities Coordinating Center Director Statistics & Data Support Facility Director Radiation Physics Support Facility Director Molecular Genetic Bank Support Facility Director Bio-Pathology Center Support Facility Director mHealth Technology Center	Todd Gibson, PhD* Wendy Leisenring, ScD* Rebecca Howell, MD* Stella Davies, MD, PhD Mike Arnold, MD, PhD Mark Pletcher, MD, MPH*
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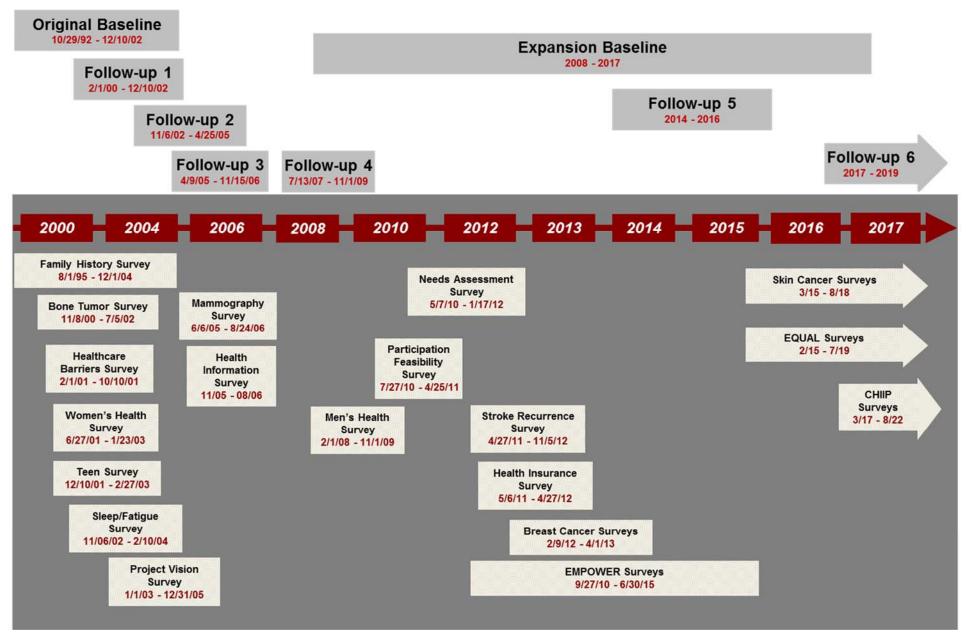
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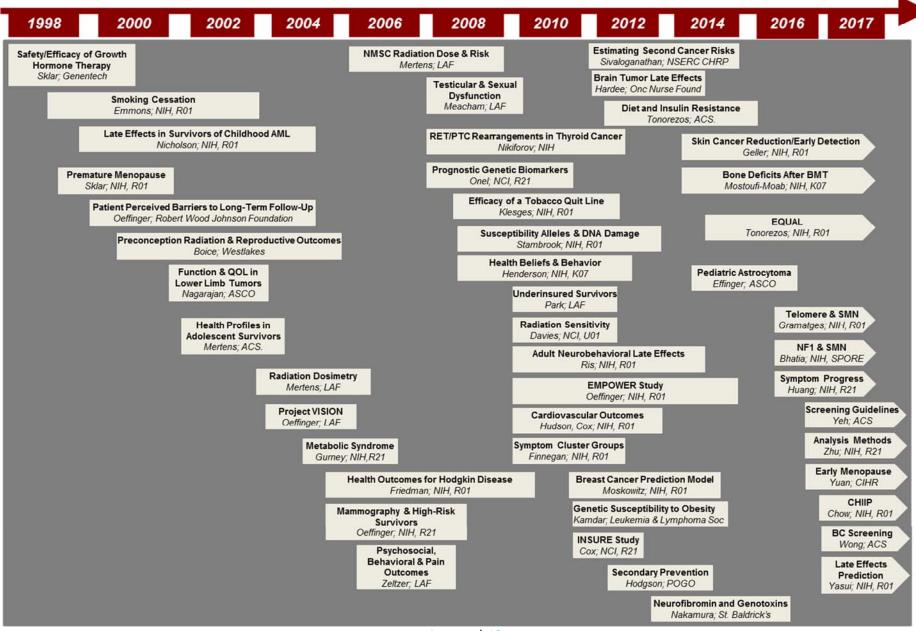
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# COSS Cohort Surveys



# Externally-Funded Ancillary Studies



### Demographic and Cancer Treatment Data of Participants in the Expansion, Original and Overall Cohort

Characteristic			Expansion cohort <sup>1</sup>		Original cohort <sup>2</sup>		Overall cohort <sup>3</sup>		ling ort <sup>4</sup>
		N	%	N	%	N	%	N	%
Total		10002	100.0	14361	100.0	24363	100.0	5059	100.0
Sex	Male	5313	53.4	7714	53.7	13027	53.6	2411	47.7
	Female	4689	46.6	6647	46.3	11336	46.4	2642	52.3
Race	White	8032	80.1	12688	88.4	20720	84.4	4467	88.3
	Black	868	8.3	713	5.0	1581	6.6	153	3.0
	American Indian/Alaska Native	61	0.6	88	0.6	149	0.6	23	0.5
	Asian or Pacific Islander	204	2.2	167	1.2	371	1.7	53	1.0
	Other	650	6.8	649	4.5	1299	5.6	182	3.6
	Unknown	187	2.0	56	0.4	243	1.1	181	3.6
Hispanic	Yes	1064	11.0	742	5.2	1806	8.0	214	4.3
'	No	8817	87.8	13063	91.0	21880	89.4	4661	92.6
	Unknown	121	1.2	556	3.9	677	2.6	157	3.1
Diagnosis	Acute lymphoblastic leukemia	1819	38.5	4329	30.1	6148	34.2		
3	Acute myeloid leukemia	510	3.8	356	2.5	866	3.1		
	Other leukemia	158	1.2	145	1.0	303	1.1		
	Astrocytomas	1412	10.6	1182	8.2	2594	9.4		
	Medulloblastoma, PNET	617	4.6	380	2.6	997	3.6		
	Other CNS tumors	420	3.2	311	2.2	731	2.6		
	Hodgkin lymphoma	1069	8.0	1927	13.4	2996	10.8		
	Non-Hodgkin lymphoma	907	6.8	1082	7.5	1989	7.2		
	Kidney tumors	903	6.8	1258	8.8	2161	7.8		
	Neuroblastoma	898	6.8	955	6.6	1853	6.7		
	Soft tissue sarcoma	460	3.5	1246	8.7	1706	6.2		
	Ewing sarcoma	310	2.3	405	2.8	715	2.6		
	Osteosarcoma	472	3.5	733	5.1	1205	4.4		
	Other bone tumors	46	0.3	52	0.4	98	0.4		
Age at diagnosis	<1	829	6.3	1003	7.0	1832	6.7		
	1-3	2373	29.7	3637	25.3	6010	27.4		
	4-7	2174	25.1	3238	22.5	5412	23.8		
	8-10	1177	12.1	1575	11.0	2752	11.5		
	11-14	1856	14.5	2417	16.8	4273	15.7		
	15-20	1591	12.3	2491	17.3	4082	14.9		
Status at 12/31/2013	Alive	9300	93.6	11695	81.4	20995	87.3	4993	98.7
	Dead	701	6.3	2652	18.5	3353	12.6	66	1.3

(Continued on next page)

Cha	racteristic	Expar coh		Orig coh		Ove coh		Sibl coh	
Age at 12/31/2013	<20	1427	14.6	681	4.7	2108	9.5	154	3.0
	20-29	4883	53.8	1071	7.5	5954	29.8	773	15.3
	30-39	3262	28.2	5574	38.8	8836	33.7	1748	34.6
	40-49	429	3.3	5195	36.2	5624	20.4	1529	30.2
	50-59			1754	12.2	1754	6.3	767	15.2
	≥60			72	0.5	72	0.3	88	1.7
Year of diagnosis	1970-79			6612	46.0	6612	23.9		
l state of the sta	1980-89	2042	20.9	7749	54.0	9791	38.1		
	1990-99	7958	79.1			7958	38.0		
Medical records available	Yes	9758	97.7	12783	89.0	22541	93.2		
	No	244	2.3	1578	11.0	1822	6.8		
Treatment modality	Surgery only (S)	1151	8.7	920	6.4	2071	7.5		
, and the second	Chemo only (C)	1422	25.1	830	5.8	2252	15.1		
	Radiation only (R)	34	0.3	31	0.2	65	0.2		
	C + R	631	9.2	1434	10	2065	9.6		
	C + S	2861	25.0	2359	16.4	5220	20.6		
	R + S	464	3.5	1449	10.1	1913	6.9		
	C + R + S	3076	25.1	5440	37.9	8516	31.7		
	No treatment	46	0.4	13	0.1	59	0.2		
1,11,000	Unknown treatment	317	2.9	1885	13.1	2202	8.2		

<sup>1 14,962</sup> survivors were eligible for the Expansion Cohort
2 20,687 eligible
3 35,649 eligible
4 4030 siblings from the original cohort, 1029 from the expansion

<b>Expansion Cohort: Recrui</b>	tment Status b	y Institution

Name	Eligible	HIPAA Returned	HIPAA Returned (% Elig)	Baseline Completed	Baseline Completed (% HIPAA)	Baseline Completed (% Elig)
St. Jude Children's Res. Hosp	2,089	1,912	91.5%	1,789	93.6%	85.6%
Children's Hospital Colorado	594	517	87.0%	457	88.4%	76.9%
University of Minnesota	277	229	82.7%	197	86.0%	71.1%
St. Louis Children's Hospital	418	339	81.1%	289	85.3%	69.1%
U of M/Mott Children's	662	532	80.4%	457	85.9%	69.0%
Nationwide Children's Hosp	501	396	79.0%	344	86.9%	68.7%
UAB/Childrens Hospital of AL	364	294	80.8%	248	84.4%	68.1%
Minneapolis Children's	581	471	81.1%	394	83.7%	67.8%
Children's Hospital at Stanford	371	301	81.1%	251	83.4%	67.7%
Children's Hospital of Phil.	1,006	797	79.2%	673	84.4%	66.9%
Children's Hospital of Pitt.	754	597	79.2%	502	84.1%	66.6%
Emory University	715	578	80.8%	470	81.3%	65.7%
Riley Hospital for Children/IU	834	670	80.3%	545	81.3%	65.3%
City of Hope	128	97	75.8%	83	85.6%	64.8%
U.T.M.D. Anderson CC	605	478	79.0%	382	79.9%	63.1%
Texas Children's Hospital	593	445	75.0%	372	83.6%	62.7%
UCLA Mattel Children's Hosp	67	47	70.1%	42	89.4%	62.7%
UT Southwestern Medical Cntr	638	516	80.9%	397	76.9%	62.2%
Seattle Children's Hospital	818	621	75.9%	499	80.4%	61.0%
Memorial Sloan-Kettering CC	648	459	70.8%	391	85.2%	60.3%
Roswell Park Cancer Institute	239	173	72.4%	141	81.5%	59.0%
Children's Hosp of Los Angeles	741	560	75.6%	436	77.9%	58.8%
Children's National Med Cntr	295	198	67.1%	169	85.4%	57.3%
Univ. of California at San Fran	392	273	69.6%	222	81.3%	56.6%
Dana-Farber Cancer Institute	900	631	70.1%	466	73.9%	51.8%
Sub-Total	15,230	12,131	79.7%	10,216	84.2%	67.1%
Active Recruitment Ongoing						
University of Chicago	349	226	64.8%	181	80.1%	51.9%
Cook Children's Hospital	526	351	66.7%	267	76.1%	50.8%
Lurie Children's Hospital	782	463	59.2%	368	79.5%	47.1%
Children's of Orange County	468	240	51.3%	170	70.8%	36.3%
"New Sites" Sub-Total	2,125	1,280	60.2%	986	77.0%	46.4%
All Sites Total	17,355	13,411	77.3%	11,202	83.5%	64.5%

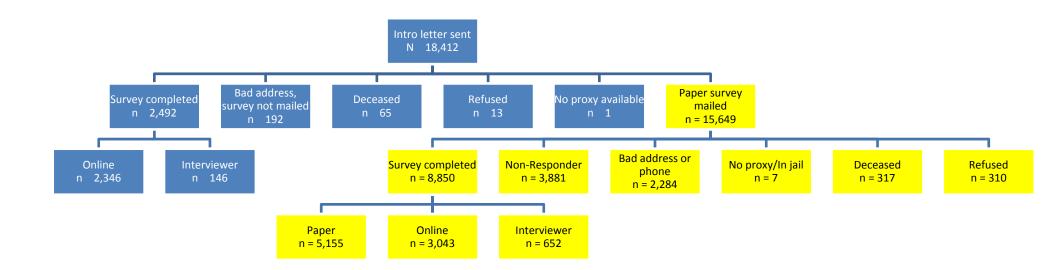
Follow-Up Survey Participation (Survivors)							
Questionnaire	Number of Pages	Presumed Eligible	Participation Rate	Non- Response	Refused Questionnaire	Dropout of Study	Lost to Follow-Up
Follow-Up 1	16	n = 12,884	81%	6%	2%	4%	7%
Follow-Up 2	24	n = 11,859	78%	8%	3%	5%	6%
Follow-Up 3	4	n = 11,393	78%	5%	1%	3%	13%
Follow-Up 4	28	n = 10,143	79%	12%	2.4%	1.6%	5.1%
Follow-Up 5	36	n = 18,022	63% <sup>1</sup>	22%	1.8%	1.3%	13.7%

#### Note:

- 63% if all eligible is used as denominator, or
- 66% if pre-FU5 lost to follow-up cases are excluded

<sup>&</sup>lt;sup>1</sup> = 956 cases were lost to follow-up before Follow-Up 5 but were mailed a FU5 invitation and were traced, but not found. Follow-Up 5 participation rate was:

#### Follow-Up 5 Survey Status - Survivors



#### **Summary Numbers**

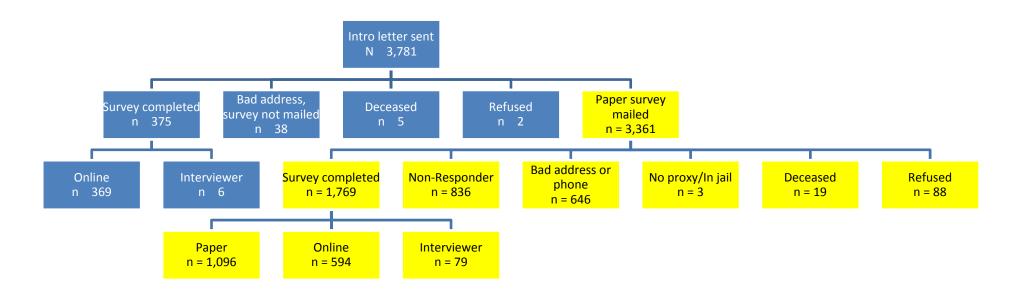
- Total completed surveys: 11,342/18,022\*= 62.9%
- Total refusals: 323 (1.8%\*)
  - o Of these, 232 have refused further participation in CCSS
- Total in tracing: 2,476 (13.7%\*)
- Total deceased: 382

Yellow = Paper survey mailed to non-responders 3-weeks after initial incentive letter. No iPad incentive offered.

Blue = Letter sent offering iPad incentive (drawing) for completion of survey online or with an interviewer prior to paper survey being mailed. One iPad per month was given away.

<sup>\*</sup>Excludes deceased, in jail, no proxy

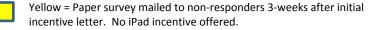
#### Follow-Up 5 Survey Status - Siblings



#### **Summary Numbers**

- Total completed surveys: 2,144/3,754\* = 57.1%
- Total refusals: 90 (2.4%\*)
  - o Of these, 73 have refused further participation in CCSS
- Total in tracing: 684 (18.2%\*)
- Total deceased: 24

Blue = Letter sent offering iPad incentive (drawing) for completion of survey online or with an interviewer prior to paper survey being mailed. One iPad per month was given away.



<sup>\*</sup>Excludes deceased, in jail, no proxy

# Oragene DNA Kit Status Summary

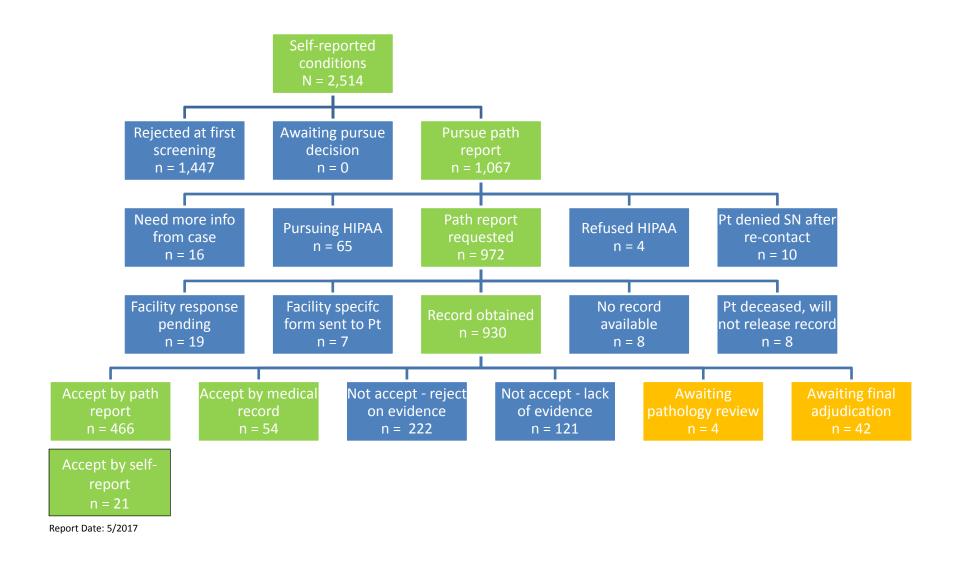
Kits Sent	Original Cases (n = 8,530)			
	n	% of Sent		
Returned	4,691	54.9%		
Refused	822	9.6%		
Pending	2,069	24.3%		
In Tracing	670	7.9%		
Deceased	278	3.3%		

Original S	Original Siblings (n = 2,712)				
n	% of Sent				
1,014	37.4%				
199	7.3%				
1,073	39.6%				
403	14.9%				
23	0.8%				

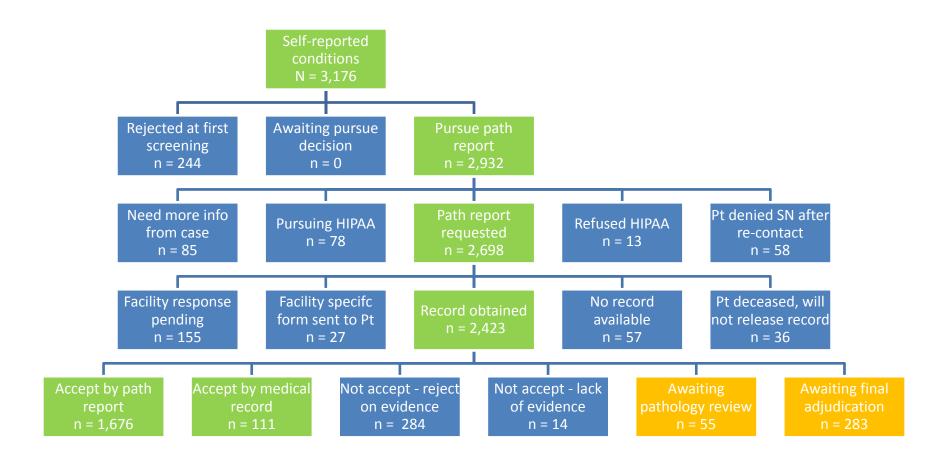
Kits Sent	Expansion Cases (n = 8,959)			
	n	% of Sent		
Returned	4,651	51.9%		
Refused	346	3.9%		
Pending	3,277	36.6%		
In Tracing	649	7.2%		
Deceased	36	0.4%		

Expansion Siblings (n = 841)								
n	% of Sent							
419	49.8%							
35	4.2%							
349	41.5%							
38	4.5%							
0	0.0%							

### **Expansion Cohort Subsequent Neoplasm (SN) Confirmation – Baseline Survey**



### **Subsequent Neoplasm (SN) Confirmation – Follow-Up 5 Survey (Overall Cohort)**



# Subsequent Neoplasms by Primary Cancer Diagnosis – Expansion Cohort

	Primary Cancer Diagnosis									
Subsequent Neoplasm*	Leukemia	CNS	HL	NHL	Kidney (Wilms)	Neuro- blastoma	Soft tissue sarcoma	Bone cancer	Total	
Breast	5	4	42	3	1	1	0	11	67	
Meningioma	7	37	1	1	0	4	2	0	52	
Other CNS	16	23	0	2	0	1	2	0	44	
Thyroid	19	19	25	4	3	7	2	6	85	
Soft tissue sarcoma	1	6	3	1	4	0	4	3	22	
Leukemia	11	2	2	2	0	0	0	2	19	
Bone	2	0	3	0	0	2	2	1	10	
Melanoma	3	2	0	3	0	1	0	4	13	
Lymphoma	1	1	7	3	1	1	0	2	16	
Renal carcinoma	2	2	3	1	0	1	1	0	10	
Other carcinoma	6	7	9	4	3	2	2	5	38	
NMSC	102	177	103	42	1	50	1	20	496	
All others	2	6	2	3	1	1	0	3	18	
Total	177	286	200	69	14	71	16	57	890	

<sup>\*</sup>Includes all invasive neoplasms, in-situ breast cancer, and non-invasive meningioma

# Subsequent Neoplasms by Primary Cancer Diagnosis – Overall Cohort

	Primary Cancer Diagnosis									
Subsequent Neoplasm*	Leukemia	CNS	HL	NHL	Kidney (Wilms)	Neuro- blastoma	Soft tissue sarcoma	Bone cancer	Total	
Breast	49	10	292	18	20	4	29	64	486	
Meningioma	202	144	7	18	0	8	13	3	395	
Other CNS	53	49	10	7	1	2	6	2	130	
Thyroid	76	43	88	17	10	19	12	22	287	
Soft tissue sarcoma	10	16	30	5	11	6	28	11	117	
Leukemia	18	5	16	7	0	3	1	5	55	
Bone	7	5	9	3	5	2	14	10	55	
Melanoma	15	12	12	5	2	4	10	10	70	
Lymphoma	8	4	28	9	1	4	5	2	61	
Renal carcinoma	6	4	9	5	4	11	3	6	48	
Other carcinoma	52	19	75	23	19	8	22	31	249	
NMSC	1,178	464	1,363	240	83	100	102	102	3,632	
All others	9	10	12	8	6	6	4	6	61	
Total	1,683	785	1,951	365	162	177	249	274	5,646	

<sup>\*</sup>Includes all invasive neoplasms, in-situ breast cancer, and non-invasive meningioma

# Subsequent Neoplasms Identified Prior To and During Most Recent Data Freeze (5/2017)

	SNs Identifie Most Recer		SNs Identified During Most Recent Freeze#				
SN Diagnosis	Participants with SN*	Total SNs	Participants	SNs	Participants	SNs	1st SN of this type since last freeze
Breast	407	486	325	392	89	94	82
Meningioma	326	395	221	254	129	141	105
Other CNS	128	130	105	107	23	23	23
Thyroid	284	287	209	210	76	77	75
Soft tissue sarcoma	113	117	97	100	17	17	16
Leukemia	55	55	48	48	7	7	7
Bone	55	55	53	53	2	2	2
Melanoma	68	70	56	58	12	12	12
Lymphoma	57	61	44	48	13	13	13
Renal carcinoma	47	48	34	34	14	14	13
Other carcinoma	243	249	155	157	91	92	88
NMSC	1,034	3,632	679	2,020	477	1,612	355
All others	61	61	46	46	15	15	15

<sup>\*</sup>SN = Subsequent Neoplasm and includes all invasive neoplasms, in-situ breast cancer, and non-invasive meningiomas

<sup>\*</sup>Review and confirmation process for conditions reported during Follow-Up 5 is ongoing

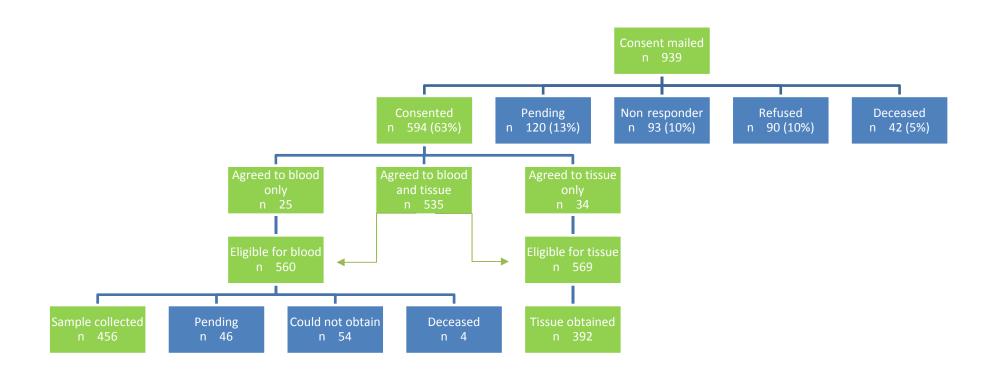
# Subsequent Neoplasms Identified Prior To and During Most Recent Data Freeze (5/2017) by Primary Diagnosis

				SNs Identifie Most Recen			uring Most	
Primary Diagnosis	N	Participants with SN*	Total SNs	Participants	SNs	Participants	SNs	1st SN occurred in recent freeze
Leukemia	7,317	704	1,683	487	970	302	713	217
CNS	4,323	343	785	251	465	117	320	92
HD	2,996	718	1951	581	1352	214	599	137
NHL	1,989	164	365	114	216	70	149	50
Kidney (Wilms)	2,161	106	162	64	93	48	69	42
Neuroblastoma	1,853	92	177	65	73	34	104	27
Soft tissue sarcoma	1,706	169	249	129	172	53	77	40
Bone cancer	2,018	188	274	147	186	57	88	41
Total	24,363	2,484	5,646	1,838	3,527	895	2,119	646

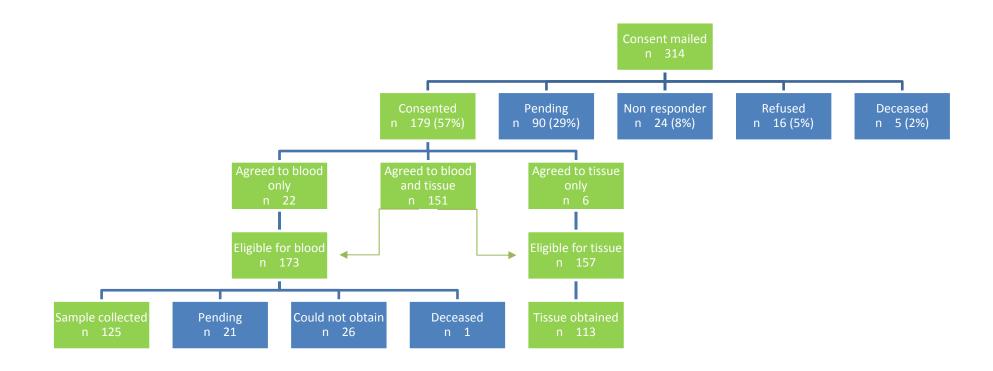
<sup>\*</sup>SN = Subsequent Neoplasm and includes all invasive neoplasms, in-situ breast cancer, and non-invasive meningiomas

<sup>\*</sup>Review and confirmation process for conditions reported during Follow-Up 5 is ongoing

## **Blood and Tissue Collection for Cases with a SMN - Original Cohort (Ongoing)**



## **Blood and Tissue Collection for Cases with a SMN – Expansion Cohort (Ongoing)**



#### Distribution of Biologic Material Available for Subsequent Neoplasms Host tissue # with host tissue Number of Cases with Tissue Type Total with Total case (any kind) Total with Total with SMN path reported Buccal and MRAF MRAF data SMN tissue Unstained Blood **H&E Slides** Scrolls **Blocks** reports Oragene cells Slides data **Breast** Meningioma\* Other CNS Thyroid Sarcoma Leukemia Bone Melanoma Lymphoma Renal Cell Other Carcinoma NMSC\* 3,632 1,626 1,920 2,160 2,669 3,384 All Other **TOTALS** 5,646 2,699 2,786 3,134 1,673 3,928 5,300

<sup>\*</sup>includes all invasive and non-invasive cases

# 2015 to 2017 RT Dosimetry Analyses Summary as of May 2017

Concept #	Study Title	Study PI	Cohort	Dosimetry Data Required	Dosimetry Status
	Case control studies				
11-16	Second primary breast cancers among childhood cancer survivors: Joint effects of treatment and host factors	Berrington Gonzalez Vega (Orig PI: Inskip)	Original (females only)	Average dose to specific breast locations, average thyroid dose	Completed: breast 9/15; thyroid 3/16
	Cohort studies				
11-20	Solid organ transplant in 5- year survivors of pediatric cancer	Termuhlen/ Dietz	Overall	Average doses for heart, kidney, lung; maximum dose to abdomen body region, prescribed TBI Dose	Completed 3/16
13-16	Comparison of radiation dose reconstruction methods for subsequent neoplasm studies	Morton	Original	Maximum dose for body regions, treatment field type(s) for each patient (requested 7/16)	Completed body region 12/13; other organs 12/14; field data 9/16
14-11	Analysis of late mortality by treatment era	Greg Armstrong	Expanded	Maximum dose for body regions and CNS field/dose summary	Completed 3/15
15-02	Esophageal disease after childhood cancer therapy: Experience from three childhood cancer survivor cohorts	Peter Asdahl	Original	Average dose for esophagus or maximum dose for chest, average doses for thyroid and heart	Completed: chest 3/15; thyroid 7/13; heart 1/12
15-05	Cyclophosphamide equivalent dosing and male health late effects — Infertility, erectile dysfunction, sexual function and testosterone replacement therapy in survivors diagnosed from 1970-1986: A report from the CCSS	Lillian Meacham	Original	Average dose for testes and pituitary	Completed 9/14
15-06	Exome sequencing to discover genetic variants that predispose childhood cancer survivors to the development of subsequent neoplasms	Lindsay Morton	Original	Maximum dose for body regions, average doses for other organs and active bone marrow (ABM) for GWAS group	Completed: body region 12/13; other organs 12/14; ABM 2/14
15-07	Changes in long-term outcomes in Hodgkin lymphoma survivors with contemporary risk-adapted therapy	Kevin Oeffinger	Overall	Treatment summaries with treatment field types and maximum dose for body regions	Completed 10/15

Concept #	Study Title	Study PI	Cohort	Dosimetry Data Required	Dosimetry Status
15-08	Impact of radiation dose and volume to the pancreas on subsequent risk of diabetes mellitus in long-term survivors of childhood cancer treated with abdominal radiation	Danielle Novetsky Friedman	Overall	Average dose for pancreas (entire, head, body, tail), V <sub>20</sub> and V <sub>30</sub> for whole pancreas	Completed 12/16
15-14:	Burden of morbidity after basal cell carcinoma in childhood cancer survivors	Smita Bhatia	Original	Maximum dose for body regions	Completed 3/15
15-16	Human papillomavirus (HPV)- associated malignancies as second cancers in childhood cancer survivors	Tara Henderson	Overall	Y/N for any RT	Y/N data provided by Statistics and Data Center
15-17	Risk for late effects of treatment in children newly diagnosed with mature B-cell non-Hodgkin lymphoma	Matthew Ehrhardt	Overall	Y/N for any RT (possibly with cutoff using recurrence date); maximum dose for body regions	Completed 9/16 for maximum dose for body regions – 5 yr cut-off; unable to provide doses from primary XRT only unless recurrence dates provided
16-01	Cause-specific mortality among childhood cancer survivors with a subsequent thyroid cancer	Dana Barnea	Overall	Average dose for right and left thyroid	Completed: expansion cohort 7/16: original cohort 7/13
16-02	Medulloblastoma and Primitive Neuroectodermal Tumor (PNET) outcomes across three decades of diagnosis	Ralph Salloum	Overall	Dose for CSI specified as: Y/N for brain, spine, TBI; Maximum dose for brain, brain four segments, spine, and TBI; Minimum CSI dose (min dose received by whole brain or spine)	Completed 9/16
16-03	Hospitalization and mortality due to Infection among survivors of childhood cancer with asplenia	Brent Weil	Overall	Average dose for upper left quadrant of abdomen (spleen surrogate)	Completed 12/16
16-04	Cognitive and behavioral outcomes in survivors of neuroblastoma	Daniel Zheng	Overall	Y/N for RT: any, cranial, TBI, and chest/neck	Completed 9/16
16-05	Long-term incidence of venous thromboembolism among survivors of childhood cancer	Arin Madenci	Overall	Maximum dose for body regions	Completed 9/16
16-06	Psychosocial outcomes in adolescent survivors of Wilms tumor	Rebecca Foster	Overall	Y/N for RT: any, abdomen, and chest	Completed 9/16

Concept #	Study Title	Study PI	Cohort	Dosimetry Data Required	Dosimetry Status
16-07	The impact of developmental status on radiation-associated late cardiac toxicities in long-term survivors of childhood cancer	James Bates	Overall	Average heart dose Also of interest: V <sub>5</sub> , V <sub>10</sub> , V <sub>15</sub> , V <sub>20</sub> . Note that metrics > V <sub>20</sub> cannot be calculated due to inconsistent or missing details of heart blocking in RT records	Completed: Average doses completed for original cohort 1/12; expanded cohort 1/16; V <sub>5</sub> , V <sub>10</sub> , V <sub>15</sub> , V <sub>20</sub> completed 12/16
16-08	Social adjustment in adolescent survivors of pediatric CNS tumors	Fiona Schulte	Overall	Maximum dose for brain and brain four segments	Completed 9/16
16-10	Secondary cancers among NF1 cancer survivors	Bhatia	Overall	Y/N for RT, maximum dose to body regions	Completed 9/16
16-11	Neurocognitive functioning in survivors of osteosarcoma	Nina Kadan- Lottick	Original	Y/N for RT, maximum dose to chest/neck	Completed 9/16
16-12	Prevalence and patterns of prescription psychoactive medication use in adolescent survivors of childhood cancer	Yin Ting Cheung	Overall	Y/N for RT: any and cranial, maximum dose to Brain	Completed 9/16
16-13	Sleep behaviors and patterns and their relationship to health and mental health outcomes in adult survivors of childhood cancers	Lauren Daniel	Overall	Y/N for RT: any, cranial, and chest	Completed 9/16
16-14	Long-term incidence of anorectal complications among childhood cancer survivors	Christopher Weldon	Overall	Y/N for RT to abdomen and pelvis, maximum dose for abdomen and pelvis body regions	Completed 9/16
16-15	Incidence, predictors and impact of hearing impairment in long-term survivors of childhood cancer	Austin Brown	Overall	maximum dose for posterior fossa and temporal lobe brain segments (surrogate for cochlea)	Completed 9/16
16-16	Incidence of chronic disease among childhood cancer survivors by treatment era and temporal trends in treatment exposure	Todd Gibson	Overall	maximum dose for Body Regions, Y/N for RT: any, chest, abdominal, CSI, and/or pelvis	Completed 9/16
16-17	Psychological distress, functional dependence and neurologic morbidity among adult survivors of childhood cancer treated with CNS- directed therapies	Stephanie Vuotto	Overall	Cranial RT Y/N, maximum dose for brain and brain four segments	Completed 9/16

Concept #	Study Title	Study PI	Cohort	Dosimetry Data Required	Dosimetry Status
16-18	Incidence of cardiac outcomes by treatment era and temporal trends in treatment exposure in adult survivors of childhood cancer	Daniel Mulrooney	Expanded	Average dose to heart	Completed: Average doses completed 1/16 V <sub>5</sub> , V <sub>10</sub> , V <sub>15</sub> , V <sub>20</sub> completed 12/16
16-19	The effects of neurofibromatosis type 1 on late outcomes in adult survivors of childhood cancer	Peter de Blank	Overall	Y/N for any RT	Y/N data will be provided by Statistics and Data Center
16-20	Psychological, behavioral, and educational outcomes in pediatric acute myeloid leukemia survivors	Kristen Stefanski	Overall (AML only)	Y/N for any RT, Max dose for cranial radiation, cranial and spine radiation, Total CNS radiation, and TBI dose	Data was provided in 9/16
17-01	Exercise and late mortality in 5-year survivors of childhood cancer	Lee Jones	Overall	Max dose for chest	Completed 9/16
17-02	Projections in trends in life expectancy and quality-adjusted life expectancy among childhood cancer survivors	Jennifer Yeh	Overall	Y/N for RT, maximum dose for body regions, TBI dose	Completed 9/16
17-04	Predictors of longitudinal pain in long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study	Cynthia Karlson	Original	Y/N for any RT, Y/N for cranial RT, maximum dose for brain	Completed 9/16
17-05	Quantifying the individual absolute risk of premature ovarian failure in female survivors of childhood cancer	Yan Yuan	Overall (female)	Max dose for abdomen and pelvis body regions, and age at exposure, average dose to left ovaries and pituitary, TBI dose	Max dose to abdomen and pelvis, and TBI dose completed 9/16 Average ovary dose expected 5/17 Average pituitary dose expected 6/17
17-06	Subsequent neoplasms among survivors of childhood cancer not previously treated with radiation	Lucie Turcotte	Overall	Y/N for RT and maximum dose for body regions	Completed 9/16

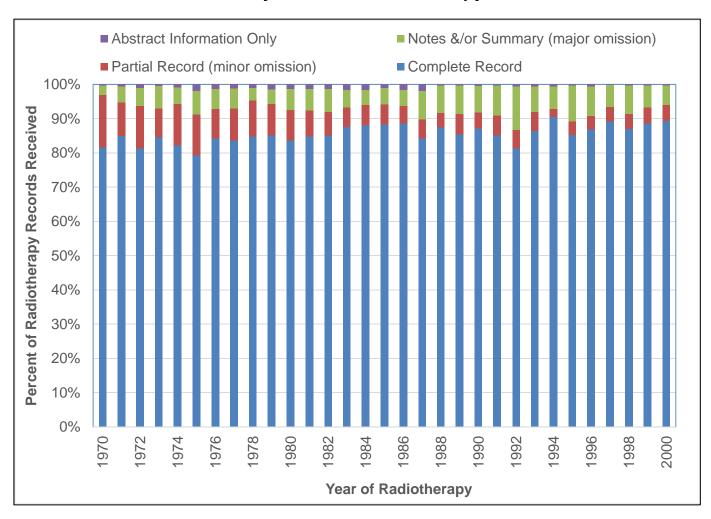
Abbreviations: radiation therapy (RT), cranial spinal irradiation (CSI), central nervous system (CNS)

# Radiation Therapy Record Status as of May 2017: Original (diagnosed 1970-1986) & Expanded Cohorts (diagnosed 1987-1999)\*

INSTITUTION (#)	Records received		Records processed <sup>1</sup>		Dosimetry Status <sup>2</sup>	
Cohort:	Original	Expanded	Original	Expanded	Original	Expanded
Children's Hospital at Stanford University	386	144	386	144	Complete	Ongoing†
Nationwide Children's Hospital	391	173	391	173	Complete	Complete
Children's Hospital of Los Angeles	279	173	279	173	Complete	Complete
Children's Hospital of Philadelphia	492	355	492	355	Complete	Complete
Children's Hospital of Pittsburgh	387	254	387	254	Complete	Complete
Children's National Medical Center	113	9	113	9	Complete	Complete
City of Hope	-	55	-	55	-	Complete
Dana-Farber Cancer Institute	428	240	428	240	Complete	Complete
Emory University	69	226	69	225	Complete	Ongoing
Mayo Clinic	299	-	299	-	Complete	-
Memorial Sloan-Kettering Cancer Center	377	214	377	214	Complete	Complete
Minneapolis Children's Medical Center	145	183	145	183	Complete	Complete
Riley Hospital for Children, IN University	209	189	209	189	Complete	Complete
Roswell Park Cancer Institute	221	96	221	96	Complete	Complete
Seattle Children's Hospital	274	267	274	267	Complete	Complete
St. Jude Children's Research Hospital	979	939	979	937	Complete	Ongoing
St. Louis Children's Hospital	228	132	228	132	Complete	Complete
Texas Children's (Baylor)	220	104	220	104	Complete	Complete
Children's Hospital Colorado	377	180	377	180	Complete	Complete
Toronto Hospital for Sick Children	697	-	697	-	Complete	-
U.T.M.D. Anderson Cancer Center	408	196	408	175	Complete	Ongoing
UAB/The Children's Hospital of Alabama	97	91	97	90	Complete	Ongoing
UCLA Mattel Children's Hospital	250	21	250	21	Complete	Complete
University of California at San Francisco	236	109	236	98	Complete	Ongoing
University of Michigan - Mott Children's	431	212	431	212	Complete	Complete
University of Minnesota	370	84	370	84	Complete	Complete
UT - Southwestern Medical Center	147	175	147	175	Complete	Complete
Cook Children's Medical Center		94	-	94	-	Complete
Total by cohort	8,510	4,915	8,510 (100%)	4,879 (98.8%)	8,510 (100%)	4,878 (98.8%)
Combined Total	13,4	25	13,389	(99.7%)	13,388	(99.7%)

<sup>†</sup> Waiting for diagnosis date information on one patient to complete dosimetry for Stanford.

## **CCSS Overall Cohort: Quality Score for Radiotherapy Information Received**



## **Summary of RT Data Analysis Completed Prior to 2015**

Study (Proposal #)	Study PI	Number exposed to RT or in study	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
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
Osteoporosis and avascular necrosis	Kadan- Lottick	~8500	Dose to gonads and pituitary and maximum brain dose	Complete Dec 2005

Study (Proposal #)	Study PI	Number exposed to RT or in study	Dosimetry required	Dosimetry status
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
Fertility	Green	4023	Ovaries and pituitary	Complete Jan 2010
GI second cancers	Henderson	46	SMN site in/near/out treatment field	Complete Jan 2010
ECHOS	Cox / Hudson	883	Treatment dose and body region	Complete Jun 2010

Study (Proposal #)	Study PI	Number exposed to RT or in study	Dosimetry required	Dosimetry status
Pregnancies during treatment	Mulvihill	16	Therapy records	Complete Sept 2010
GU complications	Shnorhavori an / 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	Maximum 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 dose by brain region	Complete May 2011
Oocyte radiosensitivity	Hamish	4324	Dose to ovaries	Complete Mar 2011
CNS longitudinal patterns of late effects	Hardie	923	Maximum dose by brain region	Complete Oct 2011
Longitudinal changes in health status	Hudson / Oeffinger	8507	Used existing maximum dose by region	Complete Feb 2011
Male infertility	Seidel	7717	Dose to testes and pituitary	Complete Mar 2011
Obesity among ALL survivors	Kamdar	1215	Maximum dose to spine and brain regions	Complete Nov 2011
Cardiac outcomes – risk model	Chow	8507	Maximum dose to chest and abdomen, heart average	Complete Jan 2012
BCC SMN – genetic risk	Davies	1282	Maximum dose by body region and brain region	Complete Nov 2012
NCI-GWA SMN risk	Morton	8507	Maximum dose by body region and brain region + specific organs and active bone marrow (ABM) for GWAS group	Complete - Body region dosimetry Dec 2013, other organs Dec 2014, ABM for GWAS subgroup Feb 2014
NCI-GWA – methods (13-16)	Morton	8507	Comparison of radiation dose reconstruction methods for SMN studies	Complete - Body region dosimetry Dec 2013, other organs Dec 2014
Lifestyle factors and pregnancy outcomes	Gawade	3567	Females. Ovary, uterus and pituitary dose previous run.	Complete Oct 2012
HL-Health status	Effinger	1675	Maximum dose by body region- update	Complete Nov2012
Ewings – Longitudinal (12-09)	Neyssa Marina	575	Maximum dose by body region	Complete Jul 2013
Exercise	Lee Jones	14370	Maximum dose by body region	Complete Aug 2013

Study (Proposal #)	Study PI	Number exposed to RT or in study	Dosimetry required	Dosimetry status
Intestinal obstruction (13-07)	Arin Mandenci	14370	Maximum dose by body region	Complete Aug 2013
STS chronic disease (13-04)	Emily Mueller	1726	Maximum dose by body region	Complete Oct 2013
Pulmonary (13-11)	Andrew Dietz	12846	Maximum dose by body region +lung dose	Complete Mar 2014
Testicular SMN	Oeffinger	14370	Maximum dose by body region + testes dose and testes proximity to nearest treatment field	Complete Dec 2013
Disease burden (14-03)	Jennifer Yeh	14364	Maximum dose by body region +heart dose	Complete Mar 2014
Alcohol consumption (13-20)	Tara Brinkman	3806	Maximum dose to brain segments + TBI	Complete Apr 2014
Cost effectiveness of COG LTFU screening guidelines for breast (12-14)	Lennie Wong	6645 (females)	Maximum dose to the chest, pelvis, TBI dose, Mantle Y/N, typical breast quadrant for patients with mantle treatments	Complete Aug 2014
Endocrine (14-02)	Sogol Mostoufi- Maob	14290	Maximum dose to body regions + thyroid, pituitary and gonads	Complete Sept 2014

## **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	TROL					
05.21.08	The Influence of Geographical Proximity to a Cancer Center on Risk Based Care among Childhood Cancer Survivors	Caplin/Utah Oeffinger/MSKCC		06.10.08	Approved	Approved
05.27.08	Longitudinal Changes in Health Status	Hudson/SJCRH	Chronic Disease Psychology	07.16.08	Approved	Approved
06.02.08	Risk-Based Health Evaluation of CCSS Participants (CPIR)	Green/SJCRH	Chronic Disease	07.16.08	Approved	Approved
06.05.08	A Comparison of Functional Outcomes between Sarcoma Survivors with Surgery or Radiation As Their Local Control	Marina/Stanford	Chronic Disease	07.16.08	Approved	Approved
06.05.08	Physical Activity in Lower Extremity Sarcoma Survivors with Amputation	Ness/SJCRH	Chronic Disease	07.16.08	Approved	Approved
06.05.08	A Comparison of Functional Outcomes between UE and LE Sarcoma Survivors	Marina/Stanford	Chronic Disease	07.16.08	Approved	Approved
06.05.08	Neurocognitive Problems and Health Behavior Outcomes	Krull/SJCRH	Psychology	07.16.08	Approved	Approved
06.18.08	Understanding Health Care Utilization Patterns and Changes Occurring over a Decade: A Report from the Childhood Cancer Survivor Study	Casillas/UCLA		07.16.08	Approved	Approved
10.14.08	Investigating the Needs of Childhood Cancer Survivors: Understanding Residual Treatment Effects (INSURE) (Ancillary Study)	Cox/SJCRH	Chronic Disease	11.12.08	Approved	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
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	Gibson/SJCRH		12.22.09	Approved	Approved
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	Not Approved
03.16.11	Risk Reduction Strategies To Prevent Subsequent Skin Cancer	Geller/Harvard	SMN Epi/Biostats	03.29.11	Approved	Approved
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	Approved
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	Withdrawn
08.01.11	Health Behaviors and Mammogram Utilization in the CCSS	Rosenberg/Harvard School of Public Health	Psychology	08.16.11	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
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	Withdrawn
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	Not Approved
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	Approved
04.26.12	Association Between Exercise Behavior and Incidence of Non-cancer Chronic Health Conditions	Jones/Duke	Chronic Disease Psychology	05.10.12	Approved	Approved
06.07.12	Receipt of a Treatment Summary and Its Relationship to Morbidities and Premature Mortality	Ford/MSKCC		07.16.12	Approved	Approved
06.07.12	Association of Surgical Procedure to Health Status in Sarcoma Survivors	Avedian/Stanford	Chronic Disease	07.16.12	Approved	Approved
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	Withdrawn	
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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
09.17.12	The Socio-economic Outcomes of Siblings of Childhood Cancer Survivors	Henderson/Univ. of Chicago		10.05.12	Approved	On Hold
10.24.12	Cancer Screening in Childhood Cancer Survivors: Grounded Theory and Discourse Analysis	Tripp/MD Anderson		11.20.12	Approved	Withdrawn
11.01.12	Evaluating Socioeconomic and Health-Related Pathways That Predict Smoking in Survivors of Childhood Cancer	Erinosho/UNC	Psychology	11.20.12	Approved	Withdrawn
11.19.12	Health Beliefs and Behaviors: Cohort Studies in Childhood Cancer Survivors Ancillary Study (KO7)	Henderson/University of Chicago	SMN	01.10.13	Approved	Pending
05.21.13	The Impact of Chronic Disease on Health Care Utilization in the CCSS Cohort	Nathan/Sick Kids		05.30.13	Approved	Approved
05.21.13	Health Status Among Adult Survivors of Childhood Cancer by Treatment Era	Ness/SJCRH		05.30.13	Approved	Approved
06.10.13	Social Outcomes in Aging Hodgkin Lymphoma Survivors	Effinger/Stanford		07.23.13	Not Approved	
07.07.13	EQUAL: Exercise and Quality Diet After Leukemia (Ancillary Study)	Tonorezos/MSKCC	SMN/Psychology	07.24.13	Approved	Pending
08.05.13	Longitudinal Evaluation of Health Status and Social Functioning in Survivors of Pediatric Astrocytomas	Effinger/Stanford	Chronic Disease Psychology	08.19.13	Approved	Approved
08.06.13	Examining the Role of Transitional Care in Facilitating Quality Clinical Health Care and Preventive Services for Adults Survivors of Childhood Cancer	Mertens/Emory			On Hold	On Hold
08.09.13	Health Care Utilization for Childhood Cancer Survivors	Mueller/U. of Michigan	Chronic Disease	08.19.13	Approved	Approved
08.30.13	The Impact of Endocrine Disorders on Physical Activity and Functional Outcomes	Pradhan/ Riley	Psychology Chronic Disease	09.26.13	Approved	Approved
09.24.13	Behavioral and Psychosocial Predictors of Health Behaviors among Adolescent/Young Adult Survivors	Wu/Univ. of Utah	Psychology	10.07.13	Withdrawn	

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
10.23.13	Social Support and Health Care Utilization	Wu/Univ. of Utah	Psychology Chronic Disease	11.07.13	Approved	Pending
11.02.13	Stages of Change and Predictors of Mammography Practices of Female Survivors of Childhood Cancer and Siblings	Szalda/CHOP		12.05.13	Approved	Approved
01.06.14	Longitudinal Mammogram Practices	Moskowitz/MSKCC	SMN	02.11.14	Approved	Approved
01.05.14	Does Intention to Undergo Screening Mammography Predict Future Screening?	Ford/MSKCC	SMN	02.11.14	Approved	Pending
04.23.14	EMPOWER Study: Promoting BC Screening in Women Who Survived Childhood Cancer (Ancillary Study)	Oeffinger/MSKCC	SMN	04.23.14	Approved	Approved
04.23.14	ECHOS (Ancillary Study)	Hudson/SJCRH		04.23.14	Approved	Approved
09.02.14	Patient-reported Concerns		Epi/Biostats Psychology	09.21.14	Approved	Approved
10.06.14	Physical Functioning in Pediatric Leukemia and Lymphoma Survivors	Le/Yale		10.06.14	Approved	Pending
10.17.14	Financial Burden of Medical Care	Fair/University of Utah	Chronic Disease	10.06.14	Approved	Approved
11.24.14	Understanding Experiences of Childhood Cancer Survivors after ACA Implementation (Ancillary Study)	Park/Harvard	Chronic Disease	12.17.14	Approved	Approved
11.24.14	Financial Burden in Survivors of Childhood Cancer	Nip/Harvard		12.17.14	Approved	Approved
12.05.14	Health Status in Extremity Sarcoma Survivors	Marina/Stanford	Chronic Disease	12.23.14	Approved	Pending
12.05.14	Trajectory of Mammography and Breast MRI among High Risk Women	Ford/MSKCC		12.23.14	Approved	Pending
06.11.15	Effects of Home-based Interval Training on Fitness and Physical Activity (Ancillary Study)	Ness/SJCRH	Chronic Disease Epi/Biostats	08.12.15	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
11.20.15	Return of Genomic Results to Research Participants (Ancillary Study)	Henderson/University of Chicago	Genetics Psychology	12.02.15	Approved	Pending
11.20.15	Advancing Skin Cancer Screening Practices among Survivors of Childhood Cancer and Skin Cancer (ASK2) (Ancillary Study)	Geller/Harvard School of Public Health	SMN	12.02.15	Approved	Pending
01.21.16	EMPOWER II Study: Promoting BC Screening in Female Survivors and Their Physicians (Ancillary Study)	Oeffinger, Ford/MSKCC	SMN	02.23.16	Approved	Pending
11.22.16	Compliance with Surveillance for SMNs and Cardiac Dysfunction in CCSS	Nathan/Hospital for Sick Children	Chronic Disease SMN	12.08.16	Approved	Approved
12.06.16	Exercise and Late Mortality in 5-Year Survivors of Childhood Cancer	Jones/MSKCC	Chronic Disease Epi/Biostats	12.16.16	Approved	Approved
03.07.17	Health Care Utilization and Estimated Costs Among Survivors of Childhood Cancer	Nathan/Sick Kids	Chronic Disease Epi/Biostats	04.04.17	Approved	Pending
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		06.15.08	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
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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
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	
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	11.20.09	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

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
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	Withdrawn
05.06.12	Chronic Medical Conditions Among Long-term Survivors of Pediatric Non-Hodgkin Lymphoma	Bluhm/Washington Hospital	Epi/Biostats Psychology		On Hold	Withdrawn
06.07.12	Longitudinal Pulmonary Complications in Survivors of Childhood Cancer	Dietz/UCSD	Epi/Biostats	07.16.12	Approved	Approved
06.07.12	Using the Cumulative Illness Rating Scale to Characterize The Burden of Chronic Conditions Among Childhood Cancer Survivors	Esbenshade/SJCRH	Epi/Biostats	07.16.12	Approved	Approved
06.07.12	Increasing Risk of Chronic Endocrine Disorders in Aging Survivors of Childhood Cancer	Mostoufi-Moab/ CHOP		07.16.12	Approved	Approved
06.15.12	Medical and Psychosocial Outcomes of Survivors of AYA Cancer	Suh/U. of Chicago	Cancer Control Psychology	07.16.12	Approved	Approved
06.16.12	Morbidity and Mortality Associated with the Diagnosis of Subsequent Meningiomas – Is it Necessary to Screen Adult Survivors of Childhood Cancer for Meningiomas?	Bowers/UT Southwestern	SMN	07.16.12	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
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
05.31.13	Changes in Long-Term Outcomes in Hodgkin Lymphoma Survivors with Contemporary Risk-Adapted Therapy	Oeffinger/MSKCC	Epi/Biostats SMN Cancer Control	07.23.13	Approved	Approved
06.10.13	Effects of Body Mass Index on Aging Childhood Cancer Survivors	Effinger/Stanford	Cancer Control	07.23.13	Not Approved	
07.31.13	Predictors of Hypertension in Adult Survivors of Childhood Cancer	Ojha/SJCRH	Psychology Epi/Biostats	08.19.13	Approved	Withdrawn
09.27.13	Anthracycline Equivalence	Feijen/Emma Children's	Epi/Biostats	10.14.13	Approved	Approved
09.27.13	Fertility following Contemporary Chemotherapy	Chow/ Univ. of Washington		10.14.13	Approved	Approved
11.07.13	Estimating the Burden of Disease Associated With Late-Effects Among Childhood Cancer Survivors	Yeh/Harvard		12.05.13	Approved	Approved
11.16.13	Updated Prevalence of Long-Term Survivors of Childhood Cancer and Estimated Burden of Morbidity Using SEER and CCSS	Phillips/NCI	Psychology	12.05.13	Approved	Approved
12.11.13	Analysis of Dose Response For Circulatory Disease in the Childhood Cancer Survivor Study Cohort with a Focus on Non-Cardiac Doses	Little/NCI	Epi/Biostats	01.16.14	Approved	Withdrawn
09.02.14	Chronic Health Conditions in Survivors Treated with Abdominal Radiation	Friedman/MSKCC	SMN	09.21.14	Approved	Approved
10.16.14	Comparison of Risks of Long-Term Outcomes with the British CCSS	Fidler/University of Birmingham, UK	SMN Epi/Biostats	10.28.14	Approved	Approved
11.11.14	Long-term Cardiovascular Mortality of Childhood Cancer Survivors - Safety and Efficacy of Percutaneous Coronary Interventions (PCI)	Iliescu/MD Anderson	Epi/Biostats	12.01.14	Approved	Pending
11.11.14	Esophageal Strictures After Childhood Cancer Therapy: Experience from Three Childhood Cancer Survivor Cohorts	Asdahl/Aarhus University		12.01.14	Approved	Approved
11.25.14	Racial Variations in Renal Function after Nephrectomy for Wilms Tumor	Christison-Legay/Yale		12.23.14	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
12.05.14	BMI in Survivors Diagnosed 1970-99 and Siblings: Prevalence and Risk Factors	Patterson/Emory		12.23.14	Approved	Pending
12.05.14	Long-term Morbidity in Survivors of CML	Hijiya/Northwestern			On Hold	
12.19.14	Improving Assessment and Treatment of Cardiovascular Risk Factors (Ancillary Study)	Chow/Univ. of Washington	Cancer Control	01.15.15	Approved	Pending
01.27.14	Cardiac Outcomes in Long-Term Survivors of Childhood Cancer	Mulrooney/SJCRH	Epi/Biostats	02.22.15	Approved	Approved
01.27.15	Chronic Health Conditions in Survivors of Non- Hodgkin Lymphoma	Ehrhardt/SJCRH	Epi/Biostats	02.22.15	Approved	Approved
05.05.15	Assessment of Hearing Impairment in Long-Term Survivors of Childhood Cancer	Brown/Baylor	Epi/Biostats	05.25.15	Approved	Approved
05.11.15	Analysis of Non-Alcoholic Fatty Liver Disease as a Modifier of Cardiovascular Disease Risk	Raghunathan/MSKCC	Epi/Biostats	06.18.15	Approved	Pending
06.09.15	Chronic Medical Conditions and Late Mortality Among Survivors of Pediatric Bone Sarcomas	Daw/MD Anderson	Epi/Biostats	07.06.15	Approved	Pending
06.11.15	Incidence of Chronic Disease Among Survivors by Treatment Era and Temporal Trends in Treatment Exposure	Gibson/SJCRH	Epi/Biostats	08.12.15	Approved	Approved
07.21.15	Changes in Long-Term Outcomes in Neuroblastoma Survivors Treated With Contemporary Therapies	Friedman/MSKCC	Cancer Control/SMN	08.12.15	Approved	Pending
08.03.15	Anthracycline Equivalence II	Feijen/Emma Children's /AMC	Epi/Biostats	08.30.15	Approved	Approved
08.04.15	Impact of Childhood Cancer and Treatment on Sperm Quality	Delbes/INRS		08.30.15	Approved	Pending
08.12.15	Gallbladder Surgery Among Childhood Cancer Survivors	Barnea/MSKCC		08.30.15	Approved	Pending
08.13.15	The Role of Developmental Status in the Dose Response Relationship of Cardiac Radiation and Cardiac Toxicity	Bates/Univ. of Rochester	Epi/Biostats	08.30.15	Approved	Approved
08.21.15	Long-term Incidence of Venous Thromboembolism Among Survivors of Childhood Cancer	Madenci/Boston Children's Hosp.	Epi/Biostats	09.08.15	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
08.21.15	Long-term Incidence of Complications from Surgical Asplenia Among Survivors of Childhood Cancer	Weil/Boston Children's Hosp.	Epi/Biostats SMN	09.08.15	Approved	Approved
08.26.15	Dietary Intake and Risk of Subsequent Cardiometabolic Complications in Survivors of Childhood Acute Lymphoblastic Leukemia	Marcil/Sainte-Justine Univ. Health Center	Epi/Biostats	09.15.15	Approved	On Hold
08.31.15	Long-term Morbidity in Survivors of Childhood CML	Williams/Lurie Children's - Northwestern	Epi/Biostats Psych SMN	09.15.15	Approved	Pending
09.09.15	Medulloblastoma and Primitive Neuroectodermal Tumor (PNET) Outcomes Across Three Decades of Diagnosis	Salloum/Cincinnati Children's Hospital	Epi/Biostats Psych SMN	09.21.15	Approved	Approved
09.10.15	Mortality and Morbidity in Childhood Cancer Survivors: Comparing Results from the CCSS and a Nationwide Cohort in Taiwan	Yu/Taipei Cancer Center	Epi/Biostats SMN	09.21.15	Approved	Pending
09.16.15	Incidence of Late Anorectal Complications among Childhood Cancer Survivors	Weldon/Boston Children's	Epi/Biostats	09.28.15	Approved	Approved
10.14.15	Comprehensive Comparative Analysis of Chronic Health Conditions, Health Status, Social Outcomes, and Mortality in Patients with Rhabdomyosarcoma by Treatment Era	Hingorani/Phoenix Children's Hospital	Cancer Control Epi/Biostats	11.30.15	Approved	Pending
12.08.15	Developing a Microsimulation Model of the Lifetime Clinical Course of Childhood Cancer	Yeh/Harvard School of Public Health	Genetics Epi/Biostats	01.20.16	Approved	Approved
04.08.16	Statin Therapy and Cardiovascular Disease Incidence in Childhood Cancer Survivors	Raghunathan/MSKCC	Epi/Biostats	04.22.16	Approved	Pending
04.09.16	Long-term Fertility Outcomes Following Ovarian Transposition	Glick/Cohen's Children Med Center	Epi/Biostats	04.22.16	Not Approved	
05.03.16	Cardiometabolic Outcomes Among Survivors of Childhood and Young Adult Cancer	Tonorezos/MSKCC	Cancer Control	05.16.16	Approved	Pending
05.23.16	Health Related Outcomes After Chronic Myeloid Leukemia	Roth/Children's Hospital at Montefiore	SMN Psychology	06.10.16	Approved	Pending
07.25.16	Reproductive Outcomes for Survivors of Childhood Cancer (Ancillary Study)	Woodruff/Northwestern	Epi/Biostats	08.24.16	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
08.24.16	Infertility, Assisted Reproductive Technology Utilization and Pregnancy Outcomes: A CCSS and SART CORS data linkage study	Keefe/Brigham and Women's Hospital	Epi/Biostats	09.06.16	Approved	Pending
<b>EPIDEMIOLO</b>	BY / 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 (Ancillary Study)	Yasui/Edmonton Alberta		03.16.09	Approved	Approved
05.12.09	Impact of Health Behaviors and Health Perceptions on Subsequent Mortality in Childhood Cancer Survivors (Ancillary Study)	Cox/SJCRH		05.28.09	Approved	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
10.27.10	Prediction of Risk of Serious Health Conditions	Salz/MSKCC		11.10.10	Approved	Pending

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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	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	
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
01.14.14	Risk of Cardiovascular Disease and Second Malignancies Attributable to Therapeutic Exposures by Treatment Era	Bhatia/UAB	SMN/Chronic Disease	02.11.14	Approved	Pending
01.14.14	Association Between Key Therapeutic Exposures And Outcomes - Gaps in Knowledge	Bhatia/UAB	SMN/Chronic Disease	02.11.14	Approved	Pending
01.20.14	Late Mortality by Treatment Era	Armstrong/SJCRH		02.11.14	Approved	Approved
04.02.14	Differences in Participant Characteristics and Changes in Treatment Characteristics from the Original to the Expanded Cohorts	Mertens/Emory		04.23.14	Approved	Approved
04.05.14	Tiled Study Design: Using Temporal Overlap as a Method to Extend Longitudinal Follow-Up Among Carefully Selected Time-Limited Cohorts	Chow/University of Washington	Chronic Disease	04.23.14	Approved	Approved
05.19.14	Use of an Incentive to Increase Biologic Sample (Oragene) Return Rate	McDonald/SJCRH		06.20.14	Approved	Approved

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08.15.14	Differences in Long-Term Outcomes by Race/Ethnicity in Childhood Cancer Survivors	Liu/University of Alberta		09.04.14	Approved	Approved
11.11.14	Relationships of Persistent Symptoms with Relapse, SMN, and Mortality	Huang/SJCRH	SMN, Chronic Disease, Psychology	12.01.14	Approved	Pending
04.02.15	Dosimetric Uncertainty in Radiation Dose Reconstruction Method used for CCSS	Howell/MD Anderson		04.26.15	Approved	Approved
05.29.15	Clinical Utilities of Various Prediction Performance Measures	Yuan/University of Alberta		06.18.15	Approved	Approved
07.17.15	Burden of Morbidity after Basal Cell Carcinoma	Bhatia/UAB	Chronic Disease, Genetics, SMN	08.12.15	Approved	Approved
10.04.15	Statistical Analysis for Various Outcome Measures in Recurrent Event Studies - Ancillary	Zhu/SJCRH		10.15.15	Approved	Approved
01.19.16	Individual Prediction of Premature Ovarian Insufficiency (Ancillary Study)	Yuan/University of Alberta		02.05.16	Approved	Approved
10.06.16	Trends in Life Expectancy and Quality-Adjusted Life Expectancy among Childhood Cancer Survivors	Yeh/Boston Children's Hospital	Chronic Disease Psychology	10.28.16	Approved	Approved
10.18.16	Cost-effective Cardiomyopathy Surveillance Strategies in Childhood Cancer Survivors	Ehrhardt/SJCRH	Chronic Disease Cancer Control	11.14.16	Approved	Approved
01.05.17	Statistical Methods for GWAS Analysis of Recurrent-event Data in Cancer Study	Zhu/University of Texas Health Science Center	Genetics	01.23.17	Approved	Pending
GENETICS						
-	GWAS of SMNs after Hodgkin Lymphoma	Onel/U. of Chicago	SMN	-	Approved	Approved
-	Genetic Epidemiology of Basal Cell Carcinoma in Childhood Cancer Survivors	Davies/Cincinnati	SMN	-	Approved	Approved
-	Susceptibility Genes for RT-induced Breast Cancer after Hodgkin Lymphoma	Van Leeuwen/Netherlands Cancer Institute	SMN		Approved	Approved
-	Radiation-related Thyroid Cancer	Nikiforov/U. of Pittsburgh	SMN		Approved	Approved
05.02.08	Characterization of Genomic Alterations in Radiation-Related Breast Cancer Using Array CGH (Comparative Genomic Hybridization)	Yang/NCI	SMN	06.02.08	Approved	Approved
05.27.08	Incidence of Familial Hodgkin Lymphoma	Metzger/SJCRH		06.10.08	Approved	Hold

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06.05.08	Genetic Predictors of Impaired and Enhanced Neurocognitive and Psychological Functioning among Survivors of Childhood Leukemia and Lymphoma	Kadan-Lottick/Yale University	Psychology	03.16.09	Approved	Pending
06.25.08	Genetic Polymorphisms and Metabolic Outcomes in Childhood Leukemia Survivors (Ancillary Study)	Kamdar/Texas Children's Hospital	Chronic Disease	08.11.08	Approved	Pending
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 (Ancillary Study)	DuBois/UCSF		12.18.08	Approved	Approved
06.15.09	Telomere Length and Risk for Second Malignancy in Pediatric Cancer Survivors	Gramatges/Baylor	SMN	07.10.09	Approved	Approved
10.15.09	Polymorphisms of Cardiomyocyte Genes in CCSS Participants with Congestive Heart Failure or Subclinical Left Ventricular Dysfunction After Treatment with Anthracyclines	Green/SJCRH		11.05.09	Approved	Withdrawn
07.28.10	Detecting Germ Cell Mutation by Family DNA Sequencing	Mulvihill/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/UAB	Epi/Biostats SMN	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 Malignancies	Morton/NCI	SMN Epi/B iostats	04.21.11	Approved	Approved

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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/UAB	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	Approved
09.26.13	Evaluation of the Intrinsic Molecular Profiles of Radiation-Preceded Breast Cancer	Barcellos-Hoff/NYU	SMN	10.14.13	Approved	Pending
03.25.14	Shortened Telomere Length and Defects in Telomere Maintenance Associated with Thyroid SMNs in Childhood Cancer Survivors (Ancillary Study)	Gramatges/Baylor	SMN, Epi/Biostats	04.14.14	Approved	Pending
04.01.14	Neurofibromatosis and Second Neoplasms (Ancillary Study)	Bhatia/UAB		04.11.14	Approved	Approved
06.20.14	Improving Delivery of Genetic Services to High Risk Childhood Cancer Survivors (Ancillary Study)	Henderson/ University of Chicago	Cancer Control	10.28.14	Approved	Pending
02.19.15	Exome Sequencing to Discover Genetic Variants that Predispose to the Development of Subsequent Neoplasms	Morton/NCI	SMN, Epi/Biostats	04.26.15	Approved	Approved
05.01.15	Validation of Interactome-based Biomarkers of Inherited Suseptibility to Radiation Induced Carcinogensis (Ancillary Study)	Amundson/Columbia University	SMN	05.11.15	Approved	Withdrawn
01.25.16	Predicting Pulmonary Late Effects in Childhood Cancer Survivors	Agrusa/Baylor College of Medicine	Chronic Disease Epi/Biostats	02.08.16	Withdrawn	
03.14.16	Molecular Characterization of Therapy-Related Pediatric High Grade Gliomas	Lucas/SJCRH	SMN	03.28.16	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
07.11.16	Late Effects Prediction Using Clinical Phenotypes and Whole Genome Sequencing	Yasui/SJCRH	Chronic Disease SMN Epi/Biostats	07.26.16	Approved	Pending
04.21.17	Germline Genomics to Identify Genetic Variants that Predispose Childhood Cancer Survivors Diagnosed During 1987-1999 to the Development of Subsequent Neoplasms	Morton/NCI	SMN Epi/Biostats	05.09.17	Approved	Pending
PSYCHOLOG'	<b>(</b>					
05.05.08	Psychosexual Adjustment in Long-Term Female Survivors of Childhood Cancer	Carpentier/Indiana University School of Medicine			Withdrawn	
06.05.08	Predictors of Future QOL in Adolescent Survivors of Childhood Cancer	Nolan/SJCRH	Chronic Disease	07.11.08	Approved	Approved
06.07.08	Quality of Life Associated with Fertility Status in Childhood Cancer Survivors	Warwick/Medical College of Wisconsin	Chronic Disease	07.11.08	Withdrawn	
06.09.08	QOL in Long-Term Survivors	Schapmire/University of Louisville		07.11.08	Withdrawn	
06.11.08	Health Behaviors and Chronic Disease	Hudson/SJCRH			Withdrawn	
07.10.08	The Psychological and General Health Status Impact of Late Sibling Death: A Report from the Childhood Cancer Survivor Study	Raber/UCSF Children's Hospital		08.11.08	Withdrawn	
08.25.08	Impact of Chronic Disease on Neurocognitive and Psychosocial Functions	Krull/ SJCRH	Chronic Disease	09.19.08	Approved	Approved
10.10.08	An Examination of the Relationship Between Fatigue/Sleep Disturbance and Neurocognitive Functioning in Adult Survivors of Childhood Cancer	Clanton/Baylor		11.12.08	Approved	Approved
11.24.08	Outcome after Stroke among Long-Term Survivors of Childhood Leukemia and Brain Tumors	Fullerton/UCSF	Chronic Disease	12.18.08	Approved	Approved
01.26.09	Localization of CNS Directed Radiotherapy and Neurocognitive, Psychological and Quality of Life Outcomes in Survivors of CNS Tumors	Armstrong/SJCRH		02.12.09	Approved	Approved
01.27.09	Chronic Pain and Psychosexual Function in Adult Survivors of Childhood Cancer	Randolph-Frye/SJCRH		02.12.09	Withdrawn	

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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/University 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
09.29.10	Longitudinal Patterns of Late Effects in Adult Survivors of Childhood Brain Tumors	Hardie/Drexel	Epi/Biostats Chronic Disease	10.21.10	Approved	Approved
10.21.10	Longitudinal Psychological Distress	Brinkman/SJCRH		11.10.10	Approved	Approved
04.22.11	Sensory-motor Problems and Associated Functional Outcomes in Survivors of Childhood Central Nervous System (CNS) Tumors	Walsh/ Children's National Medical Center	Chronic Disease	05.03.11	Approved	Withdrawn
06.23.11	Physical Activity and Risky Behavior Patterns Among Teenage Survivors of Childhood Cancers	Devine/U. of Rochester	Cancer Control	07.13.11	Approved	Approved
07.23.11	Measurement Invariance In Health-Related Quality of Life Between Young Adult Survivors of Childhood Cancer and Their Siblings	Huang/ University of Florida	Epi/Biostats	08.16.11	Approved	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		Withdrawn	Withdrawn
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	Approved
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

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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	Approved
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	Withdrawn
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	Approved
10.29.12	Sleep and Fatigue in Survivors of Pediatric CNS Tumors	Manley/Dana-Farber	Chronic Disease	11.20.12	Approved	Withdrawn
10.30.12	Eating Disorder Behaviors in Survivors of Childhood Caner	Zhang/Tufts University		11.20.12	Approved	Pending
05.01.13	Social and Behavioral Phenotypes of Adolescent Survivors of Childhood Cancer	Brinkman/SCJRH		05.30.13	Approved	Approved
05.08.13	Exploring Latent Clusters of Survivors Using the BSI-18	D'Agostino/Princess Margaret Cancer Centre		05.30.13	Approved	Approved
08.19.13	Mental Health Care Service Availability and Utilization Among Childhood Cancer Survivors	Perez/Mass General	Cancer Control	09.26.13	Approved	Approved
08.23.13	The Impact of the Sibling Sociodemographic and Health Factors on Psychological Outcomes of Childhood Cancer Survivors	Buchbinder/CHOC		09.26.13	Approved	Withdrawn
11.06.13	Impact of Social Networks on Psychological and Health-Related Quality of Life Outcomes on Young Adult Survivors of Childhood Cancer	Galligan/Univ. of Florida		12.17.13	Withdrawn	
11.14.13	Neuropsychological Outcomes in Long Term Survivors of Stem Cell Transplant	Hiniker/Stanford		12.17.13	Not Approved	

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01.20.14	Cognitive, Behavioral and Learning Problems in Survivors of Childhood ALL	Jacola/SJCRH		02.11.14	Approved	Approved
01.29.14	Adult Neurobehavioral Late Effects of Pediatric Low Grade Brain Tumors	Ris/Baylor	Epi/Biostats	02.11.14	Approved	Approved
03.14.14	Antecedents and Consequences of Personal and Interpersonal Strengths in Young Adult Survivors	Henrich/Georgia State University		03.30.14	Approved	Approved
04.03.14	Vascular Effects of Cranial Radiation Therapy (Ancillary Study)	Mueller/UCSF	Chronic Disease Epi/Biostats	04.22.14	Approved	Pending
06.30.14	Psychological Concerns Among Siblings of Childhood Cancer Survivors	Buchbinder/CHOC		08.29.14	Approved	Pending
10.06.14	Effects of Administration Modes on Patient- Reported Outcomes Assessment in CCSS	Huang/SJCRH	Epi/Biostats	10.28.14	Approved	Approved
03.05.14	Neurocognitive Function in Survivors of Osteosarcoma	Kadan-Lottick/Yale		04.26.15	Approved	Approved
05.25.15	Psychosocial Outcomes in Adolescent Survivors of Wilms Tumor	Foster/St. Louis Children's Hospital	Chronic Disease	06.18.15	Approved	Approved
08.07.15	Prevalence and Predictors of Cognitive and Behavioral Problems in Adolescent Survivors of CNS Tumors	Kunin-Batson/University of Minn.	Chronic Disease	08.30.15	Approved	Pending
08.12.15	Cognitive and Behavioral Outcomes in Adolescent Survivors of Neuroblastoma	Zheng/Yale		08.30.15	Approved	Approved
08.19.15	Social Function in Adolescent Survivors of Pediatric Brain Tumors	Schulte/Alberta Children's Hosp.		09.08.15	Approved	Approved
09.09.15	Loneliness Predictors and Outcomes in Young Adult Childhood Cancer Survivors	Fayad/University at Buffalo	Cancer Control	09.21.15	Approved	Pending
09.09.15	Sleep Behaviors and Patterns and their Relationship to Health and Mental Health Outcomes in Adult Survivors	Daniel/CHOP	Chronic Disease SMN	09.21.15	Approved	Approved
09.11.15	Psychological Distress, Neurologic Morbidity and Functional Independence Among Survivors With CNS-Directed Therapy	Vuotto/SJCRH	Chronic Disease	09.28.15	Approved	Approved
09.15.15	Effect of NF1 Status on Late Outcomes in Adult Survivors of Childhood Cancer	De Blank/University Hospitals Rainbow Babies	Epi/Biostats Chronic Disease SMN	09.28.15	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
11.11.15	Prevalence and Patterns of Prescription Psychoactive Medication Use in Adolescent Survivors of Childhood Cancer	Cheung/SJCRH		11.25.15	Approved	Approved
11.26.15	Longitudinal Patterns of Psychological Distress and Health Behaviors in Adolescents	Shin/UNC Greensboro	Cancer Control	11.30.15	Withdrawn	
12.01.15	Psychological and Behavioral Outcomes in Pediatric AML Survivors: BMT versus Chemotherapy-only	Stefanski/Cincinnati Children's Hospital Medical Center		12.14.15	Approved	Approved
02.10.16	eHealth Intervention for Insomnia in ALL Survivors (Ancillary Study)	Ruble/Johns Hopkins University	Cancer Control/Intervention	02.22.16	Approved	Pending
02.10.16	Adolescent Risk Factors and Behavior Patterns and Future Alcohol and Psychoactive Medication Use in Young Adult Survivors	Ruiz/Harbor-UCLA Medical Center	02.22.16		Approved	Pending
05.05.16	Posttraumatic Stress as a Unique Contributor to Health Outcomes and Healthcare Utilization in Adult Survivors of Childhood Cancer	Van Sickle/Florida Institute of Technology	Cancer Control 05.20.16		Approved	Pending
05.09.16	Special Education Services, Educational Attainment, and Chronic Health Conditions Among Long-Term Survivors	Bashore/Cook Children's Med. Center	Chronic Disease	05.20.16	Approved	Pending
05.16.16	Long Term Psychosocial Outcomes in Pediatric Low Grade Glioma Survivors	Ris/Texas Children's Hospital	Epi/Biostats	06.01.16	Approved	Pending
08.26.16	The Impact of Preexisting Genetic or Congenital Medical Conditions on Long-Term Psychosocial and Psychological Outcomes	Jacola/SJCRH	Chronic Disease Genetics			Pending
09.30.16	Trends in Utility-based Health-related Quality of Life Among Childhood Cancer Survivors	Yeh/Boston Children's Hospital	Chronic Disease 10.28.16		Approved	Pending
10.27.16	Cognitive Aging in Adult Survivors of Childhood Cancer	Krull/SJCRH	Chronic Disease Epidemiology/Biostatistics Cancer Control	11.15.16	Approved	Pending
11.15.16	Physical Activity as a Predictor of Neurocognitive Outcomes in Adult Survivors of Childhood Cancers	Edelstein/Princess Margaret Cancer Center	Chronic Disease Cancer Control	11.30.16	Approved	Pending

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
12.21.16	Longitudinal Changes in Functional Independence in Aging Adult Survivors of Pediatric Brain Tumors	Brinkman/SJCRH	Chronic Disease	01.12.17	Approved	Pending
01.09.17	Suicide, Homicide and Accidental Causes of Death in Childhood Cancer Survivors	Qaddoumi/SJCRH	Epi/Biostats	01.24.17	Approved	Pending
02.01.17	Determinants of Longitudinal Health-Related Quality of Life Change in Adult Survivors of Childhood Cancer	Huang/SJCRH	Chronic Disease Cancer Control	02.17.17	Approved	Pending
02.17.17	Effects of Radiation and Changes by Treatment Era on Neurocognitive Impairment, Social Attainment and Quality of Life in Adult Survivors of Pediatric Brain Tumors	Brinkman/SJCRH		02.28.17	Approved	Pending
02.28.17	Self-Reported Neuropsychological Outcomes in Adult Survivors of Neuroblastoma	Hesko/Univ. of Chicago	Chronic Disease	04.04.17	Approved	Pending
03.08.17	Daily and Chronic Experiences of Pain in Adult Survivors of Childhood Cancer	Alberts/SJCRH	Cancer Control	Cancer Control 04.04.17		Pending
03.10.17	Racial/Ethnic Differences in Neurocognitive and Psychological Function in Adult Survivors of Childhood Cancers	Dixon/SJCRH	Epi/Biostats	04.04.17	Approved	Pending
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 Leukemias in Survivors of Childhood Cancers	Nottage/SJCRH		10.06.09	Approved	Approved
05.25.10	Melanoma as a Second Malignant Neoplasm	Pappo/SJCRH	Genetics	06.14.10	Approved	Approved
06.18.10	Breast Cancer Following Chest RT	Oeffinger/MSKCC	Chronic Disease	07.01.10	Approved	Approved
10.28.10	Primary Tumor Recurrence and SMN After Pregnancy	Rokitka/Roswell Park		11.10.10	Approved	Pending
11.09.10	SMN After Diabetes Mellitus	Chang/UCSF	Chronic Disease	11.23.10	Approved	Pending
11.11.10	Breast Cancer Risk Factors	Inskip/NCI		12.07.10	Approved	Approved
11.16.10	Radiation Dose and Risk of Meningioma	Rajaraman/NCI	Epi/Biostats		Hold	
02.03.11	Renal Cell Carcinoma	Wilson/SJCRH		03.09.11	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
04.13.11	Gynecological Malignancies	Nathan/Sick Kids		05.03.11	Approved	Pending
04.20.11	Development and Validation of an Absolute Risk Prediction Model for Thyroid Cancer in Childhood Cancer Survivors	Ronckers/Netherlands	Epi/Biostats	05.03.11	Approved	Approved
04.27.11	Testicular Cancer Following Pediatric Cancer	Oeffinger/MSKCC	Chronic Disease	05.10.11	Approved	Pending
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	Approved
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 Minn.	Epi/Biostats	04.26.12	Approved	Approved
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			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
01.08.13	Beyond radiation: Understanding Thyroid Cancer Risk in Childhood Cancer	Turcotte/University of Minn.	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	05.15.13	Approved	Approved

Date Received	Title	Author/ Institution	Secondary Working Group(s)	Date Investigator Notified	AOI Outcome	Concept to Publication Committee
07.24.13	HPV-related SMNs in Childhood Cancer Survivors	Alexander/University of Chicago		08.19.13	Approved	Approved
10.02.13	Radiation Dose Reconstruction Methods for Intensity Modulated Radiation Therapy (IMRT)	Howell/MD Anderson	Epi/Biostats Chronic Disease	10.14.13	Approved	Withdrawn
01.16.14	Changing Patterns of Second Neoplasms in Childhood Cancer Survivors: Comparison of Survivor Cohorts	Turcotte/University of Minnesota	Epi.biostats 02.11.14		Approved	Approved
01.14.14	NF1 and Second Malignant Neoplasms (Ancillary Study)	Bhatia/UAB	Genetics 02.19.14		Approved	Approved
01.30.14	Breast Cancer in the Modern Treatment Era	Henderson/Univ. of Chicago	02.11.14		Approved	Pending
04.23.14	Prediction Model: Breast Cancer in Women Irradiated for a Pediatric Malignancy (Ancillary Study)	Moskowitz/MSKCC	Cancer Control		Approved	Approved
12.05.14	Changing Patterns of Non-Melanoma Skin Cancer in Childhood Cancer Survivors Who Received Radiation Therapy	Griffith/University of Miami	Epi/Biostats	01.15.15	Approved	Pending
12.25.14	The Impact of Radiation Dose Uncertainty and Heterogeneity on Subsequent Breast Cancer Risk	Berrington/NCI	Epi/Biostats	01.15.15	Approved	Pending
02.09.15	Cause-specific Mortality Among Survivors with Thyroid Subsequent Malignant Neoplasm	Barnea/MSKCC	Cancer Control 04.26.15		Approved	Approved
07.17.15	Lung Cancer as Subsequent Malignant Neoplasm	Dietz/U. of Utah	08.30.15		Approved	Pending
09.18.15	Patterns of CNS Neoplasms in Survivors of Childhood Cancer: A Report from the CCSS	Phelan/U of Minn.	Epi/Biostats 09.30.15		Approved	Pending
06.23.16	Subsequent Neoplasms Among Childhood Cancer Survivors Exposed to Chemotherapy and Not Radiation	Turcotte/U of Minn.	Epi/Biostats	07.26.16	Approved	Approved

## **Statistical Center Current Project List**

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
Submitte	ed & Draft Manuscripts				
11-03	Morbidity in Survivors of Childhood Leukemia with Down Syndrome	Shannon Raber/ Rob Goldsby	Kayla	Wendy	Submitted – Lancet Hematology
11-18	Physical Activity and Psychological Functioning among Teenage Survivors	Katie Devine/ Kevin Krull	John	Wendy	Submitted - Psycho-Oncology
12-12	Access to Health Information Technology and Health Information Seeking	Mechelle Claridy	Kayla	Wendy	Submitted - J Cancer Survivorship
11-02	Non-Surgical Premature Menopause in CCSS Update	Levine/ Sklar	John	Wendy	Submitted - Cancer
14-26	Predictors and Outcomes of Personal Strengths in Young Adult Cancer Survivors	Aurelie Weinstein	Kayla	Wendy/Local Statistician	Submitted - JNCI
15-10	Financial Burden in Survivors	Ryan Nipp	Wendy	Local Statisticians	Submitted - JCO
14-24	Patient-reported Concerns in Survivors of Childhood Cancer	Todd Gibson	Chenghong	Kumar	Submitted - JCO
11-10	Neurologic/neurosensory Sequelae in CNS Survivors	Elizabeth Wells	Kristy	Wendy	Submitted - Neuro-Oncology
11-09	Inverse Probability Censored Weighting (IPCW) to Adjust for Selection Bias and Drop Out	Chonghzi Di	Kayla	Wendy	Draft manuscript
09-15	Genitourinary Outcomes in Childhood Cancer Survivors	Margarett Shnorhavian	Pam	Wendy	Draft manuscript
13-18	Impact of Health Insurance on Utilization of Outpatient and Inpatient Health Care Services	Emily Mueller	Wendy	Anne Kirchhoff	Draft manuscript
12-10	Health Status Outcomes in HL Survivors	Karen Effinger	Wendy	Alice Whittemore (Stanford)	Draft manuscript
14-08	Adult Neuropsychological Late-Effects in Childhood Low Grade Brain Tumors	Doug Ris	Pam	Wendy/Chongzhi Di	Draft manuscript
Internal	Missing Data Imputation (Methodology)	Leah Martin/Qi Liu	Yutaka	Yutaka	Draft manuscript
12-16	Perceptions of Risk for Male Health Problems (Infertility Component)	Jordan Gilleland	Kristy	Wendy	Draft manuscript
13-09	Health Outcomes Among Survivors of Adolescent and Young Adult Cancer	Eugene Suh	Wendy	Kayla	Draft manuscript
13-04	Longitudinal Evaluation of Chronic Disease and Health Status in Soft Tissue Sarcoma Survivors	Emily Mueller	Pam	Wendy	Draft manuscript
14-17	Mental Healthcare Service Availability and Utilization Among Childhood Cancer Survivors	Giselle Perez / Park	Wendy/Kayla	Wendy/Local Statistician	Draft manuscript
13-20	Chronic Alcohol Consumption, Neurocognitive Dysfunction and Psychological Distress	Tara Brinkman	Chenghong Li	Kumar	Draft manuscript
16-04	Cognitive and Behavioral Outcomes in Survivors of Neuroblastoma	Daniel Zheng	Yan	Yutaka	Draft manuscript

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
15-17	Risk for Late Effects of Treatment in Children Newly Diagnosed with Mature B-Cell Non-Hodgkin Lymphoma	Matt Ehrhardt	Yan	Yutaka	Draft manuscript
10-04	Predicting Cardiovascular Disease; Creation of a Risk Score Model, Paper 2	Eric Chow	Yan Chen	Yutaka	Draft manuscript
12-19	Health-related Locus of Control in Childhood Cancer Survivors	Cara Kimberg	Nan Zhang	Kumar	Manuscript in preparation
09-01	Impact of Chronic Disease on Neurocognitive and Psychosocial Functions	Kevin Krull	Chenghong LI	Kumar	Manuscript in preparation
14-18	Cognitive and Academic Difficulties in Survivors of Head/Neck Rhabdomyosarcomas	Melissa Shapiro	Wei Liu	Kumar	Manuscript in preparation
14-22	Characteristics of the Expanded Childhood Cancer Survivor Study Cohort: 5-Year Survivors Diagnosed from 1970-1999	Mertens/Leisenring	John	Wendy	Manuscript in preparation
14-20	Exercise and Risk of Major Health Outcomes	Tonorezos/Jones	Linwei Wang	Yutaka	Manuscript in preparation
14-21	Impact of Endocrine Disorders on HRQL and Physical Activity	Kamnesh Pradhan	Yan Chen	Yutaka	Manuscript in preparation
15-16	Human Papillomavirus (HPV)-Associated Malignancies as Second Cancers in Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study	Tara Henderson	John	Wendy	Manuscript in preparation
09-16	First and Recurrent Stroke in Long-Term Survivors of Childhood Cancer, Paper 2	Sabine Mueller	Yan	Yutaka	Manuscript in preparation
16-02	Medulloblastoma and Primitive Neuroectodermal Tumor (PNET) Outcomes Across Three Decades of Diagnosis	Ralph Salloum	Yan	Yutaka	Manuscript in preparation
16-03	Hospitalization and Mortality Due to Infection Among Survivors of Childhood Cancer with Asplenia	Brent Weil	Qi	Yutaka	Manuscript in preparation
16-05	Long-term Incidence of Venous Thromboembolism among Survivors of Childhood Cancer	Arin Madenci	Qi	Yutaka	Manuscript in preparation
16-07	Impact of Developmental Status on Radiation-associated Late Cardiac Toxicities	James Bates	Qi	Yutaka	Manuscript in preparation
Analyse	s 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 Sequelae 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
14-15	Breast Cancer Risk Calculator After Chest Radiation	Chaya Moskowitz	Wendy	Chaya (MSKCC)	Analyses ongoing
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 with Sibling Data from CCSS	Ira Dunkel	Kayla	Yuelin Li /Joanne Chou (MSKCC)	Programs and data sent

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
10-05	Outcomes of Pregnancies Exposed to Cancer Therapy	John Mulvihill	John	Wendy	Data sent
11-22	Chronic Health Conditions and Employment Status Transitions	Anne Kirchhoff	Wendy	Anne K.	Analyses ongoing
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/Amy Berrington	Wendy	Chaya/John	Data sent
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
11-20	Solid Organ Transplant After Childhood Cancer	Drew Dietz	Kristy	Wendy	Analyses ongoing
Ancillary	Breast Cancer After HL: Collaboration with Dutch Group	Smita Bhatia	John	Wendy	Data sent
12-17	Longitudinal Predictors of QOL in Adolescent Survivors	Claire Russell/Kevin Krull	Zhenghong/Kiri	Kiri	Analysis reviewed and complete
05-06	Risk of Increased Morbidity and Mortality in Underweight Survivors	Emily Tonorezos/Lillian Meacham	Wendy	Chaya	Analyses ongoing, abstract submitted
13-05	Breast Cancer in Childhood Cancer Survivors: The Impact of Screening on Morbidity	Tara Henderson	Chaya		Analyses ongoing
13-10	Body Mass Index Trajectories among Adult Survivors of Childhood Central Nervous System Tumors	Maria Chang	Wendy		Data sent
13-15	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	Wendy	Chaya	Data sent
13-16	Comparison of Radiation Dose Reconstruction Methods for SN Studies	Lindsey Morton	NCI Statistician	Wendy	Data sent
14-03	Estimating the Burden of Disease Associated with Late- Effects Among Childhood Cancer Survivors	Jennifer Yeh	Wendy/Pam	Jennifer Yeh/Harvard Statistician	Paper 1 accepted, additional papers in analysis
12-14	Cost Effectiveness of Breast Cancer Screening Guidelines for Female Survivors	Lennie Wong	Yan Chen	Yutaka/Wendy	Data sent
13-16	Longitudinal Health Status among Astrocytoma Survivors	Karen Effinger	Kayla/Karen Effinger	Wendy/Stanford Statistician	Data sent
14-09	Epigenomic Profiling of Metabolic Outcomes	Philip Lupo	Yutaka	Yutaka/Philip	Analyses ongoing
15-06	Exome Sequencing to Discover Genetic Variants that Increase Risks of Subsequent Neoplasm	Lindsay Morton	Wendy/Yutaka	NCI Statistician	Analyses ongoing
15-04	Risk of Breast and Thyroid Cancer After Radiotherapy for Hodgkin's Lymphoma: Can Reconstructed Dosimetry Data Be Used to Predict Secondary Malignancies	David Hodgson	Pam	Wendy	Data sent, finalizing analyses (Paper 2 - RT risks)
15-01	Using the Cumulative Illness Rating Scale to Characterize the Burden of Chronic Conditions	Adam Esbenshade	Kiri/Lu Lu	Kiri / Wendy	Analyses ongoing

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
15-03	Comparison of Risks of Mortality (All-Cause, Cause- Specific) and Invasive Second or Subsequent Cancers: CCSS and BCSS	Miranda Fidler	Qi/Yutaka/Wendy	Miranda Fidler	Analyses ongoing
13-01	Pooled International Study of Radiation Related Tumors of the Brain and Nervous System	Peter Inskip	NCI statisticians	Pam	Data sent
15-07	Changes in Long-Term Outcomes in Hodgkin Lymphoma Survivors with Contemporary Risk-Adapted Therapy	Kevin Oeffinger	Kayla	Wendy	Analyses ongoing
15-09	Health Care Financial Burden and Missed Opportunities for Care	Doug Fair	Wendy	Anne Kirchhoff	Analyses ongoing
15-08	Impact of Radiation Dose and Volume to the Pancreas on Risk of Diabetes Mellitus in Survivors Treated with Abdominal Radiation	Danielle Novetsky-Friedman	Wendy/Chaya	Chaya	Data set sent
15-15	Evaluation of Risk Prediction Models of Late Effects Among Childhood Cancer Survivors	Yan Yuan	Yutaka	Yan Yuan	Analyses ongoing
14-25	Impact of Chronic Disease on Health Care Utilization (Original and Expansion Cohorts)	Paul Nathan	Pam	Wendy	Dropping - uninteresting results
15-12	Tiled Study Design: Using Temporal Overlap as a Method to Extend Longitudinal Follow-Up among Carefully Selected Time-Limited Cohorts.	Eric Chow	Qi	Yutaka	Analyses ongoing
15-11	Use of an Incentive to Increase Biologic Sample (Oragene) Participation	Aaron McDonald		Kumar	Analyses ongoing
15-02	Esophageal Disease After Childhood Cancer Therapy: Experience from Three Childhood Cancer Survivor Cohorts	Peter Asdahl	Pam	Wendy	Data sent
15-14	Burden of Morbidity After Basal Cell Carcinoma in Childhood Cancer Survivors	Smita Bhatia	John	Wendy	Main analyses completed
16-09	Derivation of Anthracycline Equivalence to Doxorubicin in Relation to Late Cardiotoxicity: Epirubicin, Idarubicin and Mitoxantrone	Lieke Feijen	Kayla	Wendy	Main analysis completed
16-01	Cause-Specific Mortality among Childhood Cancer Survivors with a Subsequent Thyroid Cancer	Dana Barnea	Yan Chen	Yutaka	Analyses ongoing
16-06	Psychosocial Outcomes in Adolescent Survivors of Wilms Tumor	Rebecca Foster	Mingjuan Wang	Kumar	Analyses ongoing
16-12	Prescription Psychoactive Medication Use in Adolescent Survivors	Yin Ting Cheung	Wei Liu	Kumar	Analyses ongoing
16-16	Incidence of Chronic Disease among Childhood Cancer Survivors by Treatment Era and Temporal Trends in Treatment Exposure	Todd Gibson	Kayla	Wendy	Analyses ongoing
16-10	Secondary Cancers among NF1 Cancer Survivors	Smita Bhatia	Pam	Wendy/Local Statistician	Sampled case/control, data sent

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
16-08	Social Adjustment in Adolescent Survivors of Pediatric CNS Tumors	Fiona Schulte	Chenghong	Kumar	Analyses ongoing
16-13	Sleep Behaviors and Patterns and their Relationship to Health and Mental Health Outcomes in Adult Survivors of Childhood Cancers	Lauren Daniel	Mingjuan	Kumar	Analyses ongoing
16-17	Psychological Distress, Functional Independence, Neurologic Morbidity among Survivors with CNS- Directed Therapies	Stefanie Vuotto	Chenghong Li	Kumar	Analyses ongoing
16-15	Incidence, Predictors and Impact of Hearing Impairment	Austin Brown	Kristy	Wendy	Initiating project
16-14	Incidence of Anorectal Complications	Chris Weldon	Daisuke	Yutaka	Initiating project
17-04	Longitudinal Pain	Cynthia Karlson	Wei Liu	Kumar	Analyses ongoing
17-05	Quantifying Individual Absolute Risk of Premature Ovarian Failure in Female Survivors	Yan Yuan	Yutaka	Yan Yuan	Data needs to be sent
15-13	Dosimetric Uncertainty in Radiation Dose Reconstruction Methods	Rebecca Howell	Wendy/Yutaka	MD Anderson	Does not need analyst
16-20	Psychological, Behavioral and Educational Outcomes in AML Survivors: Compare BMT vs. Not	Kristen Stefanski	Pam	Wendy	Initiating project
16-18	Longitudinal CV Outcomes	Dan Mulrooney	Sue	Kiri	Initiating project
Approve	d Concepts in Queue				
15-05	Cyclophosphamide Equivalent Dosing and Male Health Late Effects	Lillian Meacham	Wendy		Has multiple other projects ongoing
16-11	Neurocognitive Functioning in Survivors of Osteosarcoma	Nina Kadan-Lottick	Wendy		Hold for FU5
16-19	NF1 Effects on Late Outcomes	Peter deBlank	Wendy		Hold for FU5
17-01	Exercise and Late Mortality	Lee Jones	Yutaka		Hold for FU5
17-02	Projections in Trends in Life Expectancy and QALY	Jennifer Yeh	Wendy		
17-03	Posttraumatic Stress as a Contributor to Behavioral Health Outcomes	Emily Crochet	Wendy		
17-07	Financial Toxicity in Survivors and Siblings + Survey Tool	Paul Nathan	Wendy		Will need FU6 Financial Tox survey
17-06	Subsequent Neoplasms among Survivors Not Treated with Radiation	Lucie Turcotte	Yutaka		
17-09	Adherence to Surveillance for Second Malignant Neoplasms and Cardiac Dysfunction	Adam Yan	Wendy		
17-08	Cost-effective Cardiomyopathy Surveillance Strategies in Childhood Cancer Survivors	Matthew Ehrhardt	Yutaka		
Proposa	ls Under Development				
	Prediction of Risk of Serious Health Conditions Among Survivors	Talya Salz	Wendy/Chaya		

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
	Risk of SMN in Long-Term Survivors of Childhood Cancer with Diabetes Mellitus	Rob Goldsby	Wendy		
13-15	Evaluation of Molecular Profiles of Radiation-Preceded Breast Cancer	Helen Barcellos-Hoff	Yutaka/Wendy		
	Predictors of Healthy Aging in Childhood Cancer Survivors	Kiri Ness	Wendy/Yutaka		
	Eating Disorder Behaviors in Adolescent Survivors of Childhood Cancer	Fang Fang Zhang	Wendy		
	Impact of Perceived Social Support on Long Term Medical Follow Up	Yelena Wu	Wendy		
	Functional Outcomes for Extremity Sarcomas in Full Cohort Over Time	Neyssa Marina	Wendy		
	Lung SMNs	Drew Dietz	Wendy		
Ancillary	Study Grant Proposals				
	Adult Neuropsychological Late-Effects in Childhood Low Grade Brain Tumors	Doug Ris	Wendy		First manuscript draft
	Evaluation of Cardiac Outcomes in Survivors (ECHOS)	Melissa Hudson/Cheryl Cox	Kayla/Wendy		First manuscript published, second in analysis
	Insure (Needs Assessment) - Ancillary	Cheryl Cox	Wendy		Published
	Projecting Breast Cancer Risk	Chaya Moskowitz/Kevin Oeffinger	Chaya		Funded, multiple manuscripts published
	Efficacy of Tobacco Quit Line for Cancer Survivors	Bob Klesges	Wei/Kumar		Published
	Are Childhood Cancer Survivors Underinsured?	Elyse Park	Wendy		Several publications
	EQUAL: Exercise and Quality Diet After Leukemia	Emily Tonorezos	Chaya		Enrolling
Data Mar	nagement				
	Cleaned and Incorporated Recently Reported SMN Data	John Whitton	Joe/Greg/Lucie	Wendy	May, 2017
	Clean and Freeze Data from FU5 Survey	John Whitton	John/Wendy	Greg, Aaron, Chris	May, 2017
	New Frozen Data Set - All Expansion, Original, Siblings, SMN and Mortality Updates	John Whitton / Kayla Stratton	Pam Goodman	Wendy	Sept, 2016
	Modify and Share Chronic Disease SAS Program Files and Documentation with Bhatia BMTSS	Kayla Stratton	Smita and staff	Wendy	Sept, 2016; May, 2017
	Coding of Expansion Baseline Chronic Conditions to CTCAE	Kevin Oeffinger and others	Kayla	Wendy	Survivors Completed January, 2015, Siblings and Mortality Updated Sept, 2016
	Creation of Frozen Data Set for DNA Samples	Stella Davies	Sue Huang/Lu Lu	Kiri	Data updated - July, 2016
	Validation, Cleaning and Freezing of Expansion Cohort SMN	Greg Armstrong / Joe Neglia	John Whitton	John, Aaron,	Completed April, 2015
	Conversion of SMN Data from ICDO-2 to ICDO-3	Greg Armstrong / Joe Neglia	Pam Goodman	John, Wendy	Completed January, 2015

Concept	Project	Investigator	Stat Center Contact	Secondary/Sr. Statistician	Status
	Cleaning and Freezing of Expansion Mortality Data	Greg Armstrong / Joe Neglia	Pam Goodman	John, Wendy	Completed November 2014, Updated April 2015
	Creation of Frozen Data Sets for Baseline Expansion	John Whitton	John/Wendy	Sandrine, Pam, Aaron, Chris	Completed November 2014, Updated April 2015
	Creation of Frozen Data Set for Expansion MRAF and MDA RT Data	Kayla Stratton	Kayla/Pam/Wendy	Wendy, Aaron, Chris	Completed November 2014, Updated April 2015
	Audit and Freeze of Audited SMN Data	John Whitton	Joe/Lucie	Wendy	Completed Dec, 2012
	Cleaning of Elyse Park RO1 Insurance Study Data	Elyse Park	John/Chris Vukadinovich	Wendy	Most recent freeze May, 2013
	Created Frozen Data Through FU2007 Data (Q's, Mortality 2007, SMN)	John Whitton	Kiri/Aaron	Wendy	Data frozen, Jan, 2011
	CCSS MHQ Data Error Check	John/Chris	John	Kumar/Wendy	Complete
	Creation of Web based Public Use Tables	Jim Gurney	Kayla	John	Complete - Tables on St Jude Website
	"Toolbox" Variable Creation	John Whitton	John	Pam/Kayla/Kristy	Ongoing
	Documentation of All Data Sets	John Whitton	Pam/Kayla	Wendy	Developing comprehensive documentation for Questionnaires
	Creation of Chest RT/ Breast Cancer 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/Lu Lu	Kiri	Data frozen, June, 2014

# **Publications and Manuscripts**

# Peer-reviewed Manuscripts

- 1. Rauck AM, Green DM, Yasui Y, Mertens A, Robison LL. Marriage in the survivors of childhood cancer: a preliminary description from the Childhood Cancer Survivor Study. *Med Pediatr Oncol*, 1999; 33(1): 60-3.
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- 294. Morton LM, Sampson JN, Armstrong GT, Chen T, Hudson MM, Karlins E, Dagnall CL, Li SA, Wilson CL, Srivastava DK, Liu W, Kang G, Oeffinger KC, Henderson TO, Moskowitz CS, Gibson TM, Merino DM, Wong JR, Hammond S, Neglia JP, Turcotte LM, Miller J, Bowen L, Wheeler WA, Leisenring WM, Whitton JA, Burdette L, Chung C, Hicks BD, Jones K, Machiela MJ, Vogt A, Wang Z, Yeager M, Neale G, Lear M, Strong LC, Yasui Y, Stovall M, Weathers RE, Smith SA, Howell R, Davies SM, Radloff GA, Onel K, Gonzalez A, Inskip PD, Rajaraman P, Fraumeni JF, Bhatia S, Chanock SJ, Tucker MA, Robison LL. Genome-wide association study identifies susceptibility loci that modify radiation-related risk for breast cancer after childhood cancer. J Natl Cancer Inst, 2017; (In Press).
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## Manuscripts Submitted for Publication

- 1. Claridy M, Hudson MM, Steele J, Mitby PA, Leisenring W, Smith S, Robison LL, Mertens AC. Where, When, and Why Adult Survivors of Childhood Cancer Seek Internet-based Health Information. Submitted
- 2. 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
- 3. Devine KA, Mertens AC, Whitton JA, Wilson CL, Ness KK, Gilleland J, Leisenring W, Armstrong GT, Oeffinger KC, Robison LL, Krull KR. Psychological Functioning and Physical Activity Among Adolescent-Aged Survivors of Early Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). Submitted
- 4. Gibson TM, Li C, Armstrong GT, Srivastava D, Leisenring WM, Mertens A, Brinkman TM, Diller L, Nathan PC, Hudson MM, Robison LL. Lack of Concern about Future Health and Subsequent Cancers in Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- 5. Goldsby RE, Stratton KL, Raber S, Ablin A, Li L, Strong LC, Oeffinger KC, Sklar CA, Armstrong GT, Robison LL, Bhatia S, Leisenring WM. Long-term sequelae in survivors of childhood leukemia with Down syndrome: A report from the Childhood Cancer Survivor Study. Submitted
- Levine JM, Whitton JA, Ginsberg JP, Green DM, Leisenring WM, Stovall M, Robison LL, Armstrong GT, Sklar CA. Non-Surgical Premature Menopause in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- 7. Nipp RD, Kirchhoff AC, Fair D, Rabin J, Hyland K, Kuhlthau K, Perez GK, Armstrong GT, Nathan PC, Oeffinger K, Leisenring W, Park ER. Financial Burden in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Submitted
- 8. Weinstein AG, Henrich CC, Armstrong GT, Stratton K, Leisenring W, King T, Krull KR. The Role of Positive Psychological Outcomes in Future Health Perception and Mental Health Problems: A Report from the Childhood Cancer Survivor Study. Submitted
- Wells EM, Ullrich NJ, Seidel K, Leisenring W, Sklar CA, Armstrong GT, Diller L, King A, Krull KR, Neglia JP, Stovall M, Whelan K, Robison LL, Packer RJ. Longitudinal Assessment of Neurologic Sequelae in Survivors of Childhood Central Nervous System Malignancies: A Report from the Childhood Cancer Survivor Study (CCSS) Cohort. Submitted
- 10. Yuan Y, Zhou QM, Li B, Cai H, Chow EJ, Armstrong GT. A Threshold-free Prospective Prediction Accuracy Measure for Censored Time to Event Data. Submitted

# Childhood Cancer Survivor Study (CCSS) Presented Abstracts 1997 – 2017

Year	Number
2017	20
2016	14
2015	25
2014	18
2013	16
2012	14
2011	13
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

# 2017

A1701 Tonorezos ES, Meacham L, Chou J, Moskowitz CS, Leisenring WM, Friedman DN, Sklar CA, Dilley KJ, Hudson M, Mertens A, Armstrong GT, Robison LL, Oeffinger KC. Increased late mortality in underweight survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. ASCO Survivorship Symposium, January 2017, poster presentation.

<u>A1702</u> Weil B, Madenci A, Liu Q, Gibson T, Yasui Y, Neglia J, Leisenring W, Howell R, Tonorezos E, Friedman D, Tinkle C, Diller L, Armstrong GT, Oeffinger K, Weldon C. Infection related late mortality in survivors of childhood cancer with asplenia or radiation-induced hyposplenism: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, June 2017, poster presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

A1703 Madenci AL, Weil BR, Liu Q, Gibson TM, Yasui Y, Leisenring WM, Howell RM, Tinkle C, Nekhlyudov L, Diller L, Armstrong GT, Oeffinger KC, Weldon CB. Long-term incidence of venous thromboembolism (VTE) among survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, June 2017, poster presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, poster presentation.

A1704 Gibson TM, Mostoufi-Moab S, Stratton K, Barnea D, Chow EJ, Donaldson SS, Howell R, Hudson MM, Leisenring WM, Mahajan A, Nathan PC, Ness KK, Sklar CA, Tonorezos ES, Weldon CB, Wells EM, Yasui Y, Armstrong GT, Robison LL, Oeffinger KC. Temporal trends in chronic disease among survivors of childhood cancer diagnosed across three decades: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, June 2017, oral presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

<u>A1705</u> Bates JE, Liu Q, Yasui Y, Howell RM, Mulrooney DA, Dhakal S, Leisenring WM, Indelicato DJ, Gibson TM, Armstrong GT, Oeffinger KC, Constine LS. Age-associated vulnerability to treatment-related late cardiotoxicity: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, June 2017, oral presentation.

A1706 Salloum R, Chen Y, Yasui Y, Packer R, Leisenring W, Wells E, King A, Howell R, Gibson TM, Krull KR, Robison LL, Oeffinger KC, Fouladi M, Armstrong GT. Temporal trends in late-onset morbidity and mortality after medulloblastoma diagnosed across three decades: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, June 2017, oral presentation.

A1707 Henderson TO, Nathan PC, Whitton J, Leisenring W, Neglia J, Fowler B, Arnold MA, Howell RM, Robison LL, Armstrong GT, Alexander K. Human papillomavirus (HPV)-associated malignancies as subsequent malignant neoplasms (SMN) in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, June 2017, poster presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, poster presentation.

A1708 Brooke RJ, Chemaitilly W, Wilson CL, Krasin MJ, Li Z, Im C, Morton LM, Wu G, Wang Z, Chen W, Howell RM, Armstrong GT, Bhatia S, Chanock SJ, Zhang J, Green DM, Sklar CA, Hudson MM, Robison LL, Yasui Y. A high-risk genetic profile for premature menopause (PM) in childhood cancer survivors (CCS) exposed to gonadotoxic therapy: a report from the St. Jude Lifetime Cohort (SJLIFE) and Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, June 2017, oral presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

A1709 Dietz AC, Seidel K, Leisenring WM, Mulrooney DA, Tersak JM, Glick RD, Burnweit CA, Green DM, Diller L, Oeffinger KC, Smith SA, Howell RM, Stovall M, Robison LL, Armstrong GT, Termuhlen AM. Solid organ transplant after treatment for childhood cancer: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, June 2017, poster presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

<u>A1710</u> Fejien EA, Leisenring WM, Stratton KL, Ness KK, Van der Pal HJH, van Dalen EC, Armstrong GT, Aune GJ, Green DM, Hudson MM, Loonen J, Oeffinger KC, Robison LL, Yasui Y, Kremer LC, Chow EJ. Equivalence ratios for late cardiomyopathy after doxorubicin and other anthracyclines/anthraquinones. 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, poster presentation.

<u>A1711</u> Huang I, Hyun G, Gibson TM, Yasui Y, Leisenring W, Armstrong GT, Hudson MM, Robison LL, Krull KR. The Impact of administration modes on patient-reported outcome survey: a report from the Childhood Cancer Survivor Study (CCSS). 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

<u>A1712</u> Lupo PJ, Brown AL, Kamdar KY, Belmont JW, Armstrong GT, Leisenring WM, Oeffinger KC, Okcu F, Robison LL, Scheurer ME, Yasui Y, Bhatia S. DNA methylation and obesity in survivors of pediatric Acute Lymphoblastic Leukemia (ALL): a report from the Childhood Cancer Survivor Study (CCSS). 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, poster presentation.

A1713 Moskowitz CS, Chou JF, Sklar CA, Barnea D, Ronckers CM, Friedman DN, Neglia JP, Turcotte L, Howell RM, Henderson TO, Armstrong GT, Leisenring WM, Robison LL, van Leeuwen FE, Pike MC, Oeffinger KC. Radiation-associated breast cancer and hormone exposure: a report from the Childhood Cancer Survivor Study (CCSS). 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

A1714 Zheng DJ, Krull KR, Chen Y, Diller L, Yasui Y, Brouwers P, Howell R, Lai JS, Balsamo L, Oeffinger KC, Robison LL, Armstrong GT, Kadan-Lottick NS. Long-term psychological outcomes in survivors of neuroblastoma: a report from the Childhood Cancer Survivor Study. 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

A1715 Morton LM, Veiga L, Curtis RE, Withrow D, Inskip PD, Oeffinger KC, Moskowitz CS, Neglia JP, Turcotte LM, Howell R, Weathers RE, Smith SA, Henderson TO, Leisenring WM, Whitton JA, Gibson TM, Robison LL, Armstrong GT, Berrington A. Risk of subsequent breast cancer after radiotherapy according to hormone-receptor status: a nested case-control study in Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, June 2017, poster presentation.

<u>A1716</u> Foster RH, Hayashi R, Liu W, Mohrmann C, Howell RM, Smith SA, Gibson TM, Srivastava DK, Green DM, Oeffinger KC, Leisenring WM, Robison LL, Armstrong GT, Krull KR, Hardy KK. Social outcomes among adolescent long-term survivors of Wilms tumor: a report from the Childhood Cancer Survivor Study. International Society of Paediatric Oncology Annual Meeting, October 2017, submitted.

A1717 Foster RH, Hayashi R, Wang M, Liu W, Mohrmann C, Howell RM, Smith S, Gibson TM, Srivastava K, Green DM, Oeffinger K, Leisenring W, Robison LL, Armstrong GT, Krull K Hardy KK. Psychological and educational outcomes among adolescent survivors of Wilms tumor: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, June 2017, poster presentation; 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, poster presentation.

A1718 Tonorezos ES, Meacham L, Chou JF, Moskowitz CS, Leisenring WM, Freidman D, Sklar CA, Dilley KJ, Hudson M, Mertens A, Armstrong GT, Robison LL, Oeffinger KC. Risk of increased mortality in underweight survivors: a report from the Childhood Cancer Survivor Study. 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2017, oral presentation.

<u>A1719</u> Bates JE, Howell RM, Liu Q, Yasui Y, Mulrooney DA, Dhakal S, Leisenring WM, Indelicato DJ, Gibson TM, Armstrong GT, Oeffinger KC, Constine LS. Volumetric dose-effect analysis of late cardiotoxicity: a report from the Childhood Cancer Survivor Study (CCSS). American Society for Radiation Oncology Annual Meeting, oral presentation, September 2017.

<u>A1720</u> Mueller S, Chen Y, Yasui Y, Fullerton HJ, Howell R, Oeffinger K, Robison LL, Armstrong GT, Krull KR. Impact of stroke and stroke recurrence on late mortality as well as psychological and socioeconomic outcomes in childhood cancer survivors. Pediatric Neuro-Oncology Basic and Translational Research Conference, June 2017, poster presentation.

# 2016

A1601 Vuotto SC, Brinkman TM, Li C, Lown A, Marchak JG, Srivastava D, Nathan PC, Robison LL, Armstrong GT, Krull KR. The impact of alcohol consumption on neurocognitive dysfunction in adult survivors of childhood cancer. 44<sup>th</sup> International Neuropsychological Society Annual Meeting, February 2016, oral presentation.

<u>A1602</u> Fair D, Kirchhoff AC, Nipp P, Leisenring W, Oeffinger K, Armstrong GT, Robison LL, Park E. How costs of healthcare affect utilization in the Childhood Cancer Survivor Study. ASCO Cancer Survivorship Symposium, January 2016, poster presentation.

<u>A1603</u> Keske R, Armstrong GT, Davine J, McDonald A, Gibson T, Daniel C, Mertens A, Marghoob A, Geller A. Advancing Survivors' Knowledge (ASK) About Skin Cancer Study: a randomized intervention within the Childhood Cancer Survivor Study (CCSS). ASCO Cancer Survivorship Symposium, January 2016, poster presentation.

<u>A1604</u> D'Agostino N, Edelstein K, Zhang N, Recklitis C, Srivastava K, Leisenring W, Robison LL, Armstrong GT, Krull KR. Predicting patterns of distress in adult survivors of childhood cancer: a latent profile analysis from the Childhood Cancer Survivor Study. ASCO Cancer Survivorship Symposium, January 2016, poster presentation.

A1605 Morton LM, Sampson JN, Armstrong GT, Chen T, Hudson MM, Karlins E, Dagnall CL, Li S, Wilson CL, Srivastava K, Liu W, Kang G, Oeffinger KC, Henderson TO, Moskowitz CS, Gibson TM, Merino DM, Wong JR, Hammond S, Neglia JP, Turcotte LM, Miller J, Bowen L, Wheeler WA, Leisenring WM, Whitton JA, Burdette L, Chung C, Hicks BD, Jones K, Machiela MJ, Vogt A, Wang Z, Yeager M, Neale G, Lear M, Strong LC, Yasui Y, Stovall M, Weathers RE, Smith SA, Howell R, Davies SM, Radloff GA, Berrington de González A, Inskip PD, Rajaraman P, Fraumeni JF Jr., Bhatia S, Chanock SJ, Tucker MA, Robison LL. Genomewide association study identifies two susceptibility loci that modify radiation-related risk for breast cancer after childhood cancer: a report from the Childhood Cancer Survivor Study and St. Jude Lifetime cohort. American Association of Cancer Research, April 2016, oral presentation.

A1606 Morton LM, Sampson JN, Bhatia S, Hudson MM, Chen TH, Neglia JP, Yasui Y, Karlins E, Dagnall CL, Gibson TM, Wilson CL, Srivastava DK, Liu W, Kang G, Weathers RE, Smith SA, Tucker MA, Robison LL, Chanock SJ, Armstrong GT. Genome-wide association study of meningioma as a subsequent neoplasm: a report from the Childhood Cancer Survivor Study (CCSS) and St. Jude Lifetime cohort (SJLIFE). American Society of Clinical Oncology Annual Meeting, June 2016, oral presentation.

<u>A1607</u> Turcotte LM, Yasui Y, Liu Q, Hammond S, Arnold MA, Howell RM, Gibson TM, Leisenring WM, Armstrong GT, Robison LL, Neglia JP. Changing patterns of subsequent malignancies in the Childhood Cancer Survivor Study cohort. American Society of Clinical Oncology Annual Meeting, June 2016, oral presentation.

A1608 Oeffinger KC, Ford J, Moskowitz CS, Chou JF, Henderson TO, Hudson MM, Diller L, McDonald A, Ford J, Mubdi NZ, Rinehart D, Vukadinovich C, Gibson TM, Anderson N, Elkin EB, Garret K, Rebull M, Armstrong GT. The EMPOWER Study: promoting breast cancer screening: a randomized controlled trial (RCT) in the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2016, oral presentation.

A1609 Gibson TM, Li C, Armstrong GT, Srivastava DK, Leisenring WM, Mertens A, Brinkman TM, Diller L, Nathan PC, Hudson MM, Robison LL. Patient-reported levels of concern in the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2016, poster presentation.

<u>A1610</u> Levine JM, Armstrong GT, Ginsberg J, Green DM, Leisenring WM, Robison LL, Stovall M, Whitton J, Sklar CA. Non-surgical premature menopause (NSPM) in the Childhood Cancer Survivor Study (CCSS): prevalence, risk factors, and reproductive outcomes. American Society of Clinical Oncology Annual Meeting, June 2016, oral presentation.

A1611 Machiela MJ, Karlins E, Zhou W, Khan J, Ballet S, Lapouble E, Laurence V, Michon J, Pierron G, Mirabello L, Morton L, Armstrong GT, Robison LL, Bhatia S, Hoover R, Tucker MA, Tirode F, Delattre O, Chanock SJ. Genome-wide association study identifies new susceptibility regions associated with Ewing sarcoma risk. The American Society of Human Genetics, October 2016, poster presentation.

A1612 Moskowitz CS, Chou JF, Barnea D, Sklar CA, Leisenring WM, Neglia JP, Turcott L, Howell RM, Freidman DN, Henderson TO, Ronckers CM, van Leeuwen F, Pike MC, Armstrong GT, Oeffinger KC. Gonadal hormone exposure and radiation-associated breast cancer risk: a report from the Childhood Cancer Survivor Study. European Symposium on Late Complications after Childhood Cancer, September 2016, Poster presentation.

<u>A1613</u> Turcotte L, Liu Q, Yasui Y, Hammond S, Howell R, Gibson TM, Leisenring WM, Armstrong GT, Robison LL, Neglia J. Therapeutic modifications and changing patterns of subsequent neoplasms in the Childhood Cancer Survivor Study. European Symposium on Late Complications after Childhood Cancer, September 2016, oral presentation.

A1614 Ehrhardt MJ, Chen Y, Sandlund JT, Bluhm EC, Hayashi R, Leisenring WM, Metzger M, Ness KK, Krull KR, Oeffinger KC, Robison LL, Yasui Y, Armstrong GT, Hudson MM, Mulrooney DA. Estimated late health outcomes in children diagnosed with B-cell non-Hodgkin lymphoma treated with contemporary LMB chemotherapy: a report from the Childhood Cancer Survivor Study (CCSS). Annual American Society of Hematology, December 2016, poster presentation.

#### 2015

A1501 Park ER, Kirchhoff AC, Perez GK, Leisenring W, Weissman JS, Donelan K, Hyland K, Armstrong GT, Robison LL, Kuhlthau KA. Childhood Cancer Survivor Study participants' health insurance coverage experiences. 36th Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine, April 2015, poster presentation.

A1502 Buchbinder D, Oeffinger KC, Franco-Villalobos C, Yasui Y, Alderfer MA, Armstrong GT, Casillas J, Ford J, Krull KR, Leisenring W, Recklitis C, Robison LL, Zeltzer LK, Lown EA. Tobacco use behaviors of siblings of childhood cancer survivors: a report from the Childhood Cancer Survivor Study. 28th Annual Meeting of American Society of Pediatric Hematology/Oncology, May 2015, poster presentation.

A1503 Gibson TM, Liu W, Armstrong GT, Srivastava K, Hudson MM, Leisenring WM, Mertens AC, Klesges RC, Oeffinger KC, Nathan PC, Robison LL. Longitudinal smoking patterns in survivors of childhood cancer: a Childhood Cancer Survivor Study (CCSS) update. American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation, 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster presentation.

A1504 Ness KK, Hudson MM, Jones KE, Leisenring WM, Stovall M, Green DM, Neglia JP, Henderson TO, Casillas J, Ford JS, Effinger KE, Oeffinger KC, Armstrong GT, Robison LL, Nathan PC. Temporal trends in health status among adults in the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation, 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster discussion session.

A1505 Bowers DC, Moskowitz CS, Chou JF, Mazewski CM, Neglia J, Armstrong GT, Leisenring WM, Robison LL, Oeffinger KC. Morbidity and Mortality associated with subsequent meningioma among Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, oral presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1506 D'Agostino NM, Edelstein K, Zhang N, Recklitis CJ, Brinkman TM, Srivastava DK, Leisenring WM, Robison LL, Armstrong GT, Krull KR. Patterns and predictors of psychological distress in adult survivors of childhood cancer: a Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster presentation.

<u>A1507</u> Perez G, Kirchhoff A, Krull K, Leisenring W, Recklitis C, Armstrong GT, Nathan P, Robison LL, Kuhlthau K, Park E. Mental health care insurance coverage, utilization and perceived value among childhood cancer survivors: a report from the Childhood Cancer Survivor Study (CCSS). 2015 World Congress of Psycho-Oncology, July 2015, poster presentation.

<u>A1508</u> Bhatia S, Liu Q, Leisenring WM, Ness KK, Gibson TM, Robison LL, Armstrong GT, Yasui Y. Long-term outcomes by race/ethnicity in the Childhood Cancer Survivor Study (CCSS) Cohort. American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation.

A1509 Mostoufi-Moab S, Seidel K, Leisenring WM, Armstrong GT, Oeffinger KC, Green DM, Stovall M, Meacham LR, Ginsberg J, Robison LL, Sklar CA. Endocrine disorders in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1510 Mueller EL, Hutchinson R, Goodman P, Leisenring WM, Sklar CA, Hudson MM, Ness KK, Armstrong GT, Robison LL, Stovall M, Oeffinger KC, Nathan PC. Long-term risks for chronic medical conditions and premature mortality in survivors of pediatric soft tissue sarcoma: a Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, oral presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster presentation.

A1511 Brinkman, TM, Vuotto, SC, Li C, Oeffinger KC, Green DM, Patel S, Srivastava DK, Stovall M, Ness KK, Armstrong GT, Robison LL, Krull KR. Impact of chronic disease on psychological distress in adult survivors in the Childhood Cancer Survivor Study (CCSS). 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1512 Brinkman, TM, Li C, Vannatta KA, Marchak JG, Lai J, Kimberg C, Prasad PK, Di C, Srivastava DK, Robison LL, Armstrong GT, Krull KR. Emotional and behavioral phenotypes of adolescent survivors in the Childhood Cancer Survivor Study (CCSS). 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster presentation.

<u>A1513</u> Leisenring WM, Whitton J, Neglia JP, Green DM, Gibson T, Stovall M, Hudson MM, Robison LL, Armstrong GT, Yasui Y, Mertens AC. Temporal changes in treatment exposures in the Childhood Cancer Survivor Study (CCSS). 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1514 Effinger KE, Fisher PG, Ness KK, Krull K, Marina N, Stovall M, Oeffinger KC, Armstrong GT, Robison LL, Nathan PC, Leisenring WM, Hudson MM. Longitudinal Evaluation of Health Status and Chronic Conditions in Aging Pediatric Astrocytoma Survivors: A Childhood Cancer Survivor Study (CCSS) Report. American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1515 Schapiro M, Hayashi R, Liu W, Srivastava DK, Jeffe D, Perkins S, Armstrong GT, Robison LL, Stovall M, Leisenring W, Krull K. Neurocognitive, emotional, and quality of life outcomes in long-term survivors of rhabdomyosarcoma: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster presentation.

A1516 Madenci AL, Fisher S, Diller L, Goldsby R, Leisenring W, Oeffinger KC, Robison LL, Sklar C, Stovall M, Weathers RE, Armstrong GT, Yasui Y, Weldon CB. Intestinal obstruction in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, poster presentation.

A1517 Armstrong GT, Yasui Y, Chen Y, Leisenring W, Gibson TM, Mertens A, Stovall M, Hudson MM, Oeffinger KC, Bhatia S, Krull K, Nathan PC, Neglia J, Green D, Robison LL. Reduction in late mortality among five-year survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, June 2015, plenary session presentation; 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1518 Gilleland-Marchak J, Seidel KD, Mertens AC, Ritenour CWM, Wasilewski-Masker K, Leisenring W, Sklar CA, Ford J, Krull KR, Stovall M, Robison LL, Armstrong GT, Meacham LR. Perceptions of risk for infertility among male survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

A1519 Daniel C, Armstrong GT, Keske R, Davine J, McDonald A, Sprunck-Harrild K, Coleman C, Haneuse S, Mertens A, Emmons K, Marghoob A, Elkin E, Dusza S, Robison LL, Gibson T, Geller A. Advancing Survivors' Knowledge (ASK) About Skin Cancer Study: a randomized intervention within the Childhood Cancer Survivor Study (CCSS). New England Cancer Survivorship Research Conference: Focus on Intervention, April 2015, poster presentation.

<u>A1520</u> de Blank P, Fisher MJ, Lu L, Leisenring WM, Ness KK, Sklar CA, Stovall M, Vukadinovich CM, Robison LL, Armstrong GT, Krull KR. The Impact of vision loss among survivors of childhood central nervous system astroglial tumors. Children's Tumor Foundation NF Conference, June 2015, oral presentation.

<u>A1521</u> Mertens A, Whitton J, Gibson TM, Stovall M, Hudson MM, Robison LL, Armstrong GT, Yasui Y, Leisenring WM, Green D. Temporal changes in treatment exposures in the Childhood Cancer Survivor Study (CCSS). Children's American Society of Clinical Oncology Annual Meeting, June 2015, poster presentation.

A1522 Feijen EAM, Stratton KL, Ness KK, Van der Pal HJH, Caron HN, Armstrong GT, Green D, Hudson MM, Leisenring W, Oeffinger KC, Robison LL, Stovall M, Kremer LCM, Chow EJ. Equivalence ratio for daunorubicin to doxorubicin in relation to late heart failure. 14<sup>th</sup> International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

<u>A1523</u> Yeh JM, Hanmer J, Ward Z, Leisenring W, Armstrong GT, Hudson M, Stovall M, Robison LL, Oeffinger K, Diller L. Health utility scores in childhood cancer survivors: insights from the Childhood Cancer Survivor Study. 37th Annual Meeting of the Society of Medical Decision Making, October 2015, oral presentation.

A1524 Nipp RD, Kirchhoff AC, Fair DB, Kuhlthau K, Hyland K, Perez GK, Armstrong GT, Nathan PC, Oeffinger KC, Leisenring WM, Park ER. Financial burden among survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. ASCO Palliative Care in Oncology Symposium, October 2015, poster presentation.

A1525 Jacola LM, Edelstein K, Lui W, Pui CH, Hayashi R, Kadan-Lottick N, Srivastava D, Henderson T, Robison LL, Armstrong GT, Krull KR. Cognitive, behavior and academic problems in adolescent survivors of childhood acute lymphoblastic leukemia (ALL): a report from the Childhood Cancer Survivor Study. 57th American Society of Hematology Annual Meeting and Exposition, December 2015, oral presentation.

#### 2014

A1401 Effinger KE, Leisenring W, Oeffinger KC, Hudson MM, Ness KK, Marina N, Castellino SM, Stovall M, Armstrong GT, Robison LL, Sainani K, Whittemore AS. Longitudinal Evaluation of health status in aging pediatric Hodgkin lymphoma survivors: report from the Childhood Cancer Survivor Study. 2nd International Symposium on Childhood, Adolescent and Young Adult Hodgkin Lymphoma, May 2014, oral presentation.

<u>A1402</u> Zhou R, Ng A, Withers R, McDonald A, Leisenring W, Goodman P, Stovall M, Armstrong GT, Robison LL, Hodgson D. The evolution of pediatric Hodgkin lymphoma therapy: contemporary protocols significantly reduce radiation exposure of normal tissues. 2nd International Symposium on Childhood, Adolescent and Young Adult Hodgkin Lymphoma, May 2014, oral presentation.

A1403 Suh E, Stratton KL, Ford JS, Nathan PC, Freyer DR, McNeer J, Stock W, Leisenring W, Stovall M, Krull KR, Sklar CA, Armstrong GT, Oeffinger KC, Robison LL, Henderson TO. Chronic health conditions and premature mortality in long-term survivors of cancer diagnosed between the ages of 15 and 20 years: a report from the Childhood Cancer Survivor Study. 7<sup>th</sup> Biennial Cancer Survivorship Research Conference, June 2014, poster presentation.

A1404 Chow EJ, Chen Y, Armstrong GT, Border WL, Meacham LR, Mulrooney DA, Oeffinger KC, Sklar CA, Stovall M, Robison LL, Yasui Y. Individual risk prediction of major cardiovascular events after cancer: a Childhood Cancer Survivor Study report.

American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation.

A1405 Jones LW, Liu Q, Armstrong GT, Ness KK, Yasui Y, Devine K, Tonorezos E, Soares-Miranda L, Sklar CA, Douglas PS, Robison LL, Oeffinger KC. Exercise and risk of major cardiovascular events in adult survivors of childhood Hodgkin lymphoma: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation, European Symposium on Late Complications after Childhood Cancer (ESLCCC), September 2014, poster presentation.

A1406 King AA, Perkins SM, Seidel K, Di C, Leisenring WM, Krull KR, Green DM, Armstrong GT, Zelter LK, Wells E, Stovall M, Ullrich N, Oeffinger KC, Robison LL, Packer R. Health and functional status of long term adult medulloblastoma/PNET survivors: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation.

A1407 Henderson TO, Moskowitz CS, Onel K, Bradbury AR, Friedman DN, Chou JF, Bhatia S, Strong LC, Neglia JP, Stovall M, Leisenring WM, Robison LL, Armstrong GT, Diller L, Oeffinger KC. Breast cancer in childhood cancer survivors not treated with chest-directed radiation in the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, May 2014, oral presentation.

<u>A1408</u> Moskowitz CS, Malhotra J, Chou JF, Wolden SL, Stovall M, Armstrong GT, Leisenring WM, Neglia JP, Robison LL, Oeffinger KC. Breast cancer following spinal radiotherapy for a childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation.

<u>A1409</u> Huang IC, Brinkman TM, Armstrong GT, Robison LL, Krull KR. Mediating role of emotional symptoms on assessment of health-related quality of life of adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation.

A1410 Dietz AC, Chen Y, Ness KK, Hagood JS, Chow EJ, Yasui Y, Stovall M, Neglia JP, Oeffinger KC, Mertens AC, Robison LL, Armstrong GT, Mulrooney DA. Risk and Impact of pulmonary complications in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation, 14th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2015, oral presentation.

<u>A1411</u> Turcotte LM, Whitton J, Friedman DL, Hammond S, Armstrong GT, Leisenring WM, Robison LL, Neglia JP. Subsequent neoplasms in the 5th and 6th decades of life in the Childhood Cancer Survivor Study cohort. American Society of Clinical Oncology Annual Meeting, May 2014, poster presentation.

<u>A1412</u> Cox CL, Leisenring WM, Stratton KL, Steen BD, Ogg SW, Robison LL, Hudson MM. Combining eHealth and mHealth strategies to promote risk-based cardiovascular screening in adult survivors of childhood cancer. 7th Biennial Cancer Survivorship Research Conference, June 2014, oral presentation.

A1413 Wells EM, Ullrich NJ, Seidel K, Leisenring W, Sklar C, Armstrong GT, Diller L, King A, Krull K, Neglia JP, Stovall M, Whelan K, Robison LL, Packer RJ. Neurologic sequelae in brain tumor survivors in the Childhood Cancer Survivor Study (CCSS). 16<sup>th</sup> International Symposium on Pediatric Neuro-Oncology (ISPNO), June 2014, oral presentation.

<u>A1414</u> Hudson MM, Leisenring WM, Stratton K, Tinner N, Steen B, Ogg S, Barnes L, Robison LL, Cox CL. Increasing cardiovascular screening in at-risk adult survivors of pediatric malignancies: a randomized controlled trial. American Society of Clinical Oncology Annual Meeting, May 2014, oral presentation.

A1415 Cox C, Leisenring W, Stratton K, Steen B, Ogg S, Tinner N, Robison LL, Hudson MM. Motivating behavior change in adult survivors of childhood cancer: a randomized controlled trial (RCT) from the Childhood Cancer Survivor Study (CCSS). 142<sup>nd</sup> American Public Health Association Annual Meeting and Exposition, November 2014, oral presentation.

A1416 Tsui K, Gajjar A, Li C, Srivastava D, Broniscer A, Wetmore C, Kun LE, Merchant TE, Ellison DW, Orr B, Boop FA, Klimo Jr P, Ross JD, Robison LL, Armstrong GT. Subsequent neoplasms in survivors of central nervous system tumors: risk after modern multi-modal therapy. 16<sup>th</sup> International Symposium on Pediatric Neuro-Oncology (ISPNO), June 2014, poster presentation.

<u>A1417</u> Feijen EAM, Stratton KL, Ness KK, Van der Pal HJH, Caron HN, Armstrong GT, Green D, Hudson MM, Leisenring W, Oeffinger KC, Robison LL, Stovall M, Kremer LCM, Chow EJ. Equivalence ratio for daunorubicin to doxorubicin in relation to late heart failure. European Symposium on Late Complications after Childhood Cancer (ESLCCC), September 2014, poster presentation.

A1418 Ford JS, Chou JF, Moskowitz C, Candela J, Henderson TO, Nathan P, Hudson MM, Leisenring W, Robison LL, Armstrong GT, Oeffinger KC. Cancer treatment summaries and long-term childhood cancer survivors: a report from the Childhood Cancer Survivor Study. European Symposium on Late Complications after Childhood Cancer (ESLCCC), September 2014, poster presentation.

#### 2013

A1301 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.

A1303 Daniel CL, Kohler C, Nathan P, Oeffinger K, Stratton K, Leisenring W, Whelan K, Waterbor J, Henderson T, Armstrong GT, 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.

A1304 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.

A1305 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.

A1306 Wilson CL, Leisenring WL, Oeffinger K, Nathan PC, Wasilewski-Masker 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; 13<sup>th</sup> 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. 13<sup>th</sup> International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, poster presentation.

A1309 Gawade PL, Oeffinger KC, Sklar CA, Green DM, Krull KK, Chemaitilly W, Stovall M, Leisenring WM, Robison LL, Ness KK. Pre-pregnancy lifestyle factors, psychological distress and adverse pregnancy outcomes among female survivors in the Childhood Cancer Survivor Study (CCSS) cohort. 13<sup>th</sup> International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, oral presentation.

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). 13<sup>th</sup> International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, oral presentation.

<u>A1311</u> 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, poster presentation.

<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, oral presentation.

A1314 Van den Berg A, Cozen W, Li D, Timofeeva M, Diepstra A, Hazelet D, Delahaye-Sourdeix M, Edlund CK, Rostgaard K, Van Den Berg DJ, Glaser SL, Robison LL, Mack TM, Ghesquieres H, Salle G, Bhatia S, Strong LC, Hwang AE, Nieters A, Smedby K, de Sanjose S, Cortessis VK, Lightfoot T, Roman E, Becker N, Foretova L, 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. TCF3/E2A (19p13.3) is a novel Hodgkin lymphoma susceptibility locus: a meta-GWAS study from the Interlymph Hodgkin lymphoma consortium. 9<sup>th</sup> International Symposium on Hodgkin Lymphoma, October 2013, oral presentation.

<u>A1315</u> Cox CL, Nolan V, Leisenring W, Yasui Y, Ogg S, Neglia J, Ness K, Robison LL. Health perceptions, behavior, and medical care utilization: Links to mortality in adult survivors of childhood cancer. American Public Health Association, November 2013, oral presentation.

A1316 Ritenour CWM, Seidel KD, Leisenring W, Mertens A, Wasilewski-Masker K, Shnorhavorian M, Sklar CA, Whitton JA, Stovall M, Constine LS, Armstrong GT, Robison LL, Meacham L. Sexual health in male childhood cancer survivors: a Report from the Childhood Cancer Survivor Study (CCSS). 13<sup>th</sup> International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2013, poster presentation; Sexual Medicine Society of North America, November 2013, poster presentation.

<u>A1317</u> Effinger KE, Leisenring W, Oeffinger KC, Hudson MM, Ness KK, Marina N, Stovall M, Armstrong GT, Robison LL, Sainani K, Whittemore AS. Longitudinal evaluation of health status in aging pediatric Hodgkin lymphoma survivors: report from the Childhood Cancer Survivor Study. American Society of Hematology-Oncology, December 2013, oral presentation.

#### 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, 12<sup>th</sup> 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. 12<sup>th</sup> International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, June 2012, oral presentation.

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

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

A1205 Shnorhavorian M, Leisenring W, Goodman P, Friedman D, Stovall M, Meacham LR, Chow E, Sklar CA, Diller L, Ferrer F, Armstrong GT, Robison LL. Genito-urinary second malignant neoplasms in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). 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.

<u>A1206</u> 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; 12<sup>th</sup> 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

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

A1102 Kinahan KE, Sharp LK, Didwania A, Seidel K, Leisenring 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.

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). 50<sup>th</sup> 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 LL, 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.

A1113 Cox CL, Zhu L, Steen BD, Hudson MM, Robison LL, Oeffinger KC. Survivor profiles of health-related concerns, fear and motivation predict participation in medical surveillance: the Childhood Cancer Survivor Study. American Public Health Association 139<sup>th</sup> 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, 2010; 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 LL, 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. Chronic medical conditions, health status, and health care practices at 25 years in 5-year survivors of Wilms tumor: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology Annual Meeting, June 2010; 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 (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, June 2010, platform presentation.

A1008 Ford J, Kawashima T, Whitton J, Leisenring W, Laverdière C, Stovall M, Zeltzer L, Randolph-Frye M, Robison LL, 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. Effect of hypothalamic/pituitary radiation exposure in low doses on fertility in female Childhood Cancer Survivor Study (CCSS) participants. American Society of Clinical Oncology Annual Meeting, June 2010, poster presentation.

<u>A1010</u> 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. Association of antidepressant use and 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>A1013</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. SER, June 2010, submitted.

A1014 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 GT, Robison LL, 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>A1015</u> Brackett J, Krull K, Scheurer M, Liu W, Srivastava K, Stovall M, Merchant T, Packer R, Robison LL, 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>A1016</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. 52<sup>nd</sup> 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. 52<sup>nd</sup> American Society of Hematology Annual Meeting and Exposition, December 2010, poster.

<u>A1019</u> 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. 32nd International Lymphoma Epidemiology Consortium, April 2010, oral presentation.

#### 2009

A0901 Nathan PC, Ness KK, Hudson MM, Mahoney M, Ford JS, Landier W, Armstrong GT, 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, June 2009, platform presentation.

A0902 Boukheris H, Neglia JP, Stovall M, Hammond S, Mertens AC, Meadows AT, Donaldson SS,

Armstrong GT, 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.

<u>A0903</u> Bornstein MH, Haynes OM, Leisenring W, Hayashi R, Armstrong GT, Robison LL, 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.

<u>A0904</u> Stuber M, Meeske K, Zebrack B, Krull K, Stratton K, Leisenring W, Robison LL, 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.

<u>A0905</u> 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.

<u>A0906</u> 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, June 2008; American Society of Clinical Oncology Annual Meeting, 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, June, 2008, oral presentation; International Symposium on Pediatric Neuro-Oncology, June 2008; Child Neurology Society, 2008.

<u>A0803</u> 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, June 2008; ISPNO 13<sup>th</sup> Annual Meeting, June 2008.

<u>A0804</u> Ellenberg L, Gioia G, Liu Q, Yasui Y, Packer R, Mertens A, Donaldson S, Kaden-Lottick N, Armstrong GT, 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.

<u>A0805</u> 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, 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, 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, June 2008.

<u>A0808</u> 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, June 2008.

<u>A0809</u> 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, June 2008.

<u>A0810</u> 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, June 2008.

<u>A0811</u> 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, June 2008.

<u>A0812</u> 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, June 2008.

<u>A0813</u> 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, June 2008; 4th Biennial Cancer Survivorship Research Conference, June 2008.

<u>A0814</u> Bornstein MC, Haynes M, Hayashi R, Leisenring W, Armstrong GT, Robison LL, 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, June 2008.

A0815 Henderson T, Rajaraman P, Stovall M, Olive A, Smith S, Mertens A, Meadows A, Neglia J, Whitton J, Inskip P, Robison LL, 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, June 2008; American Society of Clinical Oncology, 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, October 2008, poster presentation.

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

A0818 Castellino SM, Tooze J, Geiger A, Leisenring W, Goodman P, Mertens A, Stovall M, Robison LL, 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, June 2008, oral presentation.

<u>A0819</u> 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, June 2008, oral presentation.

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

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

<u>A0822</u> Mertens AC, Leisenring W, Mitby P, Meadows A, Robison LL, Hudson M. Sun protection behaviour 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, June 2008, platform presentation.

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

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

<u>A0825</u> Cox CL, Mertens A, Hudson M, Whitton J, Montgomery M, Robison LL. Determinants of mammography screening participation in adult female survivors of childhood cancer. 2008 ASCO Breast Cancer Symposium, September 2008, poster presentation.

#### 2007

<u>A0701</u> 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, 2007.

<u>A0702</u> 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.

<u>A0704</u> 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, June 03, 2007.

<u>A0705</u> 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, 2007

<u>A0706</u> 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, 2007

<u>A0707</u> 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, 2007.

<u>A0708</u> 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, 2007.

<u>A0709</u> 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, 2007.

#### 2006

A0601 Baker SK, Leisenring W, Hayashi R, Mertens A, Stovall M, Donaldson S, Robison LL, 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.

<u>A0602</u>. Casillas J, Brooks S, Mertens A, Hudson M, Robison LL, 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.

<u>A0603</u> Henderson T, Whitton J, Hammond S, Stovall M, Meadows A, Mertens A, Neglia J, Robison LL, 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.

<u>A0604</u> 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.

<u>A0605</u> 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.

<u>A0606</u> Lu Q, Tsao JCI, Leisenring W, Robison LL, 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.

<u>A0607</u> 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.

<u>A0610</u> 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.

<u>A0611</u> 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.

<u>A0612</u> 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.

<u>A0613</u> Whelan KF, Kawashima T, Mitby P, Blatt J, Waterbor J, Castleberry R, Sande J, Packer R, Sklar C, Robison LL, Mertens A. Auditory and speech complications on childhood cancer survivors: a report from CCSS. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer, 2006, platform presentation.

A0614 Whelan K, Mertens A, Castleberry R, Mitby P, Kawashima T, Sklar C, Packer R, Waterbor J, Blatt J, Robison LL. Visual complications in childhood cancer survivors: a Childhood Cancer Survivor Study report. American Society of Clinical Oncology, 2006, platform presentation.

#### 2005

A0501 Owen JE, Kawashima T, Myers CD, Lu Q, Zebrack B, Mertens A, Robison LL, 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.

<u>A0502</u> 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.

<u>A0503</u> 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. American Society of Pediatric Hematology-Oncology, May 2005, submitted.

A0505 Oeffinger K, Mertens A, Sklar C, Kawashima T, Hudson M, Meadows A, Marina N, Kadan-Lottick N, Leisenring L, Robison LL. 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.

<u>A0506</u> Mertens A, Yasui Y, Liu Y, Neglia J, Robison LL. 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.

<u>A0507</u> Henderson T, Whitton J, Hammond S, Stovall M, Meadows A, Mertens A, Neglia J, Robison LL, 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.

<u>A0508</u> 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.

<u>A0509</u> 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.

<u>A0510</u> 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.

<u>A0512</u> 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 LL, Inskip P. Second primary thyroid cancer after a first childhood malignancy: a report from the Childhood Cancer Survivor Study. American Association for Cancer Research, 2004, oral presentation.

<u>A0402</u> 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, 2004, poster presentation.

<u>A0403</u> 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, 2004, 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, poster presentation.

<u>A0405</u> 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, 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, 2004, 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), 2004, oral presentation.

A0408 Termuhlen A, Tersak J, Hudson M, Mertens A, Gimpel N, Bleyer W, Yasui Y, Robison LL, 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, poster presentation.

A0411 Sklar C, Mertens A, Mitby P, Whitton J, Stovall M, Mulder J, Green D, Nicholson S, Yasui Y, Robison LL. Premature menopause in survivors of childhood and adolescent cancer: data from the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Research, 2004, oral presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, 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, 2004, oral presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, 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, 2004, poster presentation; 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake), 2004, poster presentation.

<u>A0415</u> 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), 2004, poster presentation.

<u>A0416</u> Mertens A, Riley A, Patenaude A, Bursch B, Robison LL, 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, 2004, poster presentation.

#### 2003

A0301 Neglia J, Inskip P, Liu Y, Yasui Y, Hammond S, Stovall M, Packer R, Meadows A, Mertens A, Robison LL. 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, 2003, oral presentation.

A0302 Brownstein C, Mertens A, Mitby P, Stovall M, Qin J, Heller G, Robison LL, 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, 2003, poster presentation.

<u>A0303</u> Yeazel M, Oeffinger K, Gurney J, Mertens A, Hudson M, Emmons K, Chen H, Robison LL. The cancer screening practices of long-term childhood cancer survivors. American Association for Cancer Research, 2003, poster presentation.

A0304 Perkins J, Yasui Y, Liu Y, Hammond S, Stovall M, Neglia J, Meadows A, Robison LL, 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, 2003, 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, 2003, 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, 2003, 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, 2002, oral presentation.

<u>A0202</u> 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, 2002, poster presentation.

<u>A0203</u> 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, 2002, poster presentation.

<u>A0204</u> Hudson MM, Oeffinger K, Mertens A, Hobbie W, Chen H, Gurney J, Yeazel M, Robison LL. General health status of long-term childhood cancer survivors: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, 2002, oral presentation.

<u>A0205</u> Kadan-Lottick N, Robison LL, 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, 2002, poster presentation.

<u>A0206</u> Oeffinger KC, Mertens A, Sklar C, Yasui Y, Fears T, Stovall M, Robison LL. Obesity in Adult survivors of childhood acute leukemia: a report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology, 2002, poster presentation.

<u>A0207</u> Mertens A, Yasui Y, Liu Y, Stovall M, Hutchinson R, Sklar C, Robison LL. Pulmonary complications in survivors of childhood and adolescent cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology, 2002, 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), 2002, oral presentation.

A0209 Kenney LB, Diller L, Friedman D, Neglia J, Yasui Y, Mertens A, Inskip P, Meadows A, Robison LL. 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), 2002, oral presentation.

<u>A0210</u> Oeffinger K, Mertens A, Hudson M, Castillo J, Gurney J, Yeazel M, Chen H, Robison LL. 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), 2002, oral presentation.

<u>A0211</u> Oeffinger K, Mertens A, Sklar C, Yasui Y, Fears T, Stovall M, Vik T, Robison LL. 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), 2002, oral presentation.

<u>A0212</u> Pang JWY, Friedman DL, Whitton J, Weiss NS, Mertens A, Robison LL. 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), 2002, oral presentation.

A0213 Mertens A, Yasui Y, Liu Y, Stovall M, Hutchinson R, Sklar C, Robison LL. 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), 2002, oral presentation.

<u>A0214</u> Yasui Y, Liu Y, Neglia J, Friedman D, Bhatia S, Meadows A, Mertens A, Whitton J, Robison LL. 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), 2002, oral presentation.

A0215 Mitby P, Robison LL, 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), 2002, 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 LL. 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), 2002, oral presentation.

A0217 Kadan-Lottick N, Robison LL, 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), 2002, oral presentation.

#### 2001

A0101 Sklar C, Mertens A, Mitby P, Qin J, Heller G, Yasui Y, RobisonL 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, 2001, oral presentation.

<u>A0102</u> Green D, Whitton J, Stovall M, Mertens A, Donaldson S, Ruymann F, Pendergrass T, Robison LL. Pregnancy outcome of partners of male survivors of childhood cancer. A report from the Childhood Cancer Survivor Study (CCSS). American Association of Cancer Research, 2001, poster presentation.

<u>A0103</u> Kadan N, Friedman D, Mertens A, Yasui Y, Whitton J, Robison LL, 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, 2001, poster presentation.

<u>A0104</u> Friedman D, Kadan-Lottick N, Liu Y, Mertens A, Robison LL, 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, 2001, poster presentation.

<u>A0105</u> Neglia J, Yasui Y, Mertens A, Friedman D, Hammond S, Donaldson S, Stovall M, Meadows A, Robison LL. 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, 2001, oral presentation.

<u>A0106</u> Gurney JG, Packer R, Punyko J, Sklar C, Kadan-Lottick N, Neglia J, Nicholson S, Wolden S, McNeil E, Mertens A, Robison LL. Non-neurological late effects among childhood brain tumor survivors: a preliminary analysis from the Childhood Cancer Survivor Study. Society for Neuro-Oncology, 2001, 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, 2001, poster presentation.

<u>A0108</u> Mulvihill JJ, Strong LC, Robison LL. Genetic disease in offspring of survivors of childhood and adolescent cancer. American Society of Human Genetics, 2001, poster presentation.

A0109 Hammond S, Neglia J, Qualman S, Mertens A, Yasui Y, Meadows A, Robison LL. Tissue archive of second malignant neoplasms (SMN) in the Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies, 2001, poster presentation.

#### 2000

A0001 Packer RJ, Gurney J, Zeltzer L, Mertens A, Robison LL. Long-Term Neurologic and Neurocognitive status of childhood brain tumors: a Childhood Cancer Survivor Study (CCSS) Report. Society for Neuro-Oncology, 2000, oral presentation.

A0002 Neglia J, Yasui Y, Mertens A, Friedman D, Hammond S, Donaldson S, Stovall M, Meadows A, Robison LL. 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, 2000, oral presentation.

#### 1999

A9901 Sklar C, Whitton J, Mertens A, Stovall M, Green D, Marina N, Greffe B, Wolden S, Robison LL. 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, 1999, oral presentation.

A9902 Mertens A, Neglia J, Yasui Y, Potter J, Nesbit M, Ruccione K, Smithson A, Robison LL. Mortality rates and causes of death in 5-year survivors of childhood and adolescent cancer. American Society of Clinical Oncology, 1999, oral presentation.

A9903 Neglia J, Mertens A, Yasui Y, Hammond S, Friedman D, Donaldson S, Meadows A, Robison LL. 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, 1999, oral presentation.

A9904 Neglia J, Mertens A, Yasui Y, Hammond S, Friedman D, Donaldson S, Meadows A, Robison LL. 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, 1999, oral presentation.

A9905 Mertens A, Neglia J, Yasui Y, Potter J, Nesbit M, Ruccione K, Smithson A, Robison LL. 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, 1999, poster presentation.

<u>A9906</u> Green DM, Whitton J, Stovall M, Mertens A, Ruymann F, Pendergrass T, Robison LL. 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, 1999, oral presentation.

#### 1998

A9801 Hammond S, Qualman S, Neglia J, Meadows A, Robison LL. 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, 1998, oral presentation.

#### 1997

A9701 Hammond S, Qualman S, Neglia J, Meadows A, Robison LL. Assessment and validation of second neoplasms in the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Pathology, 1997, oral presentation.

## Investigator-Initiated, Ancillary Studies for External-Funding that Utilize the CCSS Resource

#### **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

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

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

**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

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 (Vanderbilt University)

Title: Health Outcomes for Hodgkin Disease Survivors

Dates of Funding: 9/04 - 6/10

Funding Source: National Institutes of Health (R01 CA106750-05)

**Award**: \$2,279,993

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.

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

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.

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: Jean Nakamura (University of California, San Francisco)

Title: Neurofibromin and response to genotoxins

**Dates of Funding:** 7/12 - 6/15

Funding Source: St. Baldrick's Foundation

Award:

**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: Emily Tonorezos (Memorial Sloan Kettering Cancer Center)

Title: Diet and insulin resistance in survivors of childhood leukemia

**Dates of Funding**: 6/11 – 6/14

Funding Source: American Cancer Society (Career Development Award)

Award: \$300,000

**Study Aims**: 1) Determine the effectiveness of a remotely delivered diet and physical activity intervention among obese ALL survivors, 2) Calculate the effect of the diet and physical activity intervention on insulin, leptin/adiponectin, and lipids.

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

Title: Diet and insulin resistance in survivors of childhood leukemia

**Dates of Funding**: 1/14 - 3/16

Funding Source: American Institute for Cancer Research

Award: \$165.000

**Study Aims**: 1) Determine the effectiveness of a remotely delivered diet and physical activity intervention among obese ALL survivors, 2) Calculate the effect of the diet and physical activity intervention on insulin, leptin/adiponectin, and lipids.

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

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

**Dates of Funding**: 6/13 - 5/18

Funding Source: National Institutes of Health (K07 CA166177)

Award: \$153,281

**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

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

Principal Investigator: Karen Effinger (Stanford University)

Title: Longitudinal Evaluation of Health Status in Survivors of Pediatric Astrocytoma

**Dates of Funding**: 7/14 - 6/15

Funding Source: ASCO Conquer Cancer Foundation Young Investigator Award (YIA)

Award: \$50,000

Study Aims: To evaluate 1) Health status, 2) Chronic Health Conditions and 3) Treatment-related risk factors among

survivors of astrocytoma.

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

Title: Diet and insulin resistance in survivors of childhood leukemia

Dates of Funding: 8/14 - 7/19

Funding Source: National Institutes of Health (R01)

Award: \$3,220,769

**Study Aims**: 1) Determine the effectiveness of a remotely delivered diet and physical activity intervention among obese ALL survivors, 2) Calculate the effect of the diet and physical activity intervention on insulin, leptin/adiponectin, and lipids.

**Principal Investigator**: Maria Gramatges (Baylor College of Medicine)

Title: Shortened telomere length and defects in telomere maintenance associated with thyroid second malignant

neoplasm in childhood cancer survivors

**Dates of Funding: 9/15 - 6/19** 

Funding Source: National Institutes of Health (R01)

Award: \$1,444,716

Study Aims: 1) Determine whether SNPs associated with telomere maintenance are enriched in survivors with thyroid

SMN (GWAS), 2) To look at impact of defects in telomere maintenance genes upon telomerase function

Principal Investigator: Smita Bhatia (City of Hope)

Title: Developmental HyperActive Ras Tumor SPORE, (Subsequent Malignant Neoplasms among individuals with NF1)

**Dates of Funding:** 7/15 - 6/20

Funding Source: National Institutes of Health (SPORE)

Award: \$2,300,000

**Study Aims**: 1) to implement effective targeted molecular therapies for neoplasms and cancers characterized by NF1 mutations by conducting integrated, mechanistically based translational research. 2) to describe risk of SMNs and demographic/therapeutic factors associated with SMNs in individuals with NF1 and primary cancer

Principal Investigator: I-Chan Huang (St. Jude Children's Research Hospital)

Title: Symptom Progress and Adverse Health Outcomes in Adult Survivors of Childhood Cancer

Dates of Funding: 12/15 - 11/17

Funding Source: National Institutes of Health (R21)

Award: \$489,133

Study Aims: 1) To investigate individual symptom categories and clusters across multiple time points

2) To investigate the prognostic value of symptoms for developing chronic conditions

Principal Investigator: Jennifer Yeh (Harvard School of Medicine)

Title: Improving Cancer Screening Guidelines for Survivors of Childhood Cancer

**Dates of Funding: 7/16 - 6/20** 

Funding Source: American Cancer Society

Award: \$825,000

**Study Aims**: 1) Develop a microsimulation model of the natural history of late-effects among childhood cancer survivors; 2) Use the model to project the disease burden, in terms of morbidity and mortality, associated with late-effects among treatment-exposure subgroups; and 3) Assess the comparative effectiveness (and cost-effectiveness) of recommended screening strategies for secondary breast and colorectal cancers to improve long-term outcomes among at-risk survivors

Principal Investigator: Liang Zhu (St. Jude Children's Research Hospital)

Title: New Methods to Address Dilemmas in Mixed Recurrent-event and Panel-count data

**Dates of Funding: 7/16 - 6/18** 

Funding Source: National Institutes of Health (R21)

Award: \$501,312

**Study Aims**: To develop semi-parametric methods for regression analysis for mixed recurrent-event data with a terminal event and compare them with alternative methods by simulation studies for application to CCSS data.

Principal Investigator: Yan Yuan (University of Alberta)

Title: Risk Prediction Model of Premature Menopause in Childhood Cancer Survivors

**Dates of Funding:** 7/16 - 12/18

Funding Source: Canadian Institutes of Health Research

Award: \$179.858

Study Aims: To develop a prediction model for early menopause

**Principal Investigator**: Eric Chow (University of Washington)

Title: Communicating Health Issues and Improving Coordination with Primary Care (CHIIP)

**Dates of Funding: 3/17 - 2/22** 

Funding Source: National Institutes of Health (R01)

Award: \$3,720,495

**Study Aims**: 1) Determine prevalence of under diagnoses and under treatment of traditional cardiovascular risk factors, 2) Randomized controlled intervention to improve risk factors, 3) Determine barriers that lead to under diagnosis and under treatment.

Principal Investigator: Lennie Wong (City of Hope)

Title: Cost effectiveness of breast cancer screening guidelines for female survivors of pediatric cancers

**Dates of Funding: 7/17 - 6/20** 

Funding Source: American Cancer Society

Award: \$527,000

Study Aims: 1) Examine the cost-effectiveness of 1) annual clinical breast examination, 2) annual breast tomosynthesis

vs. MRI as adjunct to mammography.

**Principal Investigator**: Yutaka Yasui, Jinghui Zhang (St. Jude Children's Research Hospital) **Title**: Late Effects Prediction using Clinical Phenotypes and Whole Genome Sequencing

**Dates of Funding: 4/17 - 3/22** 

Funding Source: National Institutes of Health, RO1

Award: \$3,457,455

**Study Aims**: 1) Build individual risk prediction models with the SJLIFE cohort for 11 outcomes including meningioma, basal cell carcinoma, and multiple subsequent neoplasms, 2) Validate the risk prediction models a larger cohort study with

higher SN counts (CCSS)

#### **Ancillary Studies: Proposed**

Principal Investigator: Kevin Oeffinger (Memorial Sloan Kettering)

Title: EMPOWER II

Proposed Funding Source: National Institutes of Health R01

Study Aims: To determine the efficacy of smart phone, text-based patient and physician activation to improve breast MRI

and mammography screening rates

Status: Submitted March 2016, 23rd percentile, planned resubmission July 2017

Principal Investigator: I-Chan Huang (St. Jude Children's Research Hospital)

Title: Developing a Patient Reported Outcomes Version of the CTCAE for Survivors of Childhood Cancer (PRO-CTCAE-

SCC)

Proposed Funding Source: National Institutes of Health, R01

Study Aims: To conduct item creation, selection and validation of a PRO-CTCAE-SCC based on the current patient-

reported outcomes version of the Common Terminology Criteria for Adverse Events.

Status: Submitted October 2016

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

Title: Advancing Skin Cancer Screening Practices among Survivors of Childhood Cancer and Skin Cancer (ASK2)

Proposed Funding Source: National Institutes of Health, RO1

**Study Aims**: Among 450 CCSS participants with a diagnosis of skin cancer, determine the impact of a Patient Activation and Education intervention (PAE) (tailored print materials, text messages, and tailored phone calls) compared with generic print materials and text messages on skin cancer early detection and prevention practices measured at 6 and 12 months.

Status: Submitted June 2016, unscored. Resubmited February 2017

**Principal Investigator**: Kathy Ruble (John Hopkins University)/Lee Ritterband (University of Virginia)/Kevin Krull (St. Jude Children's Research Hospital)

Title: eHealth Insomnia Intervention in Childhood Cancer Survivors: Impact on Long-Term Complications

Proposed Funding Source: NIH R01

**Study Aims**: To assess the impact of insomnia treatment on neurocognitive impairments in childhood cancer survivors and the impact of insomnia treatment on anxiety, depression, fatigue, and indices of cardiovascular health in CCS.

Status: Submitted November 2016, unscored; resubmission planned August 2017

Principal Investigator: Elyse Park (Harvard School of Medicine)

Title: Developing a Health Insurance Navigation Program for Childhood Cancer Survivors

Proposed Funding Source: American Cancer Society

Study Aims: 1) To develop a psychoeducational health insurance navigation program (HINP), 2) To conduct a pilot

randomized trial of the HINP, 3) To refine the HINP program for future use.

Status: Scored Excellent, Resubmission May 2016

Principal Investigator: Liang Zhu (University of Texas MD Anderson)

Title: Statistical Analysis for Mixed Outcome Measures in Recurrent Event Studies

Proposed Funding Source: American Cancer Society

Study Aims: Develop a likelihood-based semiparametric estimation method for regression analysis of mixed panel-binary

and panel-count data.

Status: Submitted October 2016, scored 20, awaiting funding decision

#### **Ancillary Studies: Proposed (continued)**

Principal Investigator: Jennifer Yeh (Harvard School of Medicine)

Title: Identifying opportunities to Improve Childhood Cancer Survival with Genetic Testing

Proposed Funding Source: Pablove Foundation Grant

Study Aims: Evaluate how genetic testing may improve risk stratification

Status: Submitted April 2017

Principal Investigator: Flora van Leeuwen (Netherlands Cancer Institute)

Title: Molecular markers to improve treatment-related accelerated aging in relation to late effects among survivors of

Hodgkin lymphoma

Proposed Funding Source: Dutch Cancer Society

Study Aims: Assess whether telomere length and genetic variants linked with longevity and telomere length are

associated with risk of developing multiple SMNs and cardiac events.

Status: Submitted March 2017

#### **Ancillary Studies: Unfunded**

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

Title: Promoting Health Monitoring After Childhood Cancer Proposed Funding Source: National Institutes of Health

Study Aims: Conduct a randomized trial to test generic health risk promotion versus tailored health risk promotion with

proactive counseling to increase the rate of successful screening according to risk-based recommendations.

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

**Title**: A Web-Based Approach to Familial Cancer Risk **Proposed Funding Source**: Lance Armstrong Foundation

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

among pediatric cancer survivors.

**Principal Investigator**: Jin-Shei Lai (Northwestern University) **Title**: Cancer Fatigue Monitoring from Childhood into Adulthood

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

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

**Principal Investigator**: Anne Lown (San Francisco State University) **Title**: Alcohol Consumption Among Childhood Cancer Survivors

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

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

time.

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

Title: Childhood Cancer Survivor Study Partners

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

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

investigators.

**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.

#### **Ancillary Studies: Unfunded (continued)**

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.

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**: 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: 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.

Principal Investigator: Smita Bhatia (City of Hope) and Yutaka Yasui (University of Alberta)

Title: Genetic predisposition to non-malignant adverse events in survivors of Pediatric Hematological Malignancies

Proposed Funding Source: Leukemia and Lymphoma Society

Study Aims: 1) Identify germline variants associated with cognitive deficits, CHF, CAD, stroke, ovarian failure, and

hypothyroidism, 2) Examine role of gene-environment interactions, 3) Replication of top SNPs

Principal Investigator: Jennifer Yeh (Harvard School of Medicine)

Title: Refining risk-based follow-up guidelines to improve childhood cancer survivorship

Proposed Funding Source: National Institutes of Health (R01)

Study Aims: 1) Develop a childhood cancer survivor policy model, 2) Identify risk subgroups for identifying lifelong burden of disease

Principal Investigator: Kenneth Offit (Memorial Sloan Kettering Cancer Center) and Charles Mullighan (St. Jude)

Title: Genetic Susceptibility to Acute Lymphoblastic Leukemia

Proposed Funding Source: National Institutes of Health (R01)

Study Aims: (1) To identify novel ALL susceptibility genes using massively parallel sequencing of familial ALL kindreds, (2) To identify underlying genetic susceptibility factors for the development of second and subsequent cancers in ALL, and

(3) To determine the extent to which germline deleterious variants contribute to sporadic ALL.

**Principal Investigator**: Sabine Muelller (University of California San Francisco)

Title: Stroke in Survivors of Childhood Cancer

**Proposed Funding Source**: National Institutes of Health (R01)

Study Aims: 1) Direct MRI assessment of large/small vessel stroke, 2) Prevalence and factors for microbleeds

#### **Ancillary Studies: Unfunded (continued)**

Principal Investigator: Jennifer Yeh (Harvard School of Medicine)

Title: Identifying opportunities to Improve Childhood Cancer Survival with Genetic Testing

**Proposed Funding Source**: Alex's Lemonade Stand Foundation **Study Aims**: Evaluate how genetic testing may improve risk stratification

Status: Submitted December 2015, unfunded

Principal Investigator: Jennifer Yeh (Harvard School of Medicine)

Title: Identifying opportunities to Improve Childhood Cancer Survival with Genetic Testing

Proposed Funding Source: NIH R01

Study Aims: Evaluate how genetic testing may improve risk stratification

Status: Submitted February 2016, unfunded

Principal Investigator: Elyse Park (Harvard School of Medicine)

Title: Understanding and improving health insurance coverage experiences of childhood cancer survivors

Proposed Funding Source: American Cancer Society

Study Aims: 1) Examine longitudinal changes in health insurance coverage following implementation of the ACA, 2)

Examine health insurance challenges

Status: Scored Excellent, Resubmission May 2016, unfunded

Principal Investigator: Jennifer Yeh (Harvard School of Medicine)

Title: Identifying opportunities to Improve Childhood Cancer Survival with Genetic Testing

**Proposed Funding Source**: Collaborative Pediatric Cancer Research Award **Study Aims**: Evaluate how genetic testing may improve risk stratification

Status: Submitted January 2017, unfunded

Principal Investigator: David Brenner and Sally Amundson (Columbia University)

Title: Validation of interactome-based biomarkers of inherited susceptibility to radiation-induced carcinogenesis

Proposed Funding Source: NIH U01

**Study Aims**: To determine if the pattern of master regulator genes underlying the susceptibility to radiation-induced cancer in an Israeli cohort will be broadly generalizable to radiation-associated second cancers occurring in survivors of childhood cancer.

Status: Unfunded

Principal Investigator: Tara Henderson (Univ. of Chicago)/Angela Bradbury(Univ. of Pennsylvania)

**Title**: Return of Genomic Results to Research Participants **Proposed Funding Source**: National Institutes of Health R01

**Study Aims**: To evaluate the uptake of web-based education and return of genomic results **Status**: Submitted February 2016, 50<sup>th</sup> percentile. Resubmitted October 2016, unfunded

CCSS Career Development Award Winners						
Category	Awardee	Application Title	Direct Costs Awarded	CCSS Working Group	Primary Mentor	
2013						
Junior Faculty	Sogol Mostoufi-Moab, MD Children's Hospital of Phil.	Overall risk of Chronic Endocrine Disorders in Adult Survivors of Childhood Cancer	\$50,000	Chronic Disease	Mary Leonard	
2014						
Junior Faculty	Philip Lupo, PhD Baylor College of Medicine	Epigenomic profiling of metabolic outcomes in childhood leukemia survivors	\$20,000	Genetics	Smita Bhatia	
Junior Faculty	Rebecca Howell, PhD UT MD Anderson Cancer Center	Radiation dose reconstruction methods for intensity modulated radiation therapy	\$19,901	Second Malignancies	Marilyn Stovall	
Trainee	Giselle Perez, PhD Massachusetts General Hospital	Mental healthcare service availability and utilization among childhood cancer survivors	\$3000	Psychology/ Cancer Control	Elyse Park	
Trainee	Melissa Schapiro, MD St. Louis Children's Hospital	Cognitive and academic difficulties in survivors of head/neck rhabodo.	\$3000	Psychology	Robert Hayashi	
2015						
Junior Faculty	Danielle Friedman, MD Memorial Sloan Kettering	Impact of radiation dose to the pancreas on subsequent risk of diabetes mellitus	\$20,000	Chronic Disease	Charles Sklar	
Junior Faculty	Adam Esbenshade, MD Vanderbilt University	Using the Cumulative Illness Rating Scale to characterize the burden of chronic conditions	\$20,000	Chronic Disease	Kirsten Ness	
Trainee	Douglas Fair, MD University of Utah	Health care financial burden and missed opportunities for care	\$3000	Chronic Disease	Anne Kirchhoff	
Trainee	Aurelie Weinstein Georgia State University	Predictors and outcomes of personal strengths in young adult cancer survivors	\$3000	Psychology	Chris Heinrich	
International Trainee	Miranda Fidler University of Birmingham, UK	Comparison of risks for mortality and subsequent cancers in the CCSS and BCCSS	\$10,000	Chronic Disease	Mike Hawkins	
2016						
Junior Faculty	Ralph Salloum, MD Cincinnati Children's Hospital Medical Center	Medulloblastoma and PNET outcomes across three decades of diagnosis	\$30,000	Chronic Disease	Maryam Fouladi Greg Armstrong	
Trainee	Stephanie Vuotto, PhD St. Jude Children's Research Hospital	Psychological distress, neurologic morbidity and functional ind. among adult survivors treated with CNS-directed therapies	\$3,000	Psychology	Tara Brinkman	

### **CCSS Trainee List**

Trainee/Mentee	Training Experience	Current Position	First Authored CCSS Publications
Nina Kadan-Lottick, MD, MSPH Post-doctoral Fello		Associate Professor Division of Pediatric Hematology-Oncology Yale University New Haven CT	JAMA 2002; Epidemiology 2003 Blood Cancer 2006 J Clin Oncol 2008 J Natl Cancer Inst 2010
Brad Zebrack, PhD	Post-doctoral Fellowship	Associate Professor School of Social Work University of Michigan Ann Arbor, MI	Pediatr 2002; J Clin Oncol 2004 Pediatr Blood Cancer 2007 Psychooncology 2012
Pauline Mitby, MPH	Graduate Training	Clinical Research Associate Division of Pediatric Hematology-Oncology Children's Hospital of Minnesota Minneapolis, MN	Cancer 2003
Rajaram Nagarajan, MD, MS	Post-doctoral Fellowship and Graduate Training	Associate Professor Division of Pediatric Hematology-Oncology Cincinnati Children's Hospital Cincinnati, OH	Cancer 2003 Br J Cancer 2004 J Cancer Surviv 2009 Cancer 2011
Carrie M. Brownstein, MD	Post-doctoral Fellowship	Senior Clinical Scientist and Sr. Associate Clinical Director Roche Pharmaceuticals Assistant Clinical Professor Department of Pediatric Hematology-Oncology New York-Presbyterian/Columbia New York, NY	J Clin Endocrinol Metab 2004
Lisa Kenney, MD, MPH	Post-doctoral Fellowship	Assistant Professor Department of Pediatrics Harvard Medical School Pediatric Oncology Dana-Farber Cancer Institute Boston MA	Ann Intern Med 2004
Elyse Park, PhD	Graduate Training	Associate Professor Harvard Medical School Department of Psychiatry Massachusetts General Hospital Boston MA	J Clin Oncol 2005 Prev Med, 2006 J Cancer Surviv, 2012 J Clin Oncol, 2015
Sharon Castellino, MD, MS	Graduate Training	Associate Professor Department of Pediatrics Wake Forest University Winston-Salem, NC	J Clin Oncol 2005 Blood 2011
Joanna Perkins, MD, MS	Post-doctoral Fellowship and Graduate Training	Hematology-Oncology Children's Hospital of Minnesota Minneapolis, MN	J Clin Oncol 2005 Cancer 2014
Judy Punyko, PhD	Graduate Training	State Maternal and Child Health Epidemiologist Minnesota Department of Health St Paul, MN	Pediatr Blood Cancer 2005
Wassim Chemaitilly, MD	Post-doctoral Fellowship	Assistant Member Endocrinology St. Jude Children's Research Hospital Memphis, TN	J Clin Endocrinol Metab 2006
Mylene Bassal, MD	Post-doctoral Fellowship	Assistant Member Department of Pediatrics University of Ottawa Ottawa, Canada	J Clin Oncol 2006
Berrin Ergun-Longmire, MD Post-doctoral Fellowship		Assistant Professor Division of Pediatric Endocrinology Robert Wood Johnson Medical School New Brunswick, NJ	J Clin Endocrinol Metab 2006

Trainee/Mentee	Training Experience	Current Position	First Authored CCSS Publications
Cecile Ronckers, PhD	Post-doctoral Fellowship	Epidemiologist AMC/Emma Children's Hospital Amsterdam, Netherlands	Radiat Res 2006
Tara Henderson, MD, MPH	Fellowship and Graduate Training	Assistant Professor Department of Pediatrics University of Chicago Chicago, IL	JNCI 2007 Ann Intern Med, 2012 Int J Radiat Oncol Bio Phys, 2012 J Clin Oncol 2015
Eric Chow, MD, MPH	Fellowship and Graduate Training	Medical Director Pediatric Cancer Long Term Follow-up Program Seattle Children's Hospital Seattle, WA	J Pediatr 2007 Pediatr Blood Cancer 2008 Pediatr Blood Cancer 2009 Pediatr Blood Cancer 2013 J Clin Oncol 2015
Todd Florin, MD	Medical Student	Assistant Professor Cincinnati Children's Hospital Cincinnati, OH	CEBP 2007
Kris Ann Schultz, MD, MS	Fellowship and Graduate Training	Hematology-Oncology Children's Hospital of Minnesota Minneapolis, MN	J Clin Oncol 2007 Pediatr Blood Cancer 2014
Jenny Pang, MD, MPH	Fellowship and Graduate Training	Clinical Assistant Professor School of Public Health University of Washington Seattle, WA	Pediatr Blood Cancer 2008
Irina Dinu, PhD	Post-doctoral Fellowship	Assistant Professor Department of Public Health Sciences University of Alberta Edmonton, Alberta	Pediatr Blood Cancer 2008
Daniel Mulrooney, MD, MS	Fellowship and Graduate Training	Assistant Member St. Jude Children's Research Hospital Memphis, TN	Sleep 2008 Cancer, 2008 Br Med J 2009
Elizabeth Bluhm, MD, MPH	Post-doctoral Fellowship	Department of Internal Medicine Washington Hospital Medical Center Washington, DC	Blood 2008
Anne Lown, DrPH	Post-doctoral Fellowship	Assistant Clinical Professor Depart. of Family Health Care Nursing UCSF San Francisco, CA	Addiction 2008 Psychooncology 2013
Edward Garmey, MD	Post-doctoral Fellowship	Chief Medical Officer and Senior Vice President Cerulean Pharma Inc. Cambridge, MA	J Clin Oncol 2008
Natasha Buchanan, PhD	Post-doctoral Fellowship	Behavioral Scientist Centers for Disease Control Atlanta, GA	Cancer 2009
Meagan Lansdale, MD	Medical Student	Assistant Professor UCSF School of Medicine San Francisco, CA	Cancer 2009
Caroline Laverdiere, MD	Fellowship Training	Assistant Professor Department of Pediatrics University of Montreal Montreal, QC	JNCI 2009
Christopher Janson, MD	Medical Student	Assistant Professor CEBP 2009 Children's Hospital of Montefiore Albert Einstein College of Medicine Bronx, NY	
Karen Wasilewski-Masker, MD, Fellowship Training M.Sc.		Assistant Professor JNCI 2009 Department of Pediatrics J Cancer Surviv 2014 Emory University School of Medicine Atlanta, GA	

Trainee/Mentee	Training Experience	Current Position	First Authored CCSS Publications
isa Kahalley, PhD Post-doctoral Fellowship Assistant Professor Baylor College of Medicine Houston, TX		Baylor College of Medicine	Nicotine Tob Res 2010 Pediat Blood Cancer 2012
Beth Kurt, MD, MS	Fellowship and Graduate Training	Pediatric Oncologist Helen DeVos Children's Hospital Grand Rapids, MI	Pediatr Blood Cancer 2011
Timothy Best, PhD	Graduate degree (PhD)	Medical Science Liaison Ipsen Chicago, IL	Nat Med 2011
Anne Kirchhoff, PhD, MPH	Post-doctoral Fellowship	Assistant Professor University of Utah Salt Lake City, UT	Med Care, 2010 CEBP 2011 Cancer 2011 Med Care 2010 Support Care Cancer, 2013 J Natl Cancer Inst 2015
Michele Montgomery, PhD	Graduate degree (PhD)	Assistant Professor University of Alabama Tuscaloosa, AL	J Cancer Surv 2011
Nancy Clanton, PhD	Post-doctoral training	Pediatric Neuropsychologist LeBonheur Children's Hospital Memphis, TN	Cancer 2011
Kerri Nottage, MD	Fellowship training	Assistant Member St. Jude Children' Research Hospital Memphis, TN	Blood 2011
Carmen Wilson, PhD	Post-doctoral Fellowship	Research Associate St. Jude Children' Research Hospital Memphis, TN	Cancer 2012 JNCI 2013 CEBP 2014
Houda Boukheris, MD	Post-doctoral Fellowship	. ,	Int J Radiat Oncol Biol Phys 2012
Tanya Watt, MD	Fellowship training	Assistant Professor UT Southwestern Dallas, TN	JNCI 2012
Julienne Brackett, MD	Fellowship training	Assistant Professor Texas Children's Hospital Houston, TX	Neuro Oncol 2012
Tien Huang, PhD	Post-doctoral Fellowship	Instructor University of Oklahoma Norman, OK	Pediatr Blood Cancer 2013
Lucie Turcotte, MD, MPH	Fellowship training	Assistant Professor University of Minnesota Minneapolis, MN	J Clin Oncol, 2015
Jeanne Steele, PhD	Post-doctoral Fellowship	Program Consultant Office of Health Improvement State of Minnesota	J Cancer Surviv 2013
Casey Daniel, PhD	Graduate degree (PhD)	Research Fellow Harvard School of Public Health Boston, MA	Cancer 2015 Trials 2015
Prasad Gawade, PhD	Fellowship training	Observational Research Sr. Manager Amgen Thousand Oaks, CA	Am J Obstet Gynecol 2015
Sara Barton, MD	Assistant Professor	Assistant Professor University of Nebraska Heartland Center for Reproductive Medicine Omaha, NE	Lancet Oncol 2013
Stefan Essig, MD, PhD Research Fellow		Research Fellow University of Bern Bern, Switzerland	Lancet Oncol 2014

Trainee/Mentee	Training Experience	Current Position	First Authored CCSS Publications	
Pinki Prasad, MD, MPH	Fellowship training	Assistant Professor Louisiana State University New Orleans, LA	J Clin Oncol, 2015	
Karen Tsui, MD	Fellowship training	Assistant Professor Starship Hospital Auckland, New Zealand	Neuro Oncol 2014	
Eugene Suh, MD	Fellowship training	Assistant Professor Loyola University Chicago, IL	Analysis underway	
Giselle Perez, PhD	Post-doctoral Fellowship	Fellow Massachusetts General Hospital Boston, MA	Analysis underway	
Melissa Schapiro, MD	Fellowship training	Assistant Professor Memorial Sloan Kettering Cancer Center New York, NY	Analysis underway	
Dava Szalda, MD	Fellowship training	Fellow Analysis unde Children's Hospital of Philadelphia Philadelphia, PA		
Elizabeth Feijen	Graduate Training	Graduate Student Academic Medical Center Amsterdam, The Netherlands	J Clin Oncol, 2015	
Huiru Dong, MSc	Graduate Training	Graduate Student University of Alberta Edmonton, Alberta, Canada	Am J Epidemiol, 2015	
Kelly Kenzik, PhD	Graduate Training	Post-doctoral Fellow University of Alabama Birmingham, Alabama	Neuropsychology 2014	
Douglas Fair, MD	Fellowship Training	Fellow Analysis u University of Utah Salt Lake City, UT		
Aurelie Weinstein	Graduate Training	Graduate Student Georgia State University Smyrna, GA	Analysis underway	
Miranda Fidler	Graduate Training	Graduate Student University of Birmingham Birmingham, UK	Analysis underway	
Arin Madenci, MD	Fellowship Training	Fellow, Pediatric Surgery  Boston Children's Hospital  Boston, MA		
Karen Effinger, MD	Fellowship Training	Assistant Professor Analysis underway Children's Hospital of Atlanta Atlanta, GA		
Ryan Nipp, MD	Fellowship Training	Fellow Analysis underv Mass General Hospital Boston, MA		
Stephanie Vuotto, PhD	Post-doctoral Fellowship	Assistant Professor Cancer, 2016 College of Mount Saint Vincent New York, NY		
Austin Brown, PhD	Graduate Training	Post-doctoral Fellow Baylor College of Medicine Houston, TX	al Fellow Concept approved ge of Medicine	
Peter Asdhal, MD	Graduate Training	Graduate student Concept approved Aarhus University Aarhus, Denmark		
Daniel Zheng Medical Student Medical Student Yale University New Haven, CT		Medical Student Yale University	Concept approved	

Trainee/Mentee	Training Experience	Current Position	First Authored CCSS Publications
Laura Daniel, PhD	Post-doctoral Fellowship	Instructor	Concept approved
		Children's Hospital of Philadelphia	
		Philadelphia, PA	
Yin Ting Cheung, PhD	Post-doctoral Fellowship	Post-doctoral Fellow	Analysis underway
		St. Jude Children's Research Hospital	
		Memphis, TN	
James Bates, MD	Fellowship Training	Fellow, Radiation Oncology	Analysis underway
		University of Florida	<b>ASCO Oral Presentation</b>
		Gainesville, FL	
Matt Ehrhardt, MD	Fellowship Training	Assistant Member	Analysis Complete
		St. Jude Children's Research Hospital	ASH Poster presentation
		Memphis, TN	
Kristen Stefanski	Fellowship Training	Fellow	Analysis underway
		Cincinnati Children's Hospital	
		Cincinnati, OH	

Report date: 5/2017



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### **Appendix**

**Sample LTFU Participant Newsletter; Brief Updates** 



Odate

Spring 2017

### A NOTE FROM US

On behalf of our entire study team, thank you for your dedication to the Long-Term Follow-Up Study (LTFU). You are a vital partner in this research.

The LTFU Study is the world's longestrunning study of survivors of childhood cancer. Together we're helping to improve the health of survivors everywhere and for generations to come.

Our goal is to keep you engaged and informed. That's why we're launching a redesigned newsletter that we think is as exciting and future-oriented as the LTFU Study itself. In addition to the articles you've enjoyed in the past, you'll read about what's been happening, what's upcoming, and how your participation is making a difference.

The National Cancer Institute (NCI) recently renewed its support for the study through 2022. In announcing the award, NCI described the Long-Term Follow-Up Study as "One of the most powerful NCI-supported research efforts for tracking the needs and health of survivors."

NCI's ongoing support affirms the importance of the advances we are making, thanks to your dedication. We are proud to have their support and grateful to our 24,363 participants.

We are always glad to hear from you. We welcome your suggestions and feedback and invite you to call

us toll-free at 800-775-2167 or email **LTFU@stjude.org.** 

With thanks,

Gregory Armstrong, MD Principal investigator

## **Shorter survey coming**

We are in the process of finalizing our next survey, Follow-Up 2017. New questions in this survey will help us learn more about the important financial

issues that survivors may face as a result of their childhood illness.

*Much shorter!* Follow-Up 2017 will be short. The last survey was 36 pages, and some of you reported that it was a challenge to find the time to complete it. We value your time and recognize that you have busy lives, so we designed a much shorter survey this time.

When to expect it? We plan to start sending out Follow-Up 2017 this summer. It takes several months to actually process and send more than 20,000 surveys.

For this reason, some participants will receive their surveys in 2017, others will receive them in 2018.

We will send you an announcement a few weeks in advance so you can be on the lookout for your survey in the mail.

We need your response! When your survey arrives, please take a few minutes to fill it out. We need everyone's responses to ensure the accuracy of our results. As always, we welcome your feedback or questions on any aspect of the new survey.

## Thank you for participating!

Thank you to everyone who completed the study's most recent follow-up survey. A majority of participants completed it, and their commitment is helping to improve treatments for children newly diagnosed with cancer, and to identify ways of protecting people's health for years beyond their cancer.

The data is currently being prepared for analysis and will allow researchers to study the impact of childhood cancer in new ways, including:

- What survivors experience as they get older
- How the effects of treatment might influence the aging process



14,361





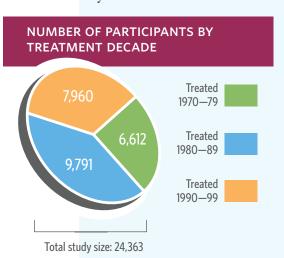
# The LTFU Study community

#### **Study size**

Treatments for childhood cancer have changed over time, in part because of what has been learned from the Long-Term Follow-Up Study. When the study began in 1994, we enrolled participants who were diagnosed between 1970 and 1986. More recently, we have added a new "generation" of participants diagnosed between 1987 and 1999.

#### Three decades of data

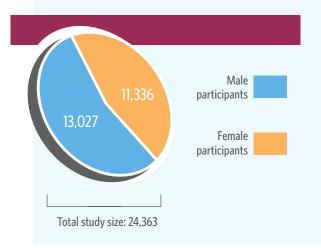
Now the study includes participants who were diagnosed and treated over the span of 30 years! This allows researchers to show how



advances in treatment have improved the lives of survivors. They can also identify areas where more progress is needed to help kids diagnosed with cancer in the future.

#### **Gender balance**

Because men and women may experience some different issues related to their childhood cancer, it is important to have good representation of both males and females.



# Founder receives ACS medal of honor

Dr. Leslie L. Robison, who founded the LTFU Study in 1994, was recently awarded the American Cancer Society (ACS) Medal of Honor Award "in recognition of his lifetime contributions and dedication to research on the long-term outcomes of pediatric cancer survivors."



Dr. Robison (far right) was one of three individuals receiving the ACS award (he's photographed here with the two other recipients, Joan Brugge, PhD, left, and Charles Sawyers, MD, middle). Past recipients of the Society's Medal of Honor include former US President George H.W. Bush and former First Lady Barbara Bush, and former US Surgeon General C. Everett Koop, MD.

# Good Morning America gives "Surprise Salute"

Dr. Gregory Armstrong, the LTFU Study's principal investigator, got a

"surprise salute" from Good Morning America's hosts on September 9, 2016. You can watch the video here:

http://abcn.ws/2iQ3iE6



### 2016 achievements

You can be proud of what you helped achieve in the past year:

- 22 publications in scientific journals
- 15 presentations at major conferences
- 9 open ancillary studies
- Funding support renewed through 2022 by the National Cancer Institute

## **EMPOWERed by research**

We conducted the EMPOWER study to increase breast cancer screening rates among women who were treated with chest radiation. Guidelines recommend an annual mammogram

and breast MRI starting at age 25, or eight years after radiation, for these survivors. "Screening is important because women who develop treatment-related breast cancer do very well if it's detected early," said Dr. Kevin Oeffinger, who led the study.

Rebekah Hughes, a participant in the LTFU study, took part in the EMPOWER study. Rebekah was diagnosed with a fast-growing sarcoma in 1979, while visiting family in England. Doctors there discovered the tumor near her right lung. The month she turned three, Rebekah's parents rushed her home to Toronto, where she was aggressively treated with surgery, chemotherapy, and chest radiation.

When Rebekah was asked to join the EMPOWER study, she says, "The timing was right. The side effects of treatment have been lifelong and challenging, and I needed to understand what I was going through. I was also glad to be able to provide information to help other patients and survivors."

#### Recognizing the importance of early detection

During the study, Rebekah had a breast MRI and a mammogram. Both tests were negative. She was

## Thanks for asking...

# I used to be in the study but I haven't completed the last few surveys. Am I still in the study?

Yes! If you were ever part of the study in the past, you will continue to be a study participant. Even if you skipped some of the surveys, we need and value you! Please get in touch so we can reconnect with you.

We hope you will contact us (call our toll-free number at 800-775-2167 or email us at LTFU@stjude.org) to make sure we have your correct contact information and find out when you might expect to receive your next survey. You can also update your contact info online: ltfu.stjude.org

relieved to get the good news. "Participating in the study showed me the importance of having these tests," she says. "I hadn't been sure that for me, personally, they were important because if I did develop breast cancer I didn't think I would be able to go through another surgery and more treatment. My doctor convinced me—he reinforced the study message about the importance of finding any cancer early when it's small



so treatment is less difficult and invasive."

Rebekah had a repeat MRI and mammogram this past summer and again got good news—both tests were negative.

#### Next step

The EMPOWER study showed that participants who received printed information and phone counseling were almost twice as likely to get a mammogram compared to others who did not, but they were no more likely to have a breast MRI. A follow-up study, EMPOWER II, is being planned to increase physicians' awareness of the importance of recommending MRI screening for women treated with chest radiation.

### Help us keep in touch

Stay connected with the Long-Term Follow-Up Study! If you have moved, changed your email address, or have a new phone number, it's easy to update your contact information:

- Call us toll-free at 800-775-2167
- Send us an email at LTFU@stjude.org
- Visit Itfu.stjude.org. Click on "Update Your Info." You can also choose to receive the LTFU newsletter by email instead of the print version by selecting that option.



# LOOKING FORWARD

(Don't Look Back. You're Not Going That Way!)

#### A NEWSLETTER FROM THE LTFU STUDY

#### A Circle of Giving

Catherine St. James, 25, of Teaneck, New Jersey, is making career plans. She recently graduated from Seton Hall University, majoring in anthropology, and is thinking of pursuing a Master's degree in Public Health.

Catherine's interest in Public Health began after she was treated for a brain tumor as a teenager. At age 14, she was diagnosed with craniopharyngioma, a type of brain tumor that involves the pituitary gland.

Shortly before she was diagnosed she began to have serious headaches. A competitive soccer player, Catherine thought the headaches might be from heading the soccer ball. But she was also unusually short for her age. Her parents took her to see an endocrinologist, who ordered an MRI that revealed the tumor in her brain.

Just before she started her freshman year of high school Catherine had surgery to remove the bulk of her tumor. She was also treated with radiation. After treatment she wanted to find a way to help other cancer and brain tumor survivors.

"Before I got sick, I wanted to be a teacher but I got interested in Public Health in college," she says, "especially the area of patient education. It seemed like it could be a way for me to use my experiences, and the things I noticed during treatment, to make things smoother for people who are going through some of the same things that I went through."

About a year after her surgery, Catherine and her family learned about the Children's Brain Tumor Foundation (CBTF). The foundation offers a host of services for brain tumor survivors and their families. CBTF counselors assisted Catherine as she began exploring career paths in Public Health. The foundation also helped her obtain an internship at a medical device company that makes equpiment for brain surgeons.

In return, Catherine has volunteered at the foundation, putting together care packages for patients. She's also shared her story as a guest speaker at some foundation events. "We have a nice give-and-take," Catherine says. "They help me and I help them!"

Catherine has had to deal with some significant side effects of treatment. "Fatigue is a big issue," she says. "If I'm active for two or three days, it seems like I have to take two or three days to recover. It's frustrating to be so tired!"

Despite the fatigue, she leads a busy life. Through CBTF, she connected with Camp Mak-a-Dream, a camp for cancer survivors, located in Montana, which hosts a "Heads Up" conference for young adult brain tumor survivors. The conference provides survivors an opportunity to meet and make friends with others



who are facing similar life challenges.

Catherine attended the Heads Up conference in June, 2016. Her favorite activities were the evening fireside chats, where participants gather to talk and share their feelings, thoughts, and experiences. She also loved the camp's beautiful surroundings. "Coming from the New York City area," she says, "I loved the chance to breathe the fresh mountain air for five days!"

Catherine hopes to attend a future Heads Up conference as a mentor to provide emotional support for future campers—planning once again to give back for what she has received.

Photo: Catherine St. James, right, with her sister at a Children's Brain Tumor Foundation event



#### Community Partners: CAMP MAK-A-DREAM

Located in western Montana near Missoula, Camp Mak-A-Dream has been providing medically supervised, cost-free camp experiences for cancer patients and survivors since 1995. The camp offers sessions for children, teens, siblings, young adults, and families. Anyone whose life has been affected by cancer is welcome.

Activities at the camp range from hot-tub soaks and movies to zipline and mountain hiking. In addition to such serious fun, the camp also offers cancer survivors the opportunity to



make life-long connections with other survivors.

Camp director Beth Jones says, "People form bonds here like nothing we

see outside the camp world."

Beth first encountered the camp
as a volunteer when, as a member of the Missoula Children's
Theater, she helped put on a
workshop for campers. "It was
a powerful experience seeing
how people at the camp support
each other," she recalls. "When
an opportunity opened up, I decided I wanted to become a part
of it permanently!"

#### **HEADS UP CONFERENCES**

Camp Mak-A-Dream offers a special program for brain tumor survivors—the Heads Up conferences for teens and young adults. The conferences are a collaborative effort with the Children's Brain Tumor Foundation. CBTF partners with the camp to develop conference programming. The foundation also helps with staffing and with travel expenses for participants.

According to Beth, the Heads Up conferences combine all the fun of camp plus workshops For more information, please contact us at: 1-800-775-2167 https://LTFU.stjude.org Email: LTFU@stjude.org



to help survivors learn to manage the long-term effects of their disease and treatment. "We schedule daily workshops on various topics, including educational and employment issues and social relationships. We also have small group and fireside chats where participants can share their thoughts and feelings about things that are important to them."

Each conference is held once a year and lasts about a week, and each session has space for about 50 participants.

Many return year after year. Experienced campers can apply to serve in a variety



of leadership positions, including as mentors, who offer peer to peer support to other participants.

As noted, all camp sessions, including the Heads Up conferences, are cost-free to participants. A limited number of travel scholarships are available for first-time campers. For more information, or to apply to attend a camp session go to: http://www.campdream.org/

#### Children's Brain Tumor Foundation

Catherine St. James and her family continue to receive a lot of support from

the Children's Brain Tumor Foundation (CBTF). The foundation provides support at every stage of the brain tumor experience, including a Survivor and Bereave-

ment program. They also provide parent and survivor mentors, educational advocacy, career development and employment programs, social and social skill groups, and regular online chats for parents and survivors. More info at: www.cbtf.org

Is there a "Community Partner" in your area that you'd like to see featured in a future issue of Looking Forward? Please submit your suggestions on our website: https://ltfu.stjude.org/

# LOOKING FORWARD

(Don't Look Back. You're Not Going That Way!)

#### INTRODUCING A NEW LTFU STUDY NEWSLETTER

This is the first issue of Looking Forward, a new LTFU publication, in which we'll feature stories about survivors like you.

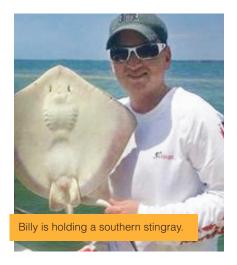
These individuals are engaged with life and "looking forward" to each new day. We'll also bring you stories about "Community Partners" people and institutions who are making a

difference by providing concrete help and services to survivors in their area or nationwide.

Did you know that you are one of more than 24,000 childhood cancer survivors who take part in the Long-Term Follow-Up Study?

You may have been in the study since it began in 1995. Or, you may have joined more recently as part of a new group of survivors diagnosed between 1987 and 1999.

Either way, many of you have asked for a publication like this. We hope you enjoy this first issue!



## **Unstoppable Billy Rivard**

Billy Rivard teaches high school biology in Mendon, Michigan. He's a recent graduate of Western Michigan University in Kalamazoo.

In 1996, at age 5, Billy was diagnosed with acute lymphoblatic leukemia (ALL). After relapsing in 1999 he received a bone marrow transplant (BMT). "I caught a virus during the transplant and was in the hospital for four months!"

he recalls. In 2012, Billy found out that he would need a kidney transplant, too. "My uncle donated a kidney for me. No one in my immediate family was a match for the transplant because my blood type had changed from A to O as a result of the BMT!"

Billy's mom Linda is a nurse who is also a cancer survivor. She manages a survivorship clinic at Advocate Health Care in the Chicago area. She says that despite having so many issues Billy takes great ownership of his follow-up care: "He has been a great teacher for me in how to handle life after cancer."

Billy loves teaching. "It's a great profession to be in especially after going through cancer treatment," he says. "I'm able to use many real-life examples from my experience that show how important science is. My goal is to inspire somebody to be a doctor

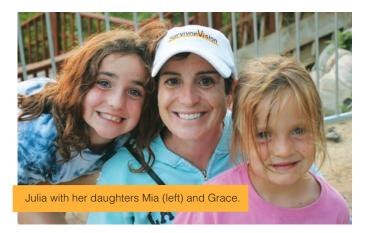
or researcher and figure out a way that nobody ever again will have to go through what I did.

Billy's favorite hobby is fishing. "And because of that I have a huge passion for the environment. I also think that being sick has made me realize how important a healthy environment is for everyone's health."

To pursue both interests, Billy is involved with an organization called the Coastal Marine Education Research Academy (CMERA), in Clearwater, Florida.

"We go out and tag sharks and sting rays as well as studying other marine life such as sea turtles.," Billy says. "This is probably my favorite thing I have ever been a part of."

With his complicated medical history, Billy has to stay on top of his health. In discovering his passions, he has found plenty of reasons to do so!



For more information, please contact us at: 1-800-775-2167

On the web: LTFU.stjude.org Email: LTFU@stjude.org



#### **Community Partners:**

## Julia Stepenske & SurvivorVision®

Julia Stepenske is a childhood cancer survivor whose experience helped decide her career path. She was diagnosed with non-Hodgkin lymphoma in 1989 at age 15. She was treated on a clinical trial at Children's Memorial Hospital in Chicago and her cancer went into remission.

"In college, I decided to make it my life's mission to help childhood cancer patients in any way possible, so I went into nursing," Julia says. She worked first as a pediatric oncology nurse at the hospital where she was treated, later moving to work at a survivorship clinic. Through her professional work Julia saw an opportunity to help in other ways. With a group of her friends she created a foundation called SurvivorVision that provides funding for programs to help childhood cancer survivors thrive and meet their goals.

100+ day packs and textbook scholarships

SurvivorVision partners with participating hospitals to provide gift packs to bone marrow transplant patients to acknowledge their 100th day after transplant. The 100th day is a major milestone for BMT recipients. The packs include gifts such as a t-shirt, a waterbottle, a notepad for journaling, and a commemorative bead from the children's charity "Beads of Courage."

The foundation also sponsors scholarships to cover the cost of college textbooks.
The scholarships are open to all childhood cancer survivors.
An application form is available on the foundation website:

#### survivorvision.org/ about-us/our-programs/

"As a bedside nurse working with transplant patients I realized that Day +100 was a really big deal and not every hospital did special things for the kids on that day," Julia says. "Also, I was blessed to have a textbook scholarship in college and figured why not start one, so we did."

While pregnant with her second child Grace, Julia's cancer unexpectedly returned 19 years after it went into remission. Fortunately, she was diagnosed and treated quickly thanks to advances in cancer treatment and to being cared for at a childhood cancer program that helped her navigate life after cancer. "Being connected to a specialized survivorship program saved my life," Julia says. "I wish that all survivors could have an opportunity to get their follow-up care at a dedicated survivorship clinic."

As a two-time cancer survivor, Julia cherishes her time with her family. "We do everything together," she says. "We cross-country ski and bike as a family. And we celebrate everything—birthdays, holidays, weekly events like pizza-and-amovie night, board game night, we make time to do things together."

#### LOOKING FOR A VOLUNTEER OPPORTUNITY?

We learned about Imerman Angels from Billy Rivard who has signed up with the program. This organization matches people who have been affected by cancer and are seeking support with a volunteer mentor who is the same age, same gender, and has faced the same type of cancer. Their website has

information about how to become a mentor "angel" as well as information about other volunteer opportunities:

imermanangels.org/ give-support/ Is there a "Community Partner" in your area that you'd like to see featured in a future issue of Looking Forward? Please submit your suggestions on our website:

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