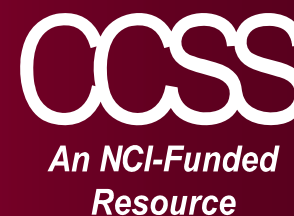
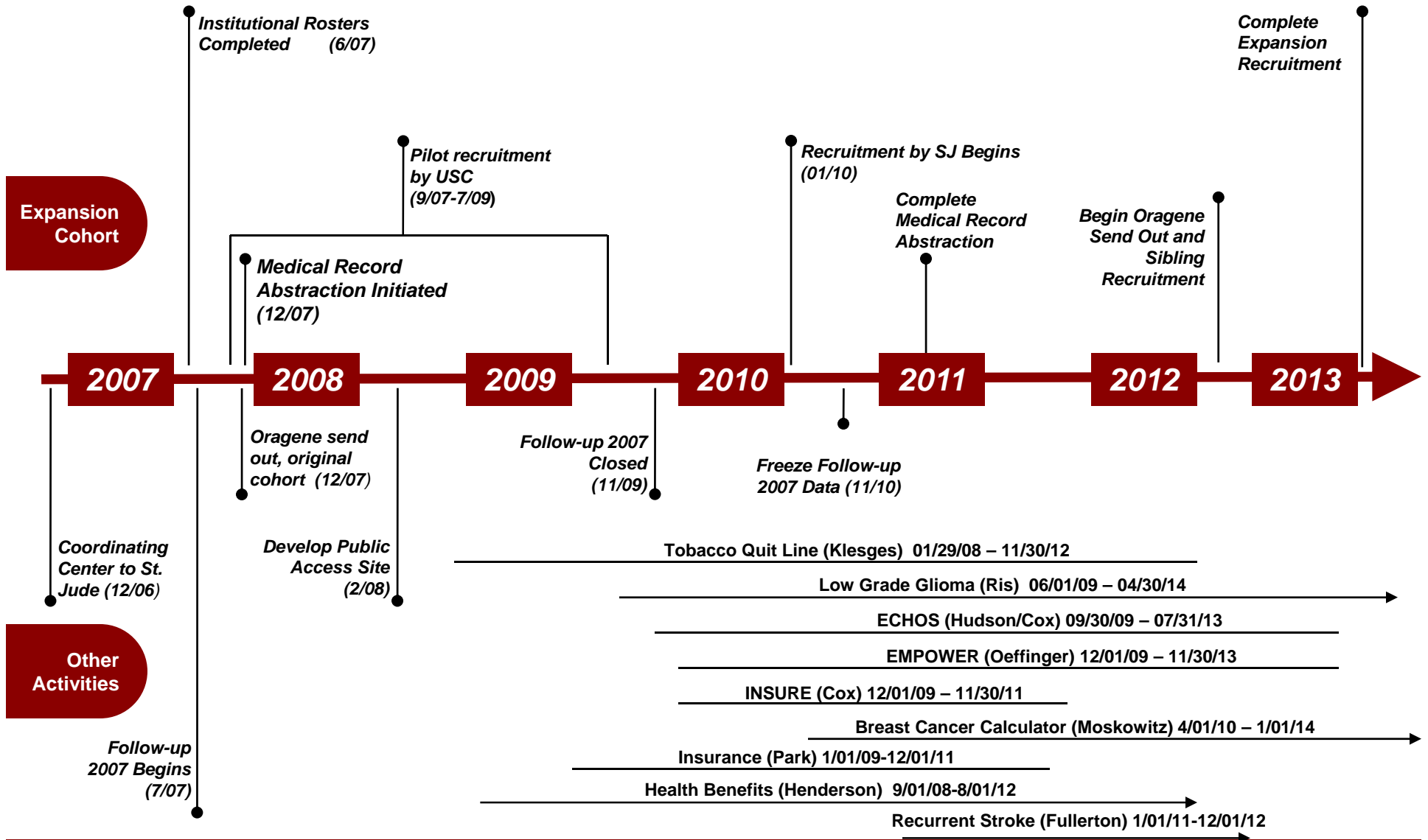
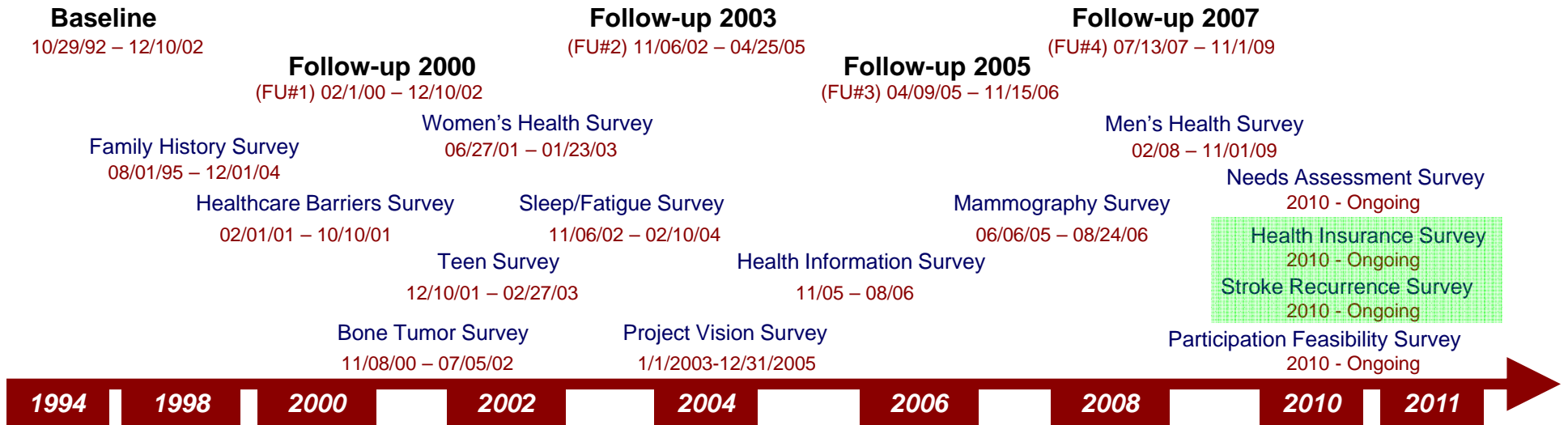


Childhood Cancer Survivor Study
Coordinating Center Report

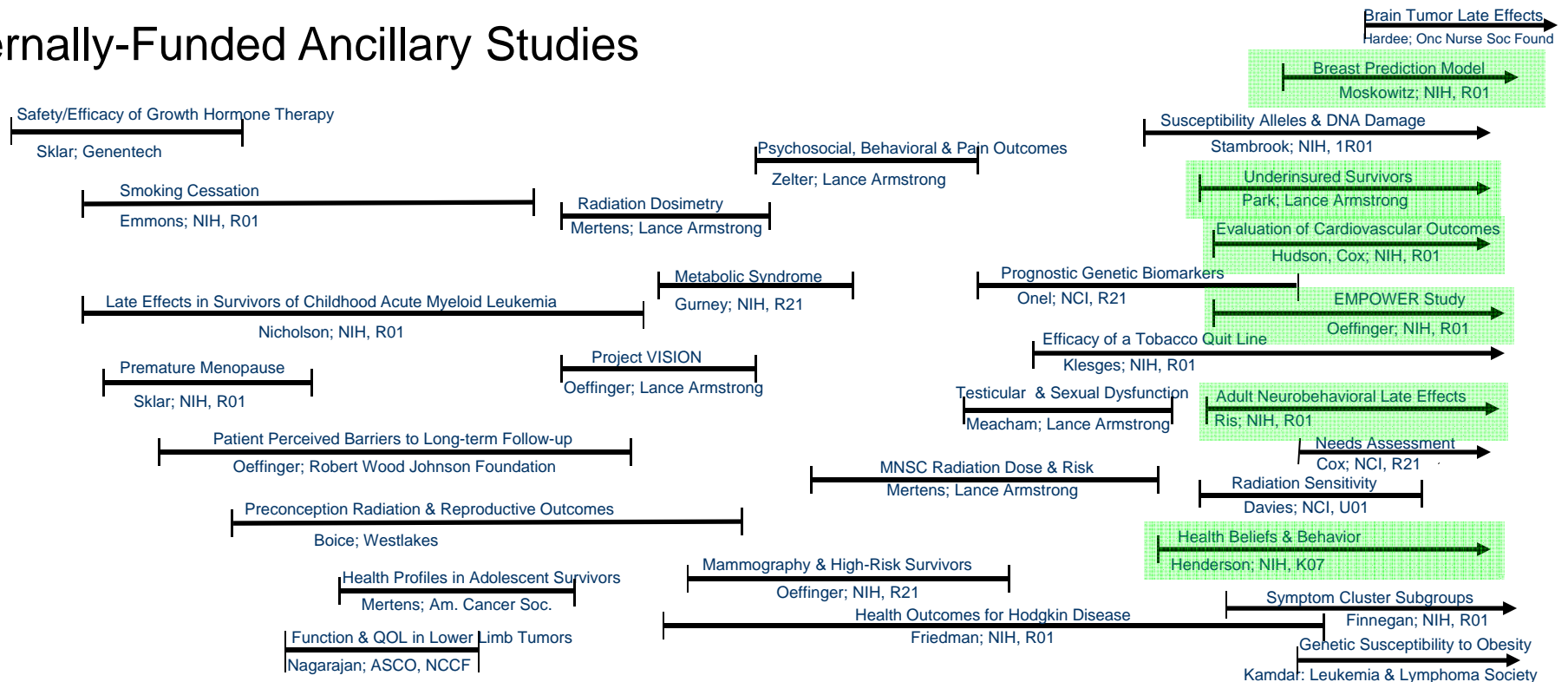
Greg Armstrong, M.D., M.S.C.E.
CCSS Project Director



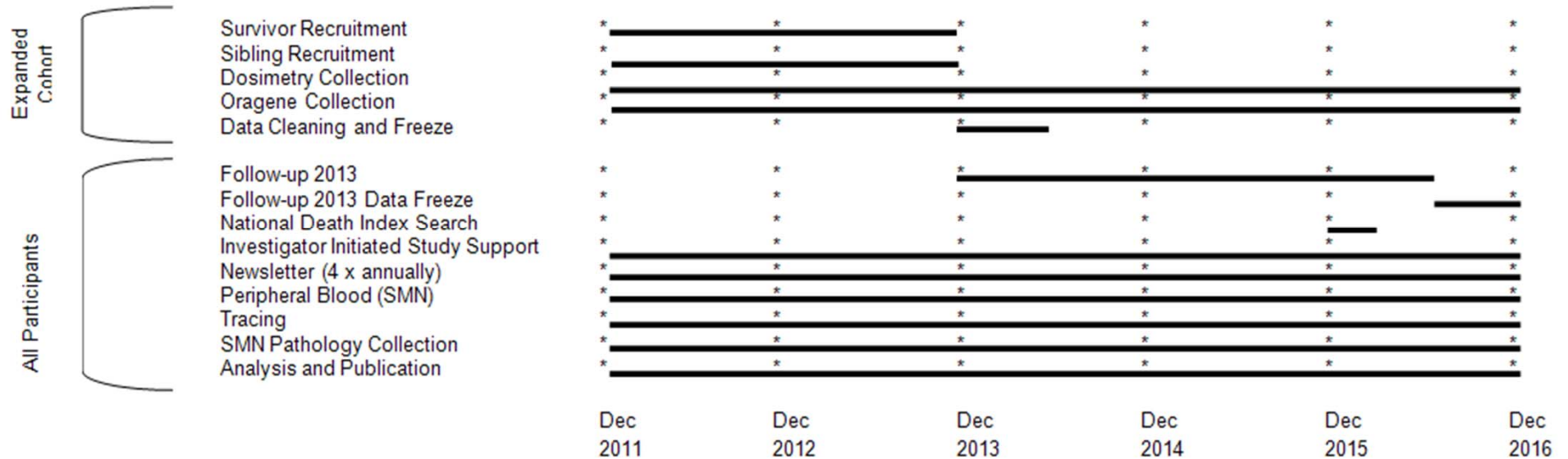




Externally-Funded Ancillary Studies



Competitive Renewal Timeline (April 2011)



- Mailed packets
 - 46,590 expansion HIPPAAs & baseline surveys
 - 7,750 ancillary study surveys/materials
 - 16,192 Oragene kits
 - 69,000 newsletters/briefs
- SMNs
 - 2,152 self-reports with follow-up
- Blood collection
 - 1,549 specimens
- Outgoing calls by CCSS call center
 - 113,088 (2011 alone)

Interviewer/Project Allocation: Weekly Hours

Expansion recruitment	184	
Baseline survey	148	
Tracing	152	
Ancillary study calls	138	
Administrative	44	
Oragene	25.6	
Blood/Tissue	15.2	
SMNs	3.2	
<hr/>		
TOTAL	740	18.5 FTE



CCSS Coordinating Center Staff

Coordinating Center

Aaron McDonald
Jenny Lanctot
Jerry Bates
Lynn Harrison
James Ford
LaKeisha Harris
Twanna Smith
Deanna Combs
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Donna Davis
Ebony Moore
Erin Pinkney
Justin Currie
Kathy Rothammer
Laura Beauchamp
Madelene Wilson
Melanie Jackson
Patsy Hall
Tracy Smith
Ines Negrette



Cohort Expansion

Cohort Expansion

- Diagnosed and treated 1987-99
 - Baseline survey based on original cohort baseline
- Recruitment
 - Privacy laws (HIPAA), new methods needed
 - USC as business associate
 - Pilot testing: Sept. 2007- July 2009

Cohort Expansion

- Diagnosed and treated 1987-99
 - Baseline survey based on original cohort baseline
- Recruitment
 - Privacy laws (HIPAA), new methods needed
 - **St. Jude** as business associate **January 2010**
 - Pilot testing: Sept. 2007- July 2009

USC as Business Associate: Summary of Results

- Identified need for intensive recruitment methods
 - Mail, web-based and phone completion, email
 - Aggressive tracing (Lexus Nexus)
 - Oral HIPPA (oral instructions for written authorization)
- Final Report. December 31, 2010:

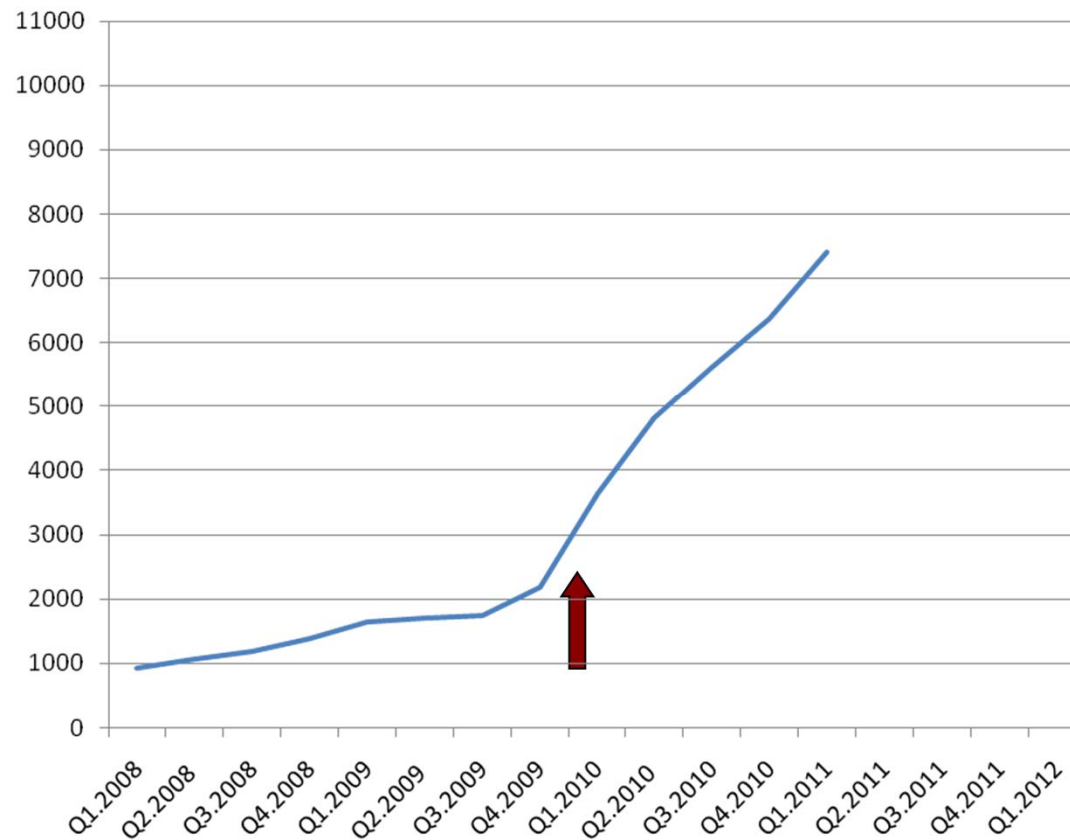
		Total N	HIPAA's Received N (%)	Refusals N (%)	Non Responders N (%)
Total		8308			
Ineligible		933			
Eligible Subjects		7375	3925 (53%)	419 (6%)	3031 (41%)
Institutions	St Jude (#15) **	2138	1150 (54%)	61 (3%)	927 (43%)
	UCSF (#11)	420	295 (70%)	44 (10%)	81 (19%)
	Roswell (#17)	243	140 (58%)	18 (7%)	85 (35%)
	Riley (#24)	885	441 (50%)	37 (4%)	407 (46%)
	Minneapolis (#19)	585	410 (70%)	64 (11%)	111 (19%)
	UTSW (#27)	646	212 (33%)	10 (2%)	424 (66%)
	Emory (#6)	729	328 (45%)	33 (5%)	368 (50%)
	Pittsburgh Children's (#3)	810	446 (55%)	63 (8%)	301 (37%)
	Dana Farber (#5)	919	503 (55%)	89 (10%)	327 (36%)

** Includes only USC recruitment data

- Amendment 9.0
 - BAA or waiver of HIPAA for SJ (not CCSS) to directly contact eligible's for HIPAA signature
 - Approved at **all** active institutions
 - “Firewall” between St. Jude and CCSS
- Recruitment (HIPAA authorization)
 - MSKCC: Jan. 2010 **64%**
 - CHOP: Feb 2010 **73%**
 - St. Jude: March 2010 **86%**

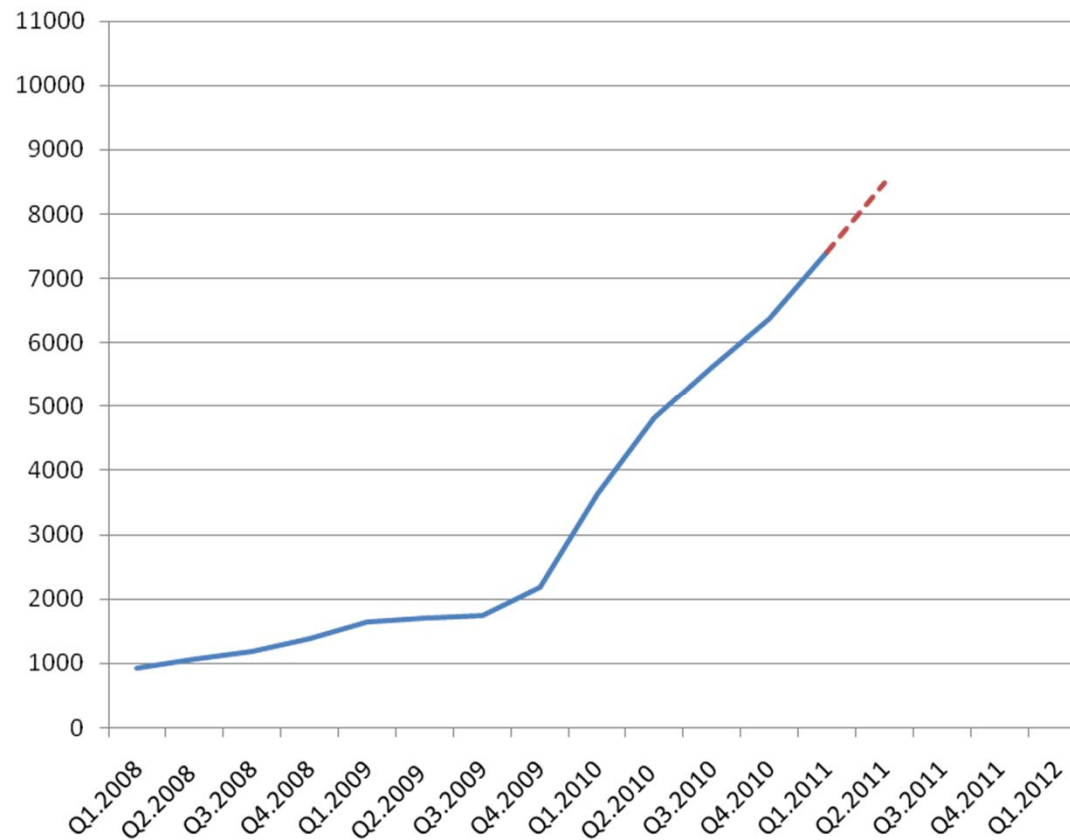
Cumulative Enrollment by Quarter

Cumulative Enrollment by Quarter



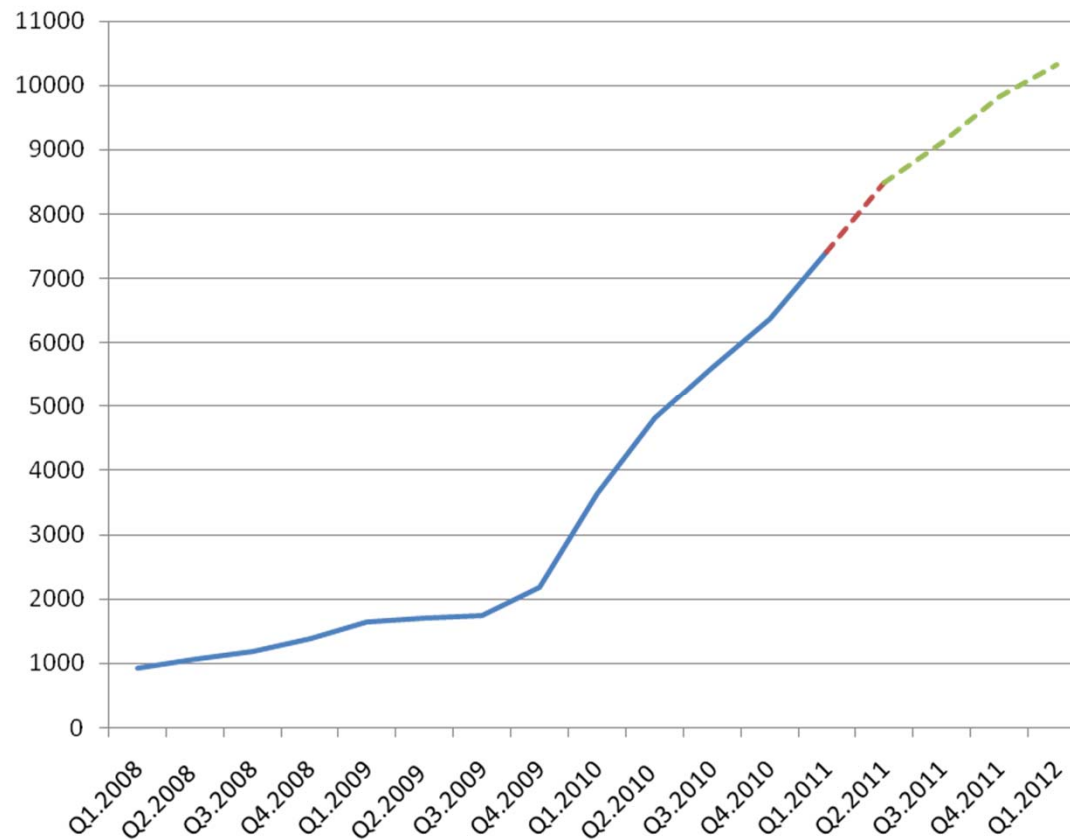
Cumulative Enrollment by Quarter

Cumulative Enrollment by Quarter



Cumulative Enrollment by Quarter

Cumulative Enrollment by Quarter



Recruitment by Institution

as of May 23, 2012

Name	Eligible	HIPAA Returned	HIPAA Returned (% of Elig)	Baseline Completed	Baseline Completed (% of HIPAA)	Baseline Completed (% of Elig)
St. Jude Children's Research Hospital	2,147	1,847	86.03%	1,607	87.01%	74.85%
Univ of Michigan - Mott Children's Hospital	670	500	74.63%	363	72.60%	54.18%
Minneapolis Children's Medical Center	582	434	74.57%	313	72.12%	53.78%
University of Minnesota	279	208	74.55%	146	70.19%	52.33%
University of California at San Francisco	419	311	74.22%	208	66.88%	49.64%
Children's Hospital Colorado	597	442	74.04%	336	76.02%	56.28%
Childrens Hospital at Stanford University	372	275	73.92%	195	70.91%	52.42%
St. Louis Children's Hospital	422	309	73.22%	215	69.58%	50.95%
Childrens Hospital of Philadelphia	1,013	736	72.66%	558	75.82%	55.08%
Riley Hospital for Children, Indiana Univ.	860	619	71.98%	395	63.81%	45.93%
Emory University	720	508	70.56%	333	65.55%	46.25%
Children's Hospital of Pittsburgh	767	520	67.80%	361	69.42%	47.07%
Children's Hospital of Los Angeles	749	507	67.69%	303	59.76%	40.45%
U.T.M.D. Anderson Cancer Center	649	436	67.18%	275	63.07%	42.37%
Nationwide Childrens Hospital (Columbus)	501	335	66.87%	250	74.63%	49.90%
Roswell Park Cancer Institute	241	160	66.39%	110	68.75%	45.64%
Dana-Farber Cancer Institute	919	597	64.96%	372	62.31%	40.48%
Memorial Sloan-Kettering Cancer Center	653	419	64.17%	337	80.43%	51.61%
Seattle Children's Hospital	831	530	63.78%	352	66.42%	42.36%
<i>Sub-Total</i>	13,391	9,693	72.38%	7,029	72.52%	52.49%
UCLA Mattel Children's Hospital	67	39	58.21%	28	71.79%	41.79%
UT Southwestern Medical Center (Dallas)	643	364	56.61%	220	60.44%	34.21%
City of Hope	132	73	55.30%	47	64.38%	35.61%
UAB/The Childrens Hospital of Alabama	365	193	52.88%	148	76.68%	40.55%
Texas Children's Hospital	622	121	19.45%	118	97.52%	18.97%
Children's National Medical Center	317	51	16.09%	43	84.31%	13.56%
<i>Total</i>	15,537	10,534	67.80%	7,633	72.46%	49.13%
Toronto Hospital for Sick Children	1,283	0	0.00%	0	0.00%	0.00%

HIPAA's Received	10,512	
Questionnaires Sent	10,506	
Pending Send out	6	
Returned	7,587	72.2% of sent
Alive		
<i>Number Sent</i>	9,817	<i>% of Sent</i>
Number Completed	7,125	72.6%
Deceased		
<i>Number Eligible</i>	689	<i>% of Sent</i>
Completed	462	67.9%

MRAF Completion

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

MRAF Completion New Centers

Inst Code	Institution	Submitted Cases	Selected	Ineligible	Eligible	MRAFs* Completed	% of Eligible Completed
<i>Probationary Institutions (New Centers)</i>							
30	Children's Hospital of Orange County	690	593	0	593	0	0%
31	University of Chicago	464	459	107	352	352	100%
32	Northwestern Children's Hospital	1,176	1,114	2	1,112	530	48%
33	Cook Children's Hospital	620	551	4	547	227	41%

Expansion: Priorities and Challenges

- **Completion of baseline survey**
 - Close the “gap”
- **Siblings** (n = 4000 proposed)
 - Recruit 2000 sibs to achieve at least n = 1000
 - Sample: every 4th survivor
 - Method: contact survivor for permission, then nearest age sibling for survey completion
 - Eligibility: sib must be at least 5 years old
- **Follow Up 2013**
 - Harmonization committee (Epi/Biostats)

Recently Completed

- Underinsurance (Park, LAF)
 - Quality, perceptions, consequences of inadequate coverage
 - Completed 5/2012
- INSURE (Cox, R21)
 - Needs assessment survey
 - Manuscripts drafted

Ongoing

- Late effects of low grade CNS tumors (Ris, R01)
 - Direct assessment of neuropsych function
 - Recruitment ongoing through 2013
- EMPOWER (Oeffinger, RO1)
 - Efficacy of stepwise, two component intervention on mammography rates
 - Recruitment ongoing through 2013
- ECHOS (Hudson/Cox, RO1)
 - Efficacy of intervention to increase CV screening
 - Nearing recruitment goal

Ongoing

- Breast cancer prediction model (Moskowitz, RO1)
 - Prediction tool: RT + traditional risk factors
 - Survey completion underway
- Health belief and behavior (Henderson, K07)
 - Characterize barriers and facilitators of breast cancer surveillance
 - Survey completion underway

Oragene, Blood & Tissue

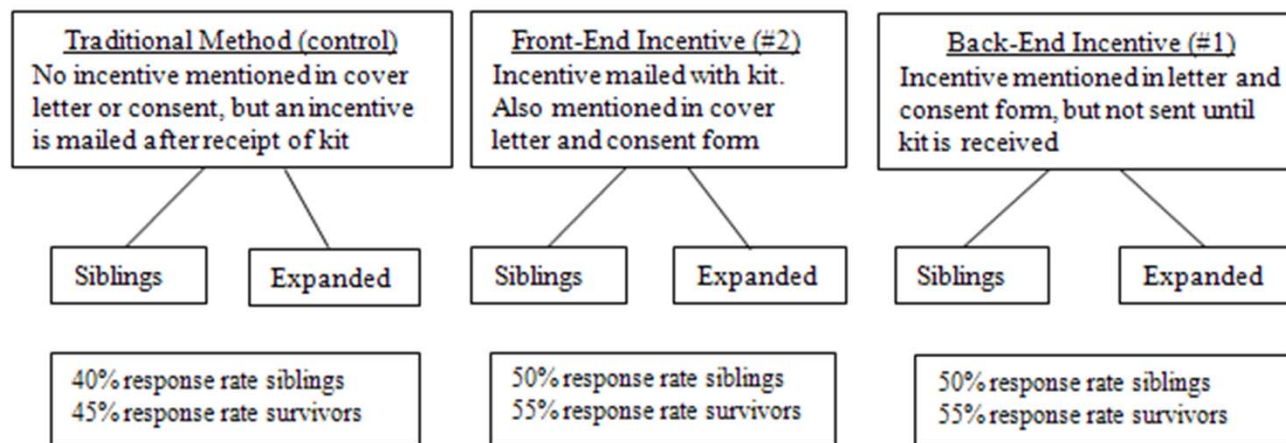
Kits Sent	Cases (n = 8,288)		Siblings (n = 2,710)	
	<i>n</i>	% of Sent	<i>n</i>	% of Sent
Returned	4,127	49.9%	737	27.2%
Refused	725	8.7%	96	3.5%
Pending	2,841	34.3%	1,672	61.7%
In Tracing	472	5.7%	201	7.4%
Deceased	123	1.5%	4	0.1%

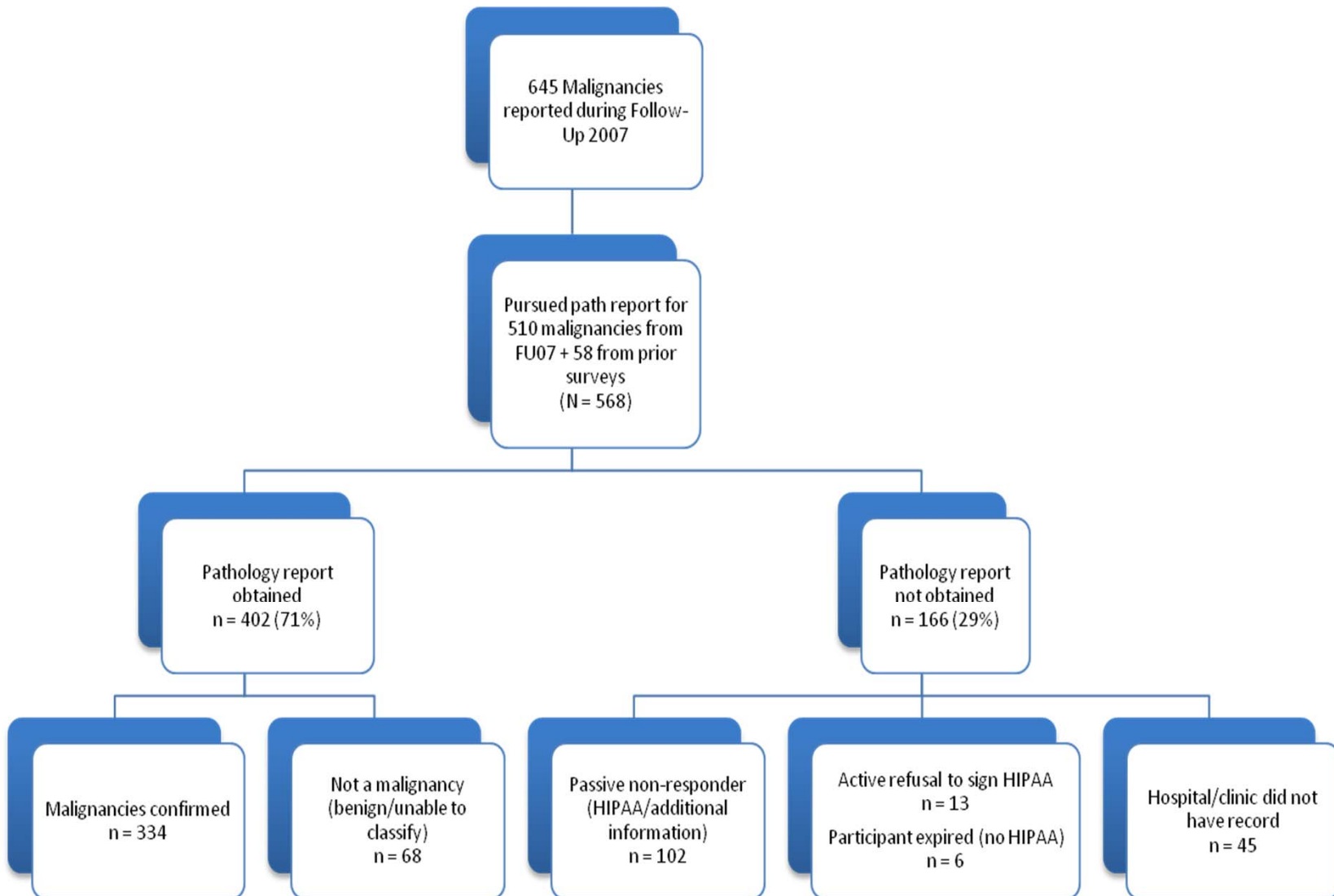
Methodology Summary

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

Oragene Incentive Pilot: Original sibs, Expansion survivors


- Assess the effect of an incentive on the oragene kit return rate







St. Jude Children's
Research Hospital
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The Childhood Cancer Survivor Study


Quick Links

- [CCSS Home](#)
- [New Public Access Data Tables](#)
- [Second Neoplasm Data](#)


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What's New In CCSS

- [New Tool for Authors to upload Abstracts and Papers](#)
- [New SOP info for the Conduct of Ancillary Studies](#)
- [2012 CCSS Investigator Meeting - New Reservation Info Available](#)
- [January LTFU Brief Update](#)

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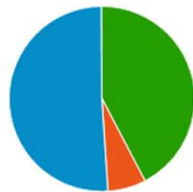
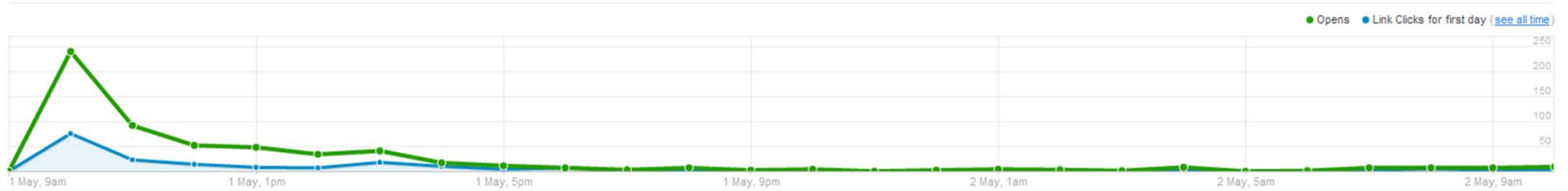
Publications Update

- [Risky Health Behavior Among Adolescents in the Childhood Cancer Survivor Study Cohort](#), Klosky JL, Journal of Pediatric Psychology, 2012
- [Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: Implications for Affordable Care Act](#), Park ER, J Cancer Survivorship, 2012

Newsletter Statistics

2012 Spring

Sent on 1 May 2012 to 577 unique subscribers in CCSS Broad Range



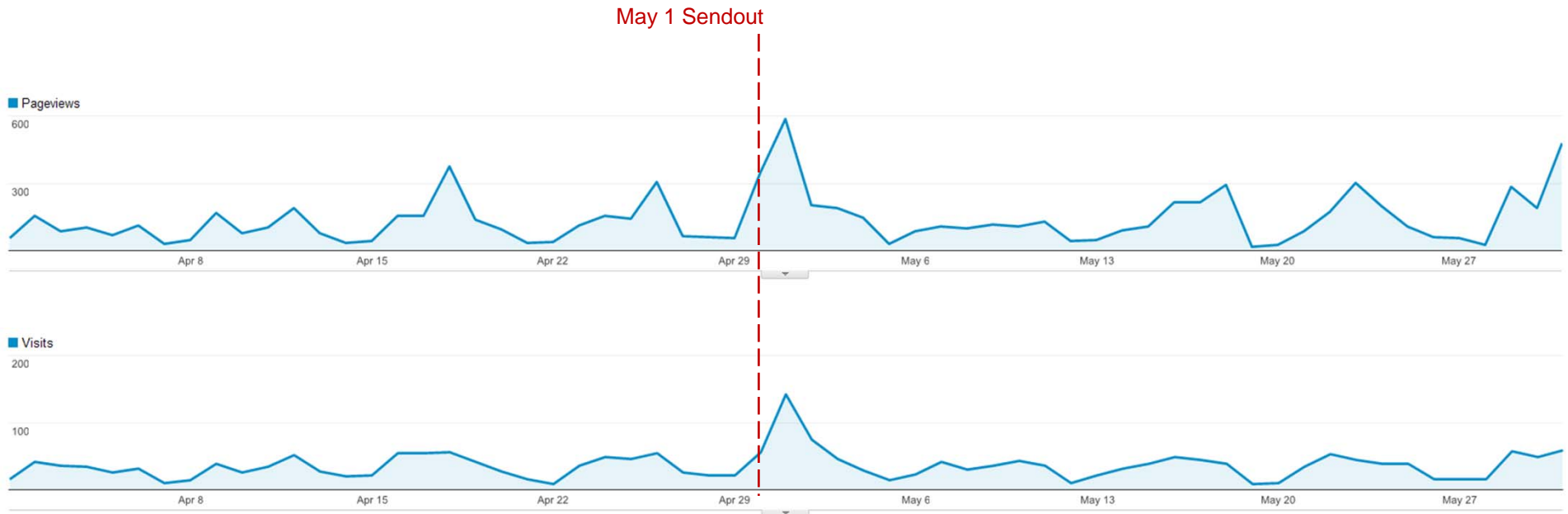
- **244 Unique opens**
894 total opens to date
- **38 Bounced**
6.59% couldn't be delivered
- **295 Not Opened**
Open rates are [only estimates](#)

- 45.27%** of all recipients [opened so far](#)
- 52.05%** [clicked a link](#) (127 people)
- 0.19%** [unsubscribed](#) (1 person)
- 0** people marked it as spam (0%)
- 3** [shares](#) across Facebook, Twitter & email

Most popular links (full report)	Clicks
ccss.stjude.org/published-research/publications#bottom	73
ccss.stjude.org/investigator-meeting/upcoming	50
ccss.stjude.org/documents/newsletters	29
ccss.stjude.org/published-research/abstracts#bottom	25
ccss.stjude.org/	23

Top countries (full report)	Opens
United States of America	778
Canada	28
United Kingdom	23
Japan	23
Switzerland	13

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1,486 people visited this site

Visits: 2,234

Unique Visitors: 1,486

Pageviews: 8,558

Pages/Visit: 3.83

Avg. Visit Duration: 00:03:53

Bounce Rate: 47.58%

% New Visits: 57.65%



57.65% New Visitor

1,288 Visits

42.35% Returning Visitor

946 Visits



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