



Childhood Cancer Survivor Study (U24 CA55727)

Report of the
Principal Investigator
Les Robison, PhD

CCSS Investigator Meeting
Williamsburg, VA
June 9-10, 2010

2010 Investigator Meeting

Wednesday

Standing Reports
Reception

Thursday

CCSS 101
Working Group Reports
Break-out Lunch Sessions
Research Presentation

Objective: To provide investigators, who are unfamiliar with the workings of CCSS, an overview of the opportunities for research and mechanisms to access the CCSS resource.

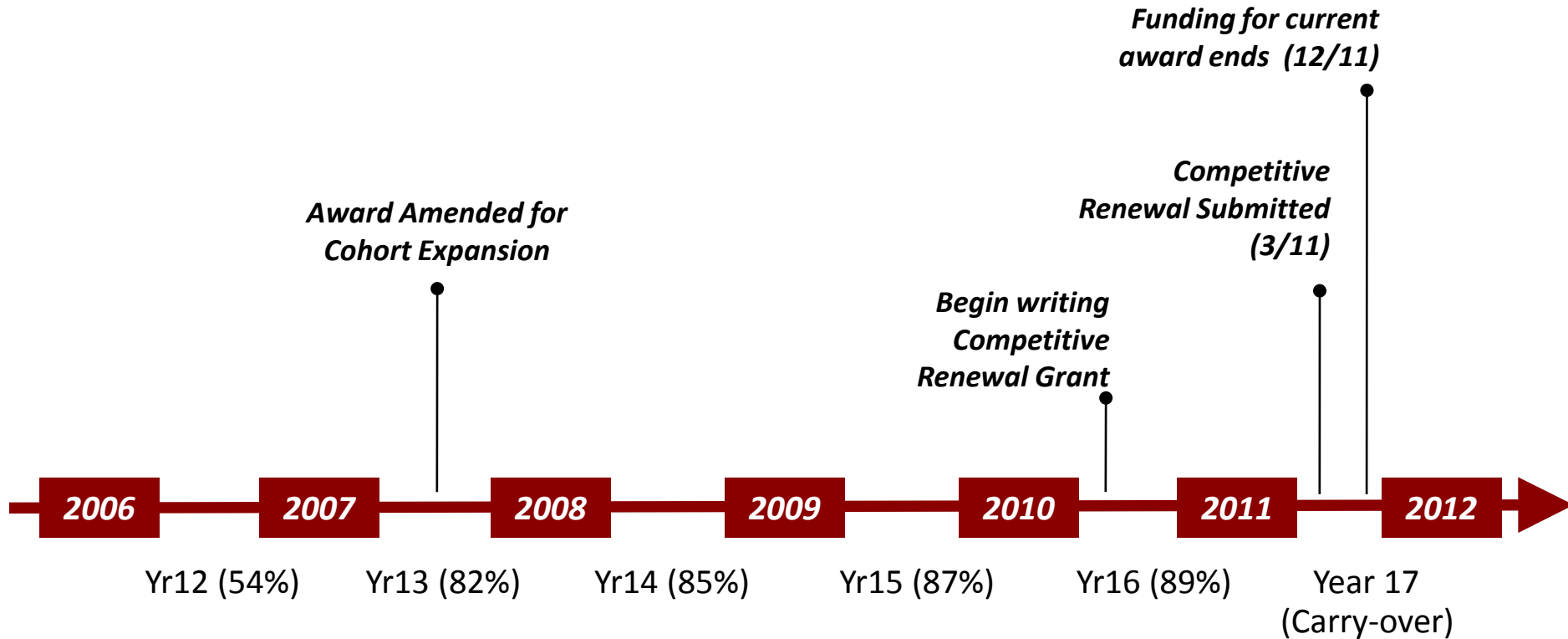
Presenters: Greg Armstrong
Eric Chow
Wendy Leisenring
Les Robison

When: Thursday, 8:00 - 9:30 am

Research Presentations

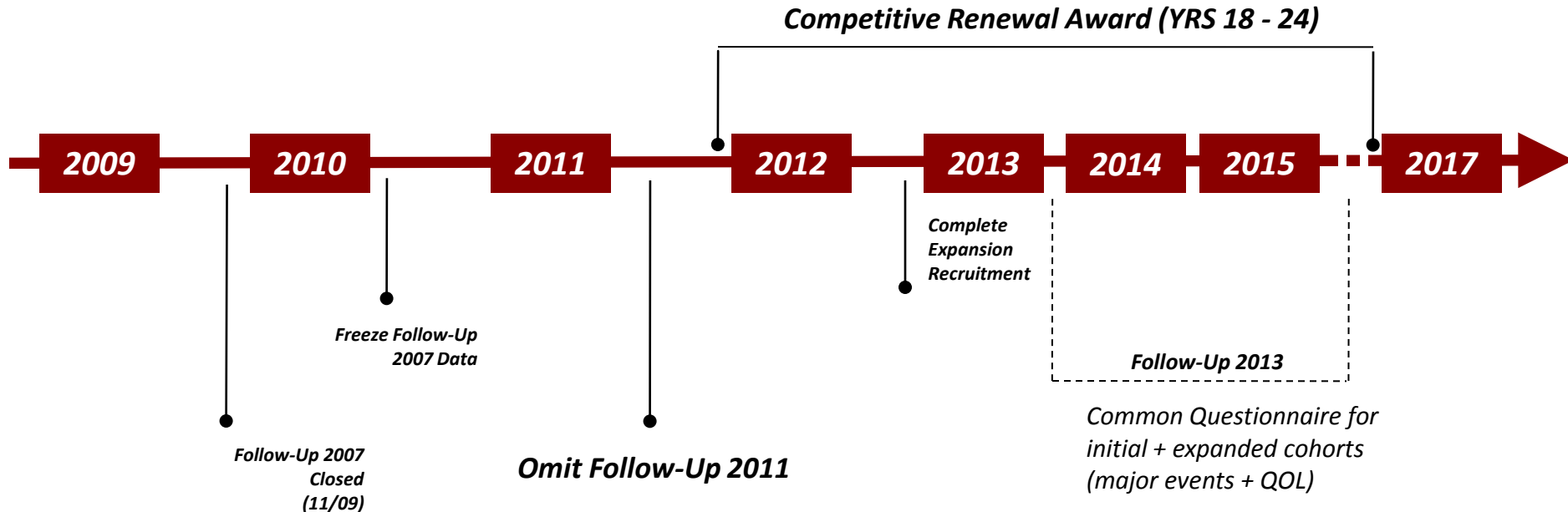
PRESENTER	TOPIC
Mike Hawkins	Results from the British Childhood Cancer Survivor Study
Lene Veiga	Chemotherapy-Associated Risk of Secondary Thyroid Cancer
Debra Friedman	Update of Second Malignancy in the CCSS Cohort
Lillian Meacham	Cardiovascular Risk Factor Analysis
Lonnie Zeltzer	Post-traumatic Growth
Nina Kadan-Lottick	NCQ in Leukemia

Funding



2011 Follow-up Survey

- Next Follow-up of Initial Cohort
- Burden on Cohort – stable participation rates
- Resources available
- Blending with Expanded Cohort (timing)
- Timeliness of SMN Validation



Workshops

- Series of small workshops
- Map the future direction for Working Groups
- Research focus
 - Ongoing ascertainment of events
 - Priorities/innovation
 - Interventional
 - Investigator-initiated
 - Collaborative
- Integration with other Working Groups
- Transition of leadership
- Genetics and Second Malignancies
- Future retreat

Additional Institutions

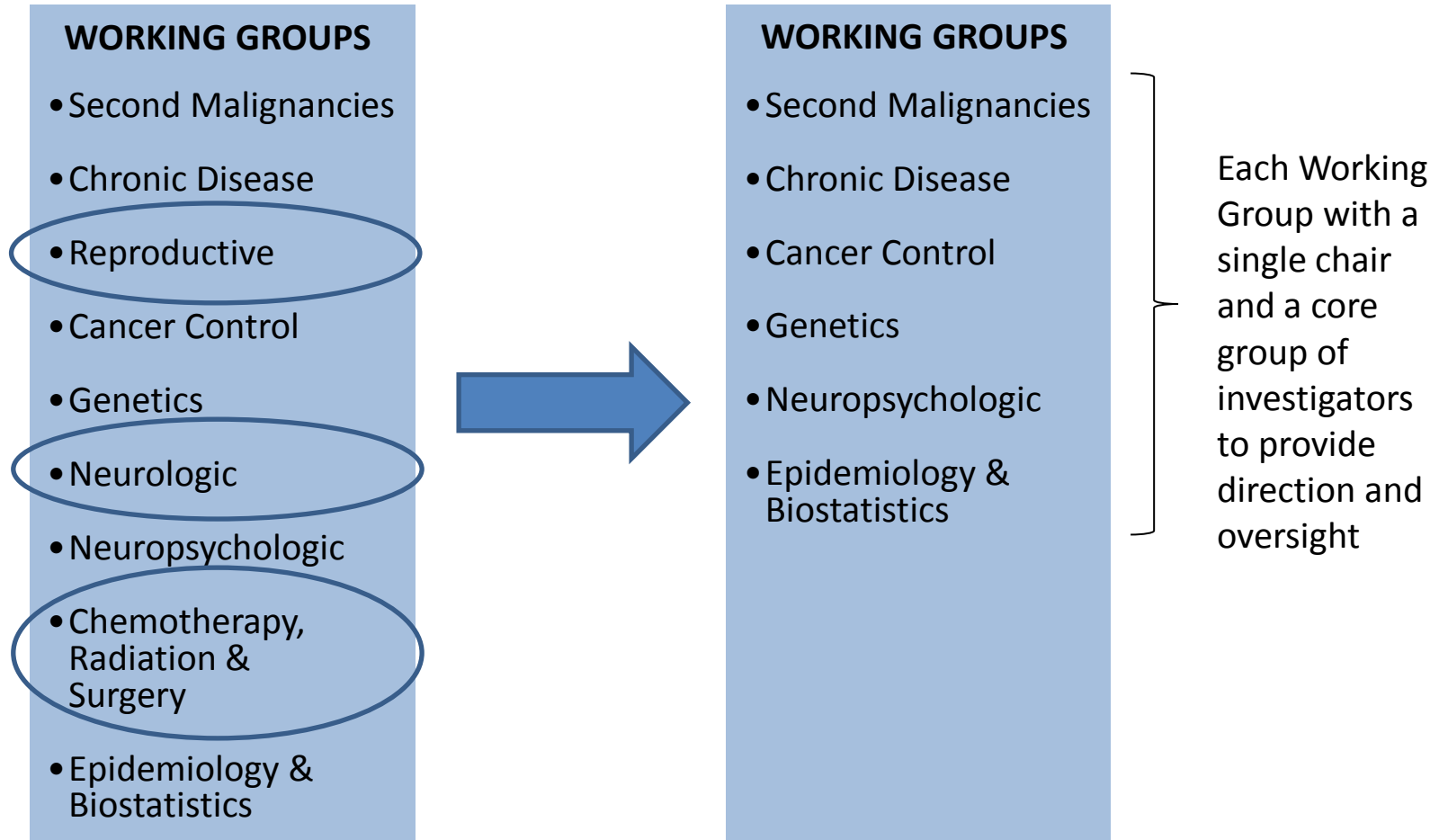
University of Chicago (Tara Henderson)

Northwestern University (Kimberly Dilley)

Children's Hospital, Orange County (Leonard Sender)

Cook Children's, Fort Worth (Paul Bowman)

CCSS Re-organization



Continued Strong Record of High Impact Publications

Since 2001:

142 Published and In Press (46 with impact factor >15)

12 Submitted

2005-2008: Five CCSS paper appear on the annual JCO list of major advances in cancer treatment, prevention, and screening

Scope of Published Research

Alcohol Use

Cardiac Outcomes

Chronic Health Conditions

Complementary/Alternative Rx

Dental

Diabetes

Education/Employment

Endocrine

General Survivorship

Genetics/Family History

Gonadal Function/Pregnancy

Growth Hormone

Health Status

Healthcare Utilization/Screening

Insurance

Marriage

Mortality

Neurologic/Neurosensory

Osteonecrosis

Physical Function

Psychology

Pulmonary

Quality of Life

Second Neoplasms

Sleep/Fatigue

Smoking

Stroke

Survivorship Methodology

Thyroid

Weight/Body Mass Index

Increase in Investigator-Initiated Ancillary Projects

Intervention-based Randomized Trials:

Tobacco Quit Line (R01) – Smoking Cessation

EMPOWER (R01) – Screening for Breast Cancer

ECHOS (R01) – Screening for Cardiac Dysfunction

High Level of Involvement by Young Investigators

- 30 trainees are first author on a CCSS publication as part of medical, graduate or post-doctoral training.
- 31% of all publications has a CCSS trainee as a first author.
- Trainee has appeared as an author on 52% of CCSS publication.

Disease-specific Publications

DISEASE	AUTHOR/MENTOR	STATUS
AML	Mulrooney/Davies	Cancer
ALL	Mody/Neglia	Blood
NBL	Laverdiere/Sklar	JNCI
NHL	Bluhm/Inskip	Blood
CNS	Armstrong/Packer	JNCI
STS	Punky/Baker	Pediat Blood Cancer
ES	Nagarajan/Marina	Cancer (In Press)
OS	Ginsberg/Oeffinger	Submitted to JNCI
HD	Castellino/Hudson	Submitted to Blood
WT	Termulhlen/Green	Manuscript – Final Draft

Sustained Participation of Cohort Members

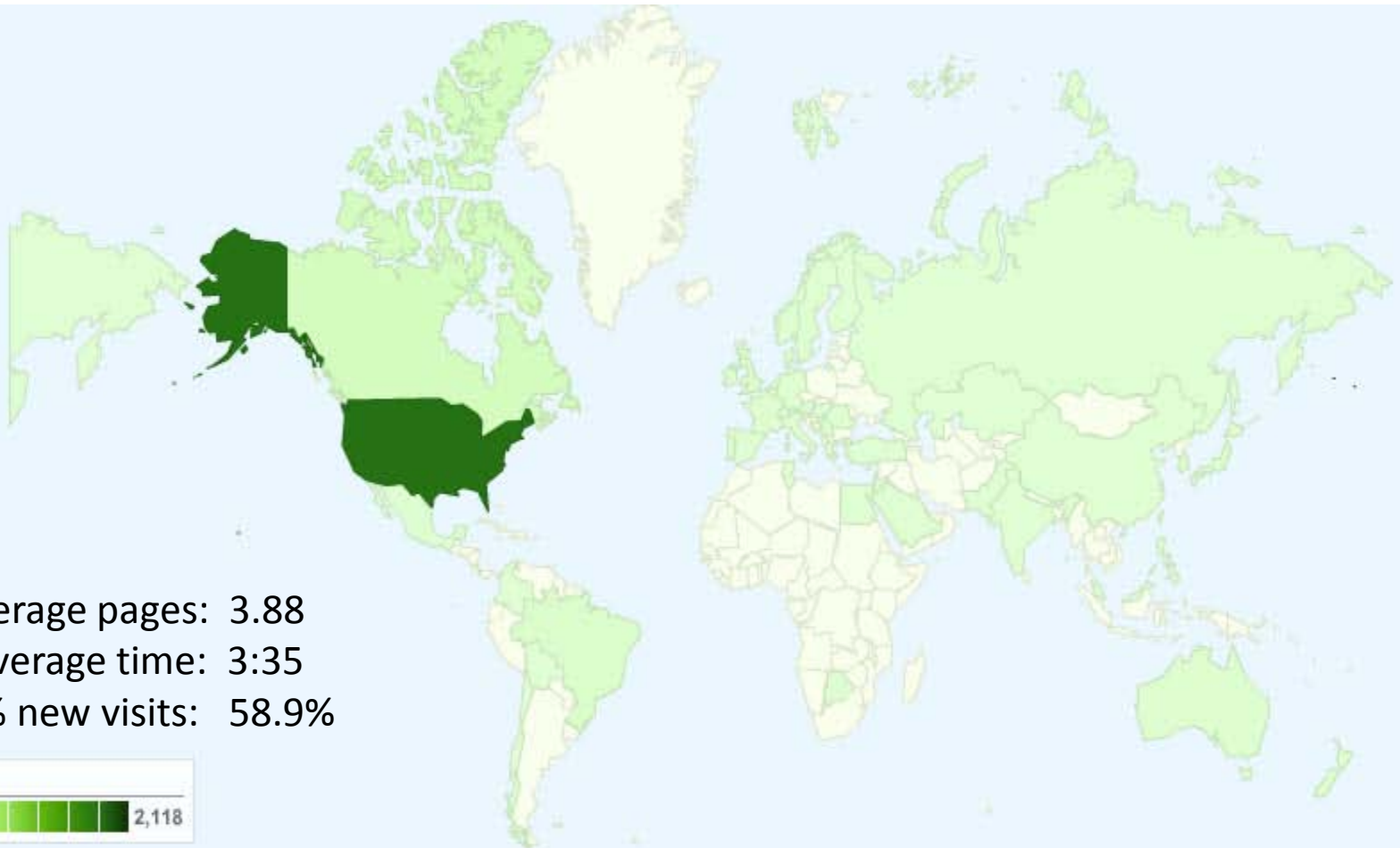
Recruitment of Expanded Cohort

Grant Renewal

Aging









Genetic-based Research

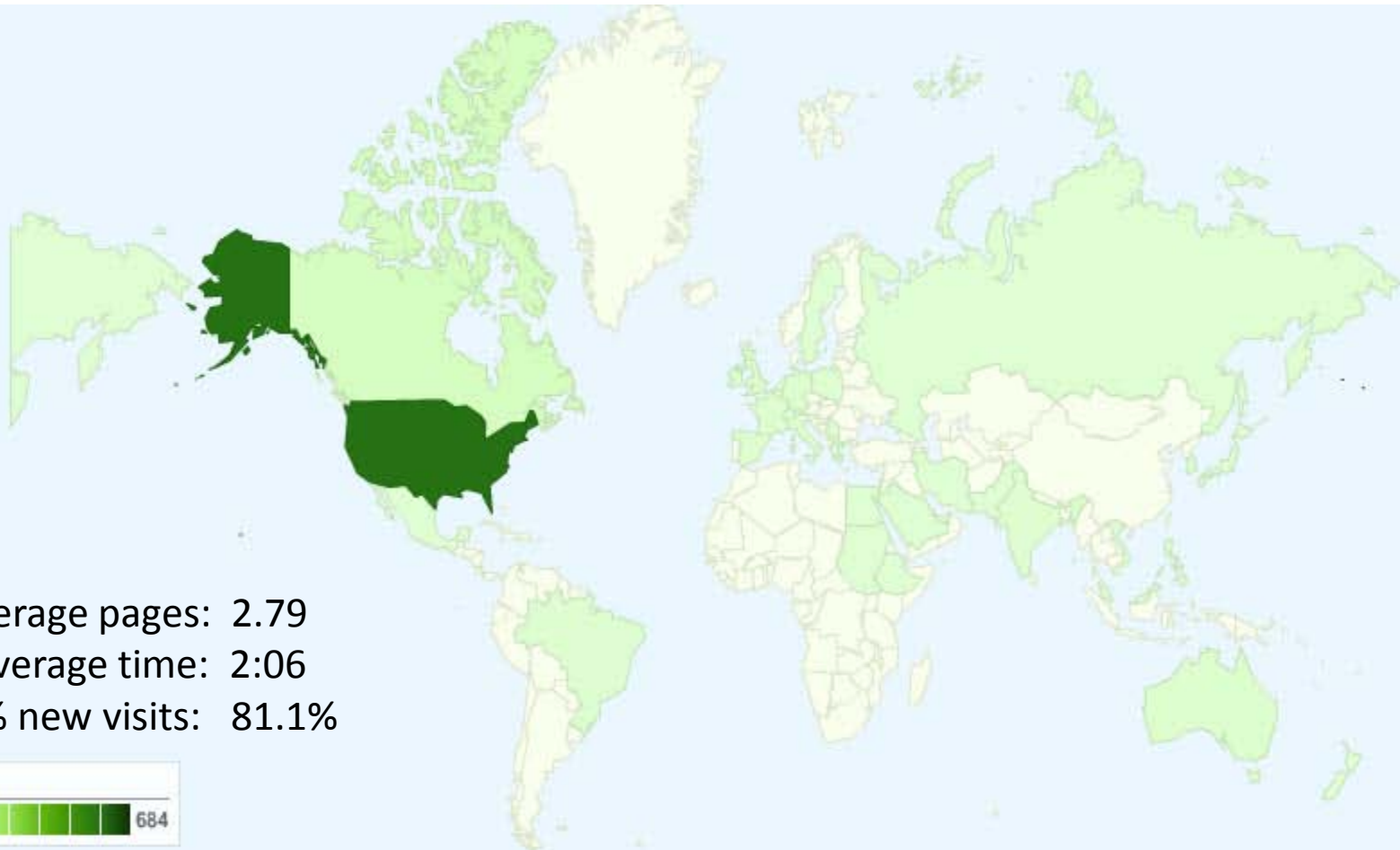
Intervention Studies



Average pages: 3.88
Average time: 3:35
% new visits: 58.9%

2,595 visits came from 55 countries/territories (1/26/2010 – 5/25/2010)

	Page	(1/26/2010 – 5/25/2010)	Pageviews ↓	Unique Pageviews	Avg. Time on Page
1.	 /		2,084	1,559	00:00:38
2.	 /investigator-meeting/upcoming		748	440	00:01:06
3.	 /data-and-analysis/public-access-data-tables		677	300	00:01:25
4.	 /documents/original-cohort-questionnaires		568	230	00:02:12
5.	 /published-research/publications		499	383	00:04:00
6.	 /documents/questionnaires		390	264	00:00:10
7.	 /investigator-meeting/11th-annual		321	216	00:01:16
8.	 /forms/ccssAppOfIntent		295	138	00:03:31
9.	 /forms/ccssRegistration		273	197	00:01:59
10.	 /about/learn-more		258	196	00:01:15



Average pages: 2.79
Average time: 2:06
% new visits: 81.1%

868 visits came from 41 countries/territories (1/26/2010 – 5/25/2010)

	Page (1/26/2010 – 5/25/2010)	Pageviews ↓	Unique Pageviews	Avg. Time on Page
1.	/	799	607	00:01:03
2.	/childhood-cancer-survivor-study/published-r...	186	145	00:03:47
3.	/about/study-participants	170	98	00:00:29
4.	/about/definition-of-terms	133	112	00:01:35
5.	/health-update-surveys	122	80	00:00:54
6.	/newsletters	116	73	00:01:44
7.	/about/ccss-organizational-structure	105	71	00:01:18
8.	/childhood-cancer-survivor-study	98	70	00:01:00
9.	/about/ltfu-faq	84	70	00:01:21
10.	/childhood-cancer-survivor-study/aims-of-ccss	81	51	00:00:42