

SURVEILLANCE RESEARCH PROGRAM

Winter 2014 e-Newsletter

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The Surveillance Research Program directs the collection and analysis of data to answer key questions about cancer incidence, morbidity, mortality, and cancer-related health status in diverse regions and populations in the United States.

SRP Associate Director's Message

As the new Associate Director of the Surveillance Research Program (SRP), I would like to thank the surveillance community and others who have collaborated with SRP over the past year. I am excited about the new opportunities to enhance the usefulness of the Surveillance, Epidemiology, and End Results (SEER) Registries for research and to explore new methods for enhancing cancer surveillance in coming years. We have several new initiatives that we are targeting to begin in 2014. These will focus on improving the completeness and relevance of the SEER data using innovative methods that leverage existing data sources. The expectation is that this will allow the SEER data to better support research while reducing the manual effort performed by the registry staff. Several of these key areas include: capture of detailed information on treatment, both orally administered anti-neoplastics and traditional infusion therapy; testing methods to create a SEER-linked Virtual Tissue Repository; expanding the data feeds from pathology laboratories (including biomarkers from serologic samples); and exploring opportunities for new partnerships for data acquisition from organizations beyond the traditional SEER data sources. I am looking forward to collaborating with many of you on these projects as we determine the feasibility and assess best practices to implement these new initiatives.



Lynne Penberthy

I would also like to congratulate SRP staff for their many accomplishments in the past year—several warrant special mention. The Cancer Intervention and Surveillance Monitoring (CISNET) project directed by Dr. Rocky Feuer has been instrumental to the U.S. Preventive Services Task Force (USPSTF) in developing guidelines on [screening for lung cancer](#). Dr. Angela Mariotto, together with the Communications staff in SRP, has directed the launch of a new [SEER website](#), which has increased the usage of the website dramatically: 238,114 users since its launch in October. The DidYou Know? videos now include 10 topic areas, with the most recent video on "The Status of Cancer." Finally, all of SRP is looking forward to the SEER 40th Anniversary celebration in March of 2014 and to working with you in the future to continue to develop new cancer surveillance methods that support the research community.

In summary, all of us at SRP look forward to an exciting new year in 2014 in which we hope to set the direction for subsequent years as leaders in surveillance research methods and applications.



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New on the Net

Highlights

SRP Welcomes Lynne Penberthy as Associate Director

Dr. Penberthy will provide leadership in advancing SRP's mission, which includes management of the SEER Program, a comprehensive population-based reporting system. SRP also provides leadership in the interpretation of cancer statistics and in developing statistical methodologies for analyzing trends and evaluating the impact of cancer control interventions and other factors on the cancer burden. Dr. Penberthy brings expertise in cancer surveillance methodology and is interested in bridging the divide between technology and the clinical research enterprise by developing research resources. She is especially interested in using surveillance informatics to improve the assessment of eligibility for clinical trials.

"Given her expertise in informatics and registries, Dr. Penberthy is ideally suited to lead NCI's surveillance efforts in the new era of electronic medical records, big data, and precision medicine," noted Dr. Robert Croyle, Division of Cancer Control and Population Sciences (DCCPS) Director.

After receiving her bachelor's degree in biology and chemistry from the University of Miami, Dr. Penberthy obtained her M.D. from the University of Michigan. She completed a general surgery internship followed by a residency in preventive medicine and an M.P.H. in epidemiology at the Johns Hopkins School of Hygiene and Public Health. Dr. Penberthy's career also includes postdoctoral training in epidemiology assigned to the Centers for Disease Control and Prevention (CDC) as an epidemic intelligence service (EIS) officer with the Commonwealth of Virginia. Prior to her current NCI appointment, she was Director of Cancer Research Informatics and Services and Associate Professor of General Internal Medicine at the Virginia Commonwealth University Massey Cancer Center. In that position, she was the recipient of many NIH grants and contracts.

SEER Celebrates Its 40th Anniversary; Annual Meeting Moved to March 2014

The annual SEER Principal Investigators (PI) and Managers Meeting has been rescheduled to March 26–28, 2014.



**Happy 40th Anniversary
to the SEER Program!
1973-2013**

NIH Director Writes Christmas Editorial for *The Washington Post*

On January 2, 2014, Dr. Francis Collins shared his thoughts on the difficult year that NIH had just experienced. He reminded us that, "There's no question that 2013 was one of the more challenging years we have faced as an Agency. Losing \$1.55 billion in March because of sequestration—after years of flat budgets—only to be shut down for 16 days in October, could lead even the most optimistic amongst us to feel discouraged. But, despite losing almost 700 grants in 2013, NIH was a major source of support for 8 of the 10 most highly touted [scientific discoveries](#) of the year. Those highlights are not just the most highly touted biomedical discoveries—this top-10 list represents all of science, in every field, from high-energy physics to chemistry to energy research to biology and medicine, around the world! And, 80 percent of the success stories were based in whole or in part on NIH support."

Dr. Collins had already contributed an op-ed piece to *The Washington Post* that appeared on Christmas Eve, 2013, which we reprint below.

Opinions – in *The Washington Post*

Investing in the Nation's Health

By Francis S. Collins, Published: December 24, 2013

Francis S. Collins is Director of the National Institutes of Health.

Biomedical research is at a critical juncture—a moment of exceptional opportunities that demand exceptional attention if their promise is to be fully realized. Many of the most exciting possibilities stem from the convergence of several factors: innovative tools and technologies arising from the [Human Genome Project](#); advances in computers and biomedical imaging that are fueling a generation of complex digital data sets known as “big data”; and increased interest by both public and private sectors in finding ways to accelerate the rate at which research findings are turned into treatments and cures.

The National Institutes of Health (NIH) is responsible for turning scientific discoveries into better health, but a combination of sequestration-mandated spending cuts and budgets that have not kept pace with biomedical research inflation over the past 10 years has weakened NIH's ability to carry out its mission.

One transformative program that hangs in the balance is the [Brain Research through Advancing Innovative Neurotechnologies \(BRAIN\) Initiative](#), part of a focus aimed at revolutionizing understanding of the human brain. By catalyzing development and application of new technologies, researchers plan to produce a dynamic picture of the brain that shows, for the first time, how individual cells and complex neural circuits interact in both time and space. This could mean enormous advances for efforts to treat and possibly even prevent epilepsy, schizophrenia, Alzheimer's disease, autism, Parkinson's disease, traumatic brain injury and many other neurological conditions.

Another area of great promise is the ability to assemble very large data sets of medical research information. The advent of electronic health records will dramatically accelerate the “big data revolution.” Details can be understood by focusing on one disease: cancer. Taking advantage of breathtaking advances in DNA-sequencing technology, NIH-funded researchers working on the [Cancer Genome Atlas](#) have conducted comprehensive analyses of more than 20 different types of cancer and plan to study dozens more. Besides expanding understanding of the molecular roots of different cancers, this pioneering work has opened doors to new therapeutic targets, as well as to new and more precise uses of chemotherapy drugs. Unfortunately, this mountain of data will be of limited use to cancer patients if researchers and clinicians lack the tools necessary to manipulate and mine it effectively.

Another fascinating frontier is the microbiome. The human body contains trillions of microbes, outnumbering human cells 10 to 1. So far, work to gather information on the genetic makeup of these microbial communities has yielded important insights into their roles in a wide range of chronic diseases, including obesity, diabetes, allergies, cancer and heart disease. The opportunity to expand and build on that knowledge to develop evidence-based treatments, such as probiotics for obesity, is just one of the exciting possibilities.

Vaccine development is also poised for rapid progress, especially in the areas of AIDS and influenza. Some researchers are exploring the production of “broadly neutralizing” antibodies that work against all strains of a virus. In the case of influenza, that could mean an end to the annual flu shot and a vaccine that would profoundly reduce the global risks of the next influenza pandemic.

In recent years, researchers have learned how to reprogram human skin cells or white blood cells into induced pluripotent stem cells, which have the amazing ability to develop into different types of cells. This opens the door to unprecedented opportunities for the advancement of basic research into human development, acceleration of drug screening for a host of diseases, and design of new “cell-based” therapies to cure some of medicine's toughest challenges, such as sickle cell anemia and inherited forms of blindness.

Clearly, NIH is not lacking for ideas. And the institutes will continue to support innovative research across the country. But without sustained investment, many high-priority efforts would move at a substantially slower pace, and years of effectively flat funding for biomedical research have left scientists facing the lowest chances in history of having their research funded by NIH. Many young scientists are on the verge of giving up, taking with them the talent needed to make tomorrow's medical breakthroughs.

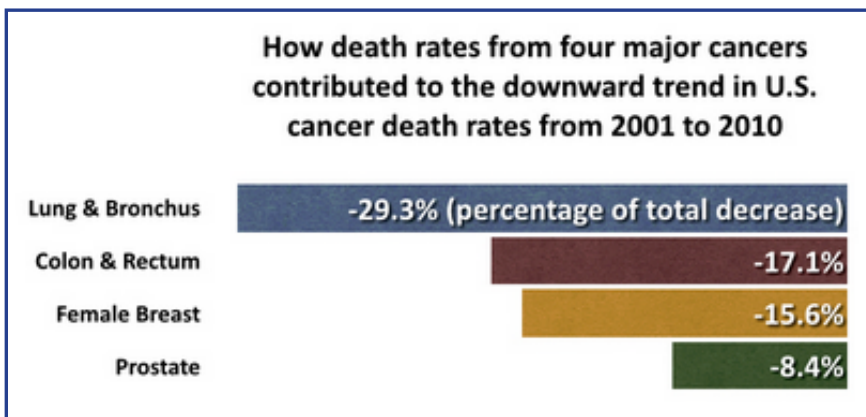
The budget deal reached last week, however, would give appropriators the chance to provide some much-needed relief for biomedical research. The economic benefits of NIH funding include a return-on-investment of research grants to local economies and cost savings from decreased disease burdens. But beyond that, for the millions of sick people awaiting treatments and cures, the investment in NIH's mission is priceless. If an investment in hope is not worth supporting, I don't know what is.

[Article available online at: http://www.washingtonpost.com/opinions/investing-in-the-nations-health-at-nih/2013/12/24/f43fc58a-61bc-11e3-bf45-61f69f54fc5f_story.html]

Annual Report to the Nation on the Status of Cancer

Lung cancer death rates continue to fall, helping to drive the ongoing decrease in overall cancer death rates. The *Annual Report to the Nation* includes a special feature highlighting the large impact of other diseases on cancer patient survival.

The *Annual Report to the Nation on the Status of Cancer*, covering the period 1975–2010, showed death rates for lung cancer, which accounts for more than one in four cancer deaths, dropping at a faster pace than in previous years. The recent larger drop in lung cancer deaths is likely the result of decreased cigarette smoking prevalence over many years, and is now being reflected in mortality trends. The lung cancer death rate decline, as well as declines in colorectal, breast, and prostate cancer death rates, has also helped drive decreases in death rates for all cancer types combined, a trend that began about 20 years ago. The decreased death rates for these four cancers accounted for more than two-thirds of the overall reduction in cancer death rates in the period 2001–2010. The report showed, however, that death rates increased for some cancers in this 10-year period, including cancers of the liver and pancreas for both sexes, cancers of the uterus in women, and, in men only, melanoma of the skin and cancers of the soft tissue.



The special feature of this year's *Report* highlights the prevalence of other disease conditions (diabetes, chronic lung disease, cardiovascular disease, and 13 others) in cancer patients over 65 years of age, and how they affect survival. Studying comorbid conditions is especially important because cancer is primarily a disease of aging, and the prevalence of comorbidities also increases with age. Comorbidity is defined as having two or more medical conditions at the same time. The report shows that one-third of patients in this study population have comorbidities, with a higher frequency of comorbidities in patients with lung or colorectal cancer, and that survival is influenced by the presence of other medical conditions as well as the type of cancer, stage at diagnosis, and age.

The *Report*, produced annually since 1998, is co-authored by researchers from the National Cancer Institute (NCI), which is part of NIH; American Cancer Society (ACS); CDC; and North American Association of Central Cancer Registries (NAACCR). It appeared online in the journal *Cancer* on December 16, 2013.

For more information, go to: <http://www.cancer.gov/newscenter/newsfromnci/2013/ReportNationDec2013Release>

Reference: Edwards BK, Noone AM, Mariotto AB, Simard EP, Boscoe FP, Henley SJ, Jemal A, Cho H, Anderson RN, Kohler BA, Ehemann CR, Ward EM. Annual Report to the Nation on the Status of Cancer, 1975-2010, Featuring Prevalence of Comorbidity and Impact on Survival among Persons with Lung, Colorectal, Breast or Prostate Cancer. *Cancer*. 2013 December (Epub ahead of print). Online at <http://onlinelibrary.wiley.com/doi/10.1002/cncr.28509/full>.

Announcements

We've Moved!

SRP has relocated to the new campus at NCI Shady Grove. Here is our new contact information:

Surveillance Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute
9609 Medical Center Drive, Room 4E542
Bethesda, MD 20892-9765 (**Postal service**)
Rockville, MD 20850 (**Deliveries**)
240-276-6740
240-276-7908 (**Fax**)

New SRP Staff

Amanda Brucker, B.A., joined the SRP as a Cancer Research Training Award (CRTA) fellow in September 2013. Ms. Brucker graduated from Cornell College with a B.A. in mathematics and a minor in physics. At SRP, Ms. Brucker works with Michelle Dunn on the Big Data to Knowledge (BD2K) training initiative. Beginning in January 2014, Ms. Brucker also will be working with Dr. Joshua Sampson from the Division of Cancer Epidemiology and Genetics (DCEG) to analyze a metabolomics data set. Her previous experience includes participating in the NIH Summer Institute for Training in Biostatistics (SIBS) program at the University of Pittsburgh and in a National Science Foundation (NSF) Research Experience for Undergraduates (REU) in applied mathematics at the University of Nebraska-Lincoln. Ms. Brucker's professional interests include pursuing a Ph.D. in statistics or biostatistics and later working at the NIH, RAND Corporation, or a pharmaceutical company.



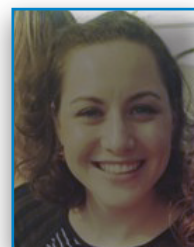
Amanda Brucker

Monique Cropp Puckett joined the DCCPS Administrative Support Team in June 2013. Prior to joining DCCPS, Ms. Puckett worked with the Division of Cancer Treatment and Diagnosis (DCTD) in the Cancer Therapy Evaluation Program's Investigational Drug Branch.



Monique Puckett

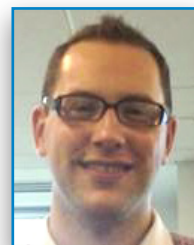
Emilee Pressman, M.P.H., is a public health advisor in SRP, where she is the lead for strategic planning and operations. Ms. Pressman started working in SRP during July 2013. Prior to joining SRP, she worked for DCCPS' Applied Research Program (ARP), also as a public health advisor.



Emilee Pressman

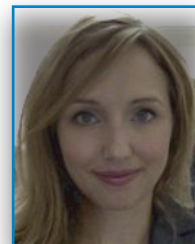
Ms. Pressman holds an M.P.H. from Columbia University and a B.A. in sociology from Brown University. After she graduated from Columbia, she was a Presidential Management Fellow for the Office of Extramural Research in the Office of the Director of NIH and the Office of Adolescent Health in the U.S. Department of Health and Human Services.

Gabriel Rosenfeld, Ph.D., joined the SRP as a Health Communications fellow in July 2013. Dr. Rosenfeld received his Ph.D. in cell and developmental biology from Weill Cornell Graduate School of Medical Sciences. He performed his doctoral research in the laboratory of Dr. Todd Evans and focused on the genetic programs regulating early morphogenesis of the embryonic heart. At SRP, Dr. Rosenfeld works on several strategic planning initiatives, including development of SEER-linked biospecimen resources with Dr. Sean Altekruse and a report highlighting a vision for future cancer surveillance efforts at SEER with Associate Director Dr. Lynne Penberthy. He also works with Ms. Judith Swan on Web analytics of the new SEER website to provide evidence-based recommendations for continued website optimization and development. Dr. Rosenfeld's professional interests include preventive and prognostic cancer biomarkers, public health genomics and its impact on clinical care, and the impact of environmental factors such as exposure to the HPV virus on cancer progression.



Gabriel Rosenfeld

Janette Bourdon, M.P.H., joined SRP as an intern through the Cancer Research Training Award (CRTA) fellowship in September 2013. Ms. Bourdon received her M.P.H. from the University of Hong Kong and her bachelor's degree from Michigan State University in communication with a cognate in business. At SRP, Ms. Bourdon works with Ms. Judith Swan on the DidYou Know? video series and strategic communications.



Janette Bourdon

Ms. Bourdon has extensive experience in communications and has won multiple awards for her work. Most recently, she worked as a segment producer for an Emmy-nominated lifestyle series, "Save My Planet." Her professional interests include health communications, social media, and behavioral health.

SRP Staff Publications in 2013

Zhang S, **Chen HS**, Pfeiffer R. A combined p-value test for multiple hypothesis testing. *J Stat Plan Inference*. 2013;143(4):764–770. [[Science Direct Abstract](#)]

Chen HS, Pfeiffer RM, Zhang S. A powerful method for combining p-values in genomic studies. *Genet Epidemiol*. 2013;37(8):814–819. [[PubMed Abstract](#)]

Peng B, **Chen H-S**, Mechanic LE, Racine B, Clarke J, Clarke L, Gillanders E, **Feuer EJ**. Genetic Simulation Resources (GSR): a website for the registration and discovery of genetic data simulators. *Bioinformatics*. 2013;29(8):1101–1102. [[PubMed Abstract](#)]

Cho H, Klabunde CN, Yabroff KR, Wang Z, Meekins A, Lansdorp-Vogelaar I, **Mariotto AB**. Comorbidity-adjusted life expectancy: a new tool to inform recommendations for optimal screening strategies. *Ann Intern Med*. 2013;159(10):667–676. [[PubMed Abstract](#)]

Yu M, **Tatalovich Z**, Gibson J, **Cronin K**. Using a composite index of socioeconomic status to investigate health disparities while protecting the confidentiality of cancer registry data. *Cancer Causes Control*. 2014;25(1):81–92. [[PubMed Abstract](#)]

Jamison PM, **Noone AM**, **Ries LA**, Lee NC, **Edwards BK**. Trends in endometrial cancer incidence by race and histology with a correction for the prevalence of hysterectomy, SEER 1992 to 2008. *Cancer Epidemiol Biomarkers Prev*. 2013;22(2):233–241. [[PubMed Abstract](#)]

Gomez SL, **Noone AM**, Lichtensztajn DY, Scoppa S, Gibson JT, Liu L, Morris C, Kwong S, Fish K, Wilkens LR, Goodman MT, Deapen D, Miller BA. Cancer incidence trends among Asian American populations in the United States, 1990–2008. *J Natl Cancer Inst*. 2013;105(15):1096–1110. [[PubMed Abstract](#)]

Liu L, **Noone AM**, Gomez SL, Scoppa S, Gibson JT, Lichtensztajn D, Fish K, Wilkens LR, Goodman MT, Morris C, Kwong S, Deapen D, Miller BA. Cancer incidence trends among native Hawaiians and other Pacific Islanders in the United States, 1990–2008. *J Natl Cancer Inst*. 2013;105(15):1086–1095. [[PubMed Abstract](#)]

Funding

Current NIH Funding Opportunities for Surveillance Research

The program announcement on "Bridging the Gap Between Cancer Mechanism and Population Science" has been published as PAR-13-081.

<http://grants.nih.gov/grants/guide/pa-files/PAR-13-081.html>

NIH BD2K Announcement of Training Activities

The NIH Big Data to Knowledge (BD2K, <http://bd2k.nih.gov/>) initiative announces the release of three related Notices of Intent to Publish (NOIPs) for Requests for Applications (RFAs) for training programs in biomedical Big Data Science:

- [Notice of Intent to Publish a Funding Opportunity Announcement for Predoctoral Training in Biomedical Big Data Science \(T32\) \(NOT-HG-14-011\)](#)
- [Notice of Intent to Publish a Funding Opportunity Announcement for Revisions to Add Biomedical Big Data Training to Ongoing Institutional Training Grants \(T32\) \(NOT-HG-14-022\)](#)
- [Notice of Intent to Publish a Funding Opportunity Announcement for Revisions to Add Biomedical Big Data Training to Ongoing Institutional Training Grants \(T15\) \(NOT-HG-14-023\)](#)

In addition to these NOIPs, three other BD2K Funding Opportunity Announcements (FOAs) related to the training of users or developers of big data methods and tools have been released recently.

- [RFA-HG-14-007](#) Mentored Career Development Award in Biomedical Big Data Science for Clinicians and Doctorally Prepared Scientists (K01)
- [RFA-HG-14-008](#) Courses for Skills Development in Biomedical Big Data Science (R25)
- [RFA-HG-14-009](#) Open Educational Resources for Biomedical Big Data (R25)

The first deadline for K01 and R25 applications is April 1, 2014, with an optional letter of intent due March 1, 2014.

BD2K is a new major trans-NIH initiative that aims to support advances in data science, other quantitative sciences, policy, and training that are needed for the effective use of big data in biomedical research. Interested applicants are encouraged to join the listserv (on the [BD2K](#) homepage) to receive the most up-to-date information about BD2K events and funding opportunities.

Please share this opportunity with your interested scientific communities. If you have questions, please contact Michelle Dunn at bd2k_training@mail.nih.gov.

SRP Grants Awarded in Fiscal Year 2013

Newly funded SRP grant awardees for Fiscal Year 2013 are listed below. In addition to these newly funded grants, SRP currently manages about 45 existing, non-competing grants that were approved for continued funding.

Branch	Program Director	Principal Investigator	Research Project Title	Institution
DMB	Margaret Stedman	Ruth D. Etzioni	PROMISS—Prostate Modeling to Identify Surveillance Strategies	Fred Hutchinson Cancer Research Center
DMB	Margaret Stedman	Jeanne Mandelblatt	Optimizing Personalized Care Using Studies of Genomic Testing	Georgetown University
SMAB	Eric Feuer	Georg E. Luebeck	Esophageal Cancer from Cells to Population: A Multiscale Approach	Fred Hutchinson Cancer Research Center
SMAB	Huann-Sheng Chen	Alice Whittemore	Bootstrap-Based Testing of Rare Sequence Variants Using Family Data	Stanford University
DMB	Michelle Dunn	Giovanni Luigi Parmigiani	Novel Tools for Familial Risk Prediction	Dana-Farber Cancer Institute
DMB	Angela Mariotto	Samiran Sinha	Innovative Approaches for Analyzing SEER Breast Cancer Data	Texas A&M University
SMAB	Huann-Sheng Chen	Lin Chen	Multivariate Functional Analysis of the Genetic Basis of Cancer	University of Chicago
DMB	Angela Mariotto	Giovanni Luigi Parmigiani	Bioinformatics Tools for Genomic Analysis of Tumor and Stromal Pathways in Cancer	Dana-Farber Cancer Institute

Branch	Program Director	Principal Investigator	Research Project Title	Institution
DMB	Angela Mariotto	Qi Long	Evaluating Prediction Models for Cancer Endpoints Subject to Dependent Censoring	Emory University
DMB	Margaret Stedman	Kristina Anne Crothers	Benefits and Harms of Lung Cancer Screening in HIV Infection	University of Washington
SMAB	Li Zhu	Andrew B. Lawson	Uncertainty in Spatial Health Analysis Due to Missingness and Aggregation Effects	Medical University of South Carolina
DMB	Angela Mariotto	Ying Qing Chen	Methods for Time-Varying Disease Attribution in Chronic Disease Prevention	Fred Hutchinson Cancer Research Center
SMAB	Eric Feuer	Yan Li	Semiparametric Inference for Case-Control Studies With Complex Sampling	University of Maryland College Park
DMB	Michelle Dunn	Huilin Li	Secondary Analysis of Longitudinal Traits in Genome Wide Association Studies	New York University School of Medicine
DAIB	Denise Lewis	Min Lian	Modeling Spatial Accessibility to Lower Endoscopy Services in the United States	Washington University in St. Louis
DMB	Michelle Dunn	Liang Zhu	Statistical Analysis for Mixed Recurrent-Event and Panel-Count Data	St. Jude Children's Research Hospital
SMAB	Li Zhu	Yongtao Guan	New Statistical Methods to Handle Spatial Uncertainty in Cancer Risk Estimation	University of Miami Coral Gables
DMB	Margaret Stedman	Martine Extermann	Decision Models to Compare Treatments in Older Patients with AML	H. Lee Moffitt Cancer Center & Research Institute
SMAB	Huann-Sheng Chen	Jaya M. Satagopan	Advances in Statistical Methods for Cancer Genetic Epidemiology	Sloan-Kettering Institute for Cancer Research
DAIB	Denise Lewis	Nancy Krieger	Long-Term Trends in Breast Cancer Tumor Profiles & Disparities	Harvard School of Public Health
DMB	Michelle Dunn	Jinbo Chen	Statistical Methods for Cancer Absolute Risk Prediction	University of Pennsylvania
DMB	Margaret Stedman	Amy H. Herring	Workshop for Junior Biostatisticians in Health Research	University of North Carolina at Chapel Hill
DMB	Angela Mariotto	Xihong Lin	Statistical Informatics for Cancer Research	Harvard School of Public Health
DMB	Michelle Dunn	Alice Whittemore	Statistical Methods for Genetic Epidemiology	Stanford University
DMB	Michelle Dunn	Danyu Lin	Statistical Methods in Chronic Disease Research	University of North Carolina at Chapel Hill

DAIB-Data Analysis and Interpretation Branch

DMB-Data Modeling Branch

SMAB-Statistical Methodology and Applications Branch

New on the Net

It has been quite a year for SRP on the Web. The SEER (<http://seer.cancer.gov/>) and Geographic Information Systems and Science (GIS) (<http://gis.cancer.gov/>) websites have been redesigned, with many new features. While on the SEER site, check out the new Cancer Stat Fact Sheets, which are providing a much more visual experience for users, and the popular "Did You Know?" videos. Or, go through the GIS Portal to view the NCI Map Stories (<http://gis.cancer.gov/portal/mapstory.html>).

