



Message From the President



Chuck Wiggins, PhD
NAACCR President

This year marks the 25th anniversary of the National Program of Cancer Registries (NPCR) at the Centers for Disease Control and Prevention. The Cancer Registries Amendment Act (Public Law 102-515) was passed by Congress in 1992 and set the stage for the development of NPCR.

I want to express a hearty “congratulations and well-done” to our colleagues, past and present, who have contributed to the success of this remarkable Program.

Planning continues for our 2017 Annual Meeting that will be held in Albuquerque from June 17-22. To whet your appetite: We’ve arranged for authentic New Mexico cuisine to be served at several meals and contracted a local salsa band to provide entertainment at our opening reception. The list of pre-conference events is also growing – please see Chris Johnson’s article about the cancer survival workshop in this issue of the *Narrative*.

I wish you all a happy and prosperous New Year!

Message From the Executive Director



Betsy A. Kohler, MPH, CTR
NAACCR Executive Director
bkohler@naaccr.org

The Annual Conference in Albuquerque will be here before you know it! I wanted to mention a few of the changes we have planned for this year.

First, we are planning to host a special "**Registry of the Future**" workshop on Monday, June 19, before the main conference. We anticipate that this will be a day-long intensive workshop with invited speakers, interactive sessions, and plenty of discussion to help us all envision what cancer registries will be like in 5-10 years. There are many new opportunities for registries, oncology is advancing rapidly, and big data is everywhere. How does the cancer registry, home of “Cancer Data You Can Trust” fit into the picture? Bring your ideas and energy for a strategizing workshop that will serve as a blueprint for the next few years.

Changes in the Schedule. This year we are trying a new format. In an effort to moderate our costs and respond to changing demands, we are eliminating the ever popular Awards Luncheon on Wednesday. Instead, the certification announcements, poster prizes, and Calum Muir and Constance Percy Awards will be interspersed throughout the Conference. We will use time during the Opening Reception and Plenary sessions to present these awards. Every year, NAACCR receives more and more requests for special meetings and sessions at the Conference. So, part of Wednesday afternoon will be set aside for NAACCR committee meetings, specialty meetings, and professional networking.

Survival Analysis Course: We are offering several pre-conference workshops this year, including a special opportunity to learn from cancer survival experts **Paul Dickman** of the Karolinska Institute in Stockholm and **Paul Lambert** of University of Leicester in the UK. These two internationally acclaimed professors will be presenting a 4-day workshop, focusing on the development and application of methods for presenting patient survival data that are relevant for patients, clinicians, and the general public. The "Pauls," as we call them, have taught this course many times in Europe, but this is a rare opportunity to have them both stateside. Don’t miss out on this important workshop.

Transportation to Old Town: The Hyatt and the Conference Center, where the main Conference will be held, are about 1.5 miles from the Old Town section of Albuquerque. The hotel will be providing limited shuttle service in the evenings for those of us wishing to visit this part of the city.

Plan on Long Days! This is not new! Sessions will run long on all of the Conference days. We will still sponsor some healthy activities like a bike ride and the NAACCR walk/run, weather permitting.

See you in Albuquerque!

Highlights From the Program Manager of Standards

Lori A. Havener, CTR
Program Manager of Standards, NAACCR

Standards Volume II, Version 17

The announcement to delay implementation of the AJCC 8th Edition to 2018 has created an opportunity to ease the burden on cancer registries by eliminating the need for registries to make adjustments to the NAACCR record layout in 2017. NAACCR will integrate the 2017 new and changed data items into Standards Volume II Version 18. There will not be a Standards Volume II Version 17. The cancer surveillance community will go from Standards Volume II Version 16 to Version 18, which is scheduled for release July 1, 2017. This means cancer registries will continue to use Standards Volume II Version 16 for another year, until January 1, 2018. The July release will describe the upcoming changes for January 1, 2018 implementation.

What You Need to Know for 2017

The NAACCR 2017 Implementation Guidelines Task Force prepared the document *What You Need to Know for 2017*, which provides guidance for cases diagnosed in 2017. This document is in response to the delay of implementing the AJCC Staging Manual 8th Edition to 2018 and the resulting decision that there will not be a NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Version 17.

Standards Volume II, Version 18 Timeline

Proposed changes submitted to CMB	October 1, 2016
Proposed changes approved by CMB	December 1, 2016
CMB submits request for change to UDS	January 1, 2017
Volume II Task Force review	March 1, 2017
Draft submitted to UDS and the S&RD SC for review/approval	May 1, 2017
Draft submitted to NAACCR Board for review/approval	June 1, 2017
Post to NAACCR website	July 1, 2017
Version 17 Implementation	January 1, 2018

XML Data Exchange Standard Work Group

Thank you to the central registries and software vendors that volunteered to participate in the XML pilot project! What a great way to start the New Year! The XML Data Exchange Standard Work Group will coordinate the efforts of central registries and software vendors implementing the NAACCR XML Data Exchange Standard, transmitting data between hospital and central registries. Results of the pilot projects will be presented at the NAACCR Annual Conference. Stay tuned!

Research and Data Use Update

Recinda Sherman, MPH, PhD, CTR
NAACCR Manager of Data Use and Research

As I write this update, the Los Angeles area is getting some welcome, if a bit confusing, weather of heavy rain, hail, and even a dusting of snow in the foothills. This intense precipitation brings both drought relief and flooding. Similarly, this update has some up and some down.

CiNA Public Use Dataset is now available!

Information (including variable list and Data Use Agreement for access) is available [here](#). Note: You can also access the CiNA Public Use Dataset landing page from the drop-down menu on the [NAACCR website](#) under the “Research” tab.

This is the first release of [CiNA Public Use Dataset](#) and includes data from 1995-2013 years of diagnosis. This dataset contains 46 states, plus DC and PR, for the United States and 12 Canadian provinces; covering 93% of the United States and 64% of the Canadian population.

We have three outstanding issues to resolve:

1. Case listing is not yet available. Researchers will need to run rates and trends from within SEER*Stat at this time. In order to work from a technical side, we are collapsing some subsites. If there are <6 cases by registry, year, sex, race/ethnicity, & site, then the site is recode to a less specific site. Age is only released in the 19 age groups. We are still working to define the larger site groups. We will clarify this in the technical documentation and notify the participating states before allowing a user to access the case listing feature in SEER*Stat.
2. The area-based SES Composite Variables is still under development. We are coordinating with SEER to provide a robust SES variable based on county-level characteristics. This same approach will also be used to create a tract-level based composite SES variable.
3. The CBTRUS variable is still under development. This variable can be used for both malignant and non-malignant brain definitions to match the classifications used by CBTRUS for their annual reports.

We anticipate all of the above issues resolved for the next release in/around July 2017 for the 1995-2014 data.

NAACCR Geocoder Update

We continue to work on improving the NAACCR Geocoder. With the release of the new NAACCR website, we have included a sample dataset and a training tutorial. NAACCR also provides tailored training to registries on the NAACCR Geocoder.

Unfortunately, we have identified some errors with the underlying street files included in the NAACCR geocoder. NAACCR members have been working with TAMU to define its extent and resolve this issue. We are also working with SEER to include additional quality measures, such as match score, in the SEER*DMS record and plan to add these measures into the NAACCR layout.

If you would like assistance with operationalizing or improving your geocoding, or if you have questions or concerns about the data quality of the geocoded data, please contact me: rsherman@naacc.org.

NAACCR Education and Training Program Update

Jim Hofferkamp, CTR

NAACCR Program Manager of Education & Training

We just finished the fourth webinar in the NAACCR 2016-2017 webinar series on January 12. The topic was TNM Staging and we focused on things like when to use x's vs blanks and when it is "OK" to use clinical values in pathologic data items and vice versa. It may not sound like much, but there is a great deal of confusion around these concepts and they are critical for entering the correct information in stage data items. We had a great response from our participants!

The February webinar will be on colon. We will discuss MP/H rules, staging, and coding treatment for colorectal cases.

We will be opening registration for the June CTR prep and review soon. The testing window for the June CTR exam starts June 17. Classes will begin in mid-May and we'll meet every Tuesday for 8 weeks. We record all of the sessions. If you can't participate in the live sessions, you can still view the recordings. One of the things I really like about the series is the interaction between the participants. Sometimes I think the support and encouragement between participants is just as important as the review of the material! There is still time to register if you are interested!

Check out the NAACCR Education and Training Calendar for a list of all of the upcoming training activities. Don't overlook the Cancer Surveillance Webinar Series. These are free webinars presented by experts in their fields. If you miss the live sessions, we post the recordings on the Webinar Recordings page.

If you have questions about any of the NAACCR educational products or are interested in having the NAACCR Education and Training team develop a training workshop for your registry, send Angela Martin or me an e-mail at jhofferkamp@naacc.org or amartin@naacc.org.

NAACCR 2017 Education and Training Calendar

February 2017

02/02/2017 Collecting Cancer Data: Colon

March 2017

03/02/2017 Abstracting and Coding Boot Camp

April 2017

04/13/2017 Collecting Cancer Data: Lip and Oral Cavity

May 2017

05/04/2017 Multiple Primary and Histology Coding Rules

June 2017

06/01/2017 Collecting Cancer Data: Liver and Bile Ducts

July 2017

07/13/2017 Hospital Cancer Registry Operations – Topic TBD

August 2017

08/3/2017 Collecting Cancer Data: Central Nervous System

September 2017

09/7/2017 Coding Pitfalls

For more information about NAACCR education and training opportunities or to register online, go to the Education and Training tab on the NAACCR website (www.naacccr.org); or contact Jim Hofferkamp (jhofferkamp@naaccr.org).

Virtual Pooled Registry Update

Castine Clerkin, MS, CTR

Program Manager of Virtual Pooled Registry, NAACCR

Happy 2017 everyone! It's exciting to embark on the New Year with a strong foundation from last year's progress in creating the Virtual Pooled Registry Cancer Linkage System (VPR-CLS). The coming year will provide an opportunity to continue this forward momentum with the amazing support of our cancer surveillance community.

I'd like to take a moment and thank the registries that have created a VPR-CLS linkage file in conjunction with the NAACCR Call for Data. Although this activity is voluntary, we are hopeful that all registries will create this file by the end of January. Once created, the file will reside at your registry and be available for future linkages should your registry choose to participate.

There will be a brief hiatus in facilitating VPR-CLS linkages as we summarize the results of the two pilot linkages that were completed in 2016. During this time, we will also finalize the online VPR-CLS portal, fine-tune the linkage software, explore funding mechanisms to support registry participation in future VPR-CLS activities, and ensure that all necessary systems are in place for a successful launch of the VPR-CLS in the coming year.

We are in the process of finalizing a draft templated IRB form based on review of individual state IRB applications. This templated form will be shared with registries for feedback on whether the form can be accepted by local IRBs. We are also developing a templated registry application form and data use agreement. Our goal is to streamline the research application process as much as possible while addressing registry and IRB needs. Your input on these forms will be essential as the project proceeds.

My intent in the New Year is to provide the registry community with ongoing and helpful information related to the VPR-CLS activities. If there is anything you need related to this project, please contact me at cclerkin@naaccr.org.

NAACCR Steering Committee Corner

Susan T. Gershman

Director, Massachusetts Cancer Registry

Welcome to the Steering Committee Corner! This column will provide brief Steering Committee updates such as new reports or projects, coding changes, new data standards, requests for priority area network members for specific workgroups, and other information that NAACCR Steering Committees feel the NAACCR community should be aware of. We hope that this column helps to connect us as we continue to move forward with enhanced cancer surveillance.



Communications Steering Committee (CSC)

Co-Chairs: Laura Ruppert and Annette Hurlbut

Committee Highlights since the last *Narrative*:

- The Strategic Management Plan (SMP) will be spotlighted throughout 2017.
- A Best Practice document, a supplement to the Communications Plan, approved by the NAACCR Board, is available to download [here](#).

Recent Reports/Publications:

- Check out our newest posts. We encourage our readers to participate – send ideas for blog features to Becky Cassidy at RCassady@llu.edu as contribution to NAACCR's NAACCRReview (<http://news.naaccr.org/>).

Other News to share with the NAACCR Community:

- Redesign of NAACCR website is in review with NAACCR staff; outside vendors and recommendations will be shared with the Committee soon.
- Causeway will soon have changes as well.

Professional Development Steering Committee (PDSC)

Co-Chairs: Frances Ross and Mignon Dryden

Committee Highlights since the last Narrative:

- Work to update the Survey Course, “Understanding Population Based Cancer Registries” to web based learning modules is nearly complete. The last of the modules needing the Voice-Over portion of their PowerPoint presentations are being done. A gradual release is planned.
- The Learning Management System (LMS), successfully in use with the CTR Prep Course, will be utilized for the Survey Course.

Other News to share with the NAACCR Community:

- Discussion on developing and implementing strategies for Recruitment and Retention in Central Registries has been a major priority. Efforts will be focused on two major careers (Registrars and Epidemiologists).
- Work continues on developing a specific action plan to increase awareness and employment in these fields.

Research and Data Use Steering Committee (RDUSC)

Co-Chairs: Hannah Weir and Susan Gershman

Training/Education:

- NAACCR Webinars
 - Personalized Medicine scheduled for February 15, 2017, 2:00 pm Eastern Time. Presenter will be Dr. Katherine Janeway, Senior Physician, Dana-Farber Cancer Institute, Assistance Professor of Pediatrics, Harvard Medical School.

Other News to share with the NAACCR Community:

- SMP Workplan Draft; Priority Area 3 Research and Data Use: The group completed review of the alignment of work groups and task forces.
- Review and comments regarding ICD-11 are in progress.
- Confidentiality Task Force goals are under discussion.
- If you have a suggestion for a journal club or surveillance webinar topics, please contact Hannah Weir (hweir@cdc.gov) or Susan Gershman (susan.gershman@state.ma.us).

NAACCR.org Getting a Makeover

Charlie Blackburn, MBA

NAACCR Chief Operating Officer

The NAACCR staff has been working with an outside company to give NAACCR.ORG a makeover. The updated website will have a new look, functionality, and updated “back-end” administrative capacity. It is approximately 80% complete and should be launched in February. We are currently working on the content migration and will begin testing the site soon. The NAACCR office will announce any updates on the launch and timeline via our current website and the NAACCR ListServ.

Please contact Dustin Dennison, NAACCR IT Administrator at ddennison@naacccr.org or at 217-698-0800, ext. 8, with any questions or comments.

Pre-Conference Workshops at the Upcoming NAACCR Annual Conference

Angela Martin, CTR

NAACCR Trainer/Project Coordinator

NAACCR 2017 Program Committee Member

“Breaking Barriers in Cancer Surveillance”

NAACCR 2017 Annual Conference

June 17-22, 2017

Pre-Conference Workshops will include:

Friday, June 16, 2017 – Monday, June 19, 2017

- Survival Analysis

Saturday, June 17, 2017

- Cancer Surveillance: An overview and hands-on experience

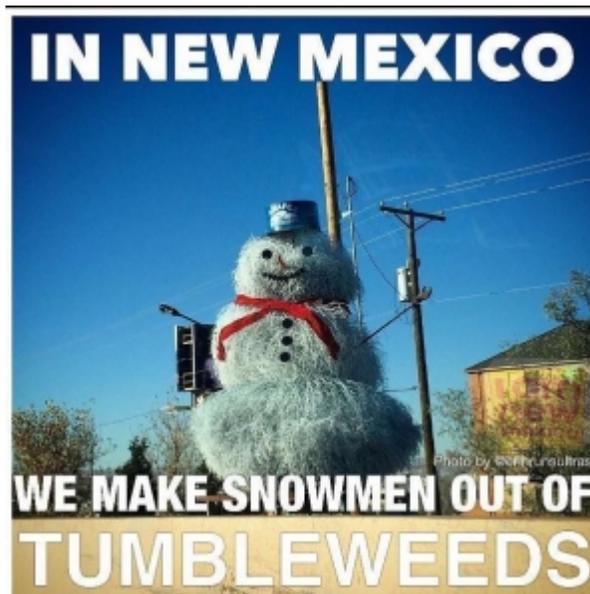
Sunday, June 18, 2017

- “How Did You Get My Name?!”: Conducting Survey Research in Central Cancer Registries and Optimizing Recruitment. [Registration is now open](#). Deadline is March 15, 2017.
- eMaRC Plus User Training
- Registry Usage of the SEER Abstracting Tool and the SEER Data Viewer
- Interactive Mapping Toolkit for Cancer Surveillance and Cancer Control
- SEER*Stat Basic

Monday, June 19, 2017

- SEER*Stat Advanced

Pre-Conference registration will be coming soon!



NAACCR 2017 Cancer Survival Course Announcement

Cancer Survival: Principles, Methods and Applications - A 4-day Course Prior to the 2017 NAACCR Annual Conference in Albuquerque

A highly experienced faculty will present a stimulating and intensive 4-day course on the principles, methods, and applications of cancer survival with population-based data. The course will cover central concepts, such as how to estimate and model net survival, as well as recent methodological developments including flexible parametric models, estimation in the presence of competing risks, and loss in expectation of life. The course will also address practical issues of relevance to North America, such as the recently developed U.S. life tables, NDI linkages, SSA linkages, problems ascertaining deaths among Hispanics and Asians, and hybrid approaches of linkages and active follow-up.

Confirmed faculty include Paul Dickman (Sweden), Paul Lambert (UK), Angela Mariotto (USA), Therese Andersson (Sweden), and Chris Johnson (USA). Additional faculty members are being recruited.

Comparison of alternative methodological approaches (e.g., to estimating and modelling net survival) will be a focus of the course and participants will get the opportunity to apply and contrast a range of methods to real data (provided) or their own data. We will devote considerable time to practical sessions where participants discuss issues of specific interest to them with faculty members (and other participants) who have relevant expertise. By providing a large faculty with a range of backgrounds, we hope that every participant will get expert instruction tailored to their needs.

The course will be held June 16-19 at the Albuquerque Convention Center, located adjacent to the conference hotel. Additional details and information about registering will be posted to the [NAACCR website](#).

National Data Exchange Agreement

Susan T. Gershman

Director, Massachusetts Cancer Registry

Winter Has Arrived, so Enjoy the Snow and Sign on!

Forty-one registries, the District of Columbia, Guam and Puerto Rico have signed the modified national data exchange agreement. For registries that are now ready to sign:

Go to www.naacccr.org. Click on "Standards and Registry Operations," and click on "National Interstate Data Exchange Agreement." Then follow the instructions below:

1. Central registry downloads agreement.
2. Central registry has proper authority review agreement and adds state-specific restrictions if needed.
3. Appropriate registry representative signs agreement.



4. Agreement is sent to NAACCR; central registry retains copy.
5. NAACCR posts states that have signed agreement on NAACCR website, including specific restrictions.
6. Registry contacts other participating states to determine the logistics of how data will be exchanged.

The registries that have signed the National Interstate Data Exchange Agreement include: Alabama, Alaska, Arkansas, Colorado, California, Connecticut, Delaware, District of Columbia, Georgia, Guam, Hawaii, Idaho, Indiana, Iowa, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, West Virginia, Washington, Washington DC, Wisconsin and Wyoming. Join our team so you can add another important step towards efficient registry operations!

Please fax your signed National Interstate Data Exchange Agreement to the NAACCR office at 217-698-0188. Jim Hofferkamp provides a listserv announcement to the NAACCR community as soon as a new registry signs on.

In Massachusetts, one of our epidemiologists, Richard Knowlton, volunteered to coordinate data exchange. He designed an ACCESS database that is organized by state so he can record date of exchange and number of cases exchanged as well as comments. The database also has a contact list for all states. This has made our data exchanges extremely efficient!

Check our updated map [here](#).

Thanks for your help!

Call for Nominations: Calum Muir and Constance L. Percy Awards

In March, the NAACCR Board of Directors considers nominations for two of the most prestigious awards in the cancer surveillance community, The Calum Muir Award, and the Constance L. Percy Award. These awards, described below, are presented at the NAACCR Annual Conference in June. Please take the time and nominate a NAACCR member who has demonstrated leadership and commitment to cancer surveillance. Please include information about why you think your candidate should be considered for the award. This information will be distributed to the Board and serve as the basis of voting. Nominations should be submitted in writing to bkohler@NAACCR.org by March 1, 2017. Thank you for your participation.

The Calum Muir Award

The purpose of the Calum Muir Award is to honor someone who has made long-term, substantive contributions in cancer registration. Preference is for the recipient to be an active member of NAACCR with a long-term commitment to the organization. The intent is that it not be a posthumous award. The award will be bestowed each year at the NAACCR Annual Conference to a recipient selected by the Board of Directors.

The Constance L. Percy Award for Distinguished Service

The purpose of the Constance L. Percy Award for Distinguished Service is to recognize an individual who contributed exceptional volunteer service to NAACCR during the past 12 months, or sustained current and long-term contributions to the organization. The award may be bestowed once each year, usually at the NAACCR Annual Conference, to a recipient selected by the Board of Directors. More than one award may be given in any year. No limit is placed on the number of times an individual may be recognized by a Constance L. Percy Award for Distinguished Service.

CBTRUS Joins with CAP and CDC to Urge use of the CAP eCC

It was a remarkable session on November 17, 2016, during the Society for Neuro-Oncology (SNO) Annual Meeting in Scottsdale, AZ, when representatives from the College of American Pathologists (CAP), the Centers for Disease Control and Prevention (CDC), and the Central Brain Tumor Registry of the United States (CBTRUS) worked together to present the CAP electronic Cancer Checklists (eCC), a tool for clinicians that would facilitate population-based collection of cancer pathology and biomarkers. The benefits of using the eCC for brain and other central nervous system (CNS) tumors were elucidated and complimented the theme of 2016 SNO Education Day, Precision Medicine, and the new WHO Classification of Central Nervous System Tumors. Speakers included Carol Kruchko (CBTRUS), Sandy Jones (CDC), Daniel Brat (Emory University School of Medicine), and Gemma Lee (Cancer Care Ontario).



SNO Annual Meeting

Sandy and Carol are members of the NAACCR Standards for Cancer Registries Volume V Revision Task Force Revision for Pathology Laboratory Electronic Reporting and met face-to-face during the NAACCR 2016 Conference in St. Louis. Their discussions moved quickly and included the CAP. Carol’s membership on the SNO Guidelines Committee provided an opportunity for a session during the SNO November Education Day especially given that the new “blue book” from the World Health Organization (WHO) for CNS Classification was a major focus of the SNO Conference. It was published in June 2016 and is a major change from the 2007 histology only classification system to a histology molecular classification system. Histology now includes specific biomarkers.

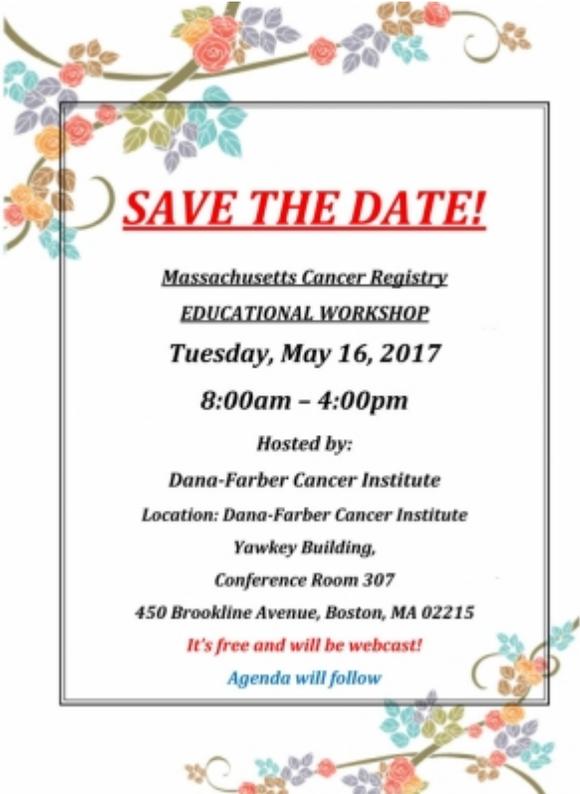
For example, classification is no longer Glioblastoma 9440/3, but Glioblastoma, IDH-wildtype (9440/3) and Glioblastoma, IDH-mutant [9445/3 (new, approved ICD-O-3 code)]. It was a real plus that Dr. Dan Brat is the first author on the CAP protocols for CNS tumors including the Template for Reporting Results of Biomarker Testing of Specimens for Patients with Tumors of the Central Nervous System, worked on the 2016 WHO, and had collaborated with CBTRUS on manuscripts. And to think it all started with working on a NAACCR Committee!

To learn more about this session, please contact Sandy Jones at sft1@cdc.gov or Carol Kruchko at ckcbtrus@aol.com.



Sandy Jones, Gemma Lee, and Carol Kruchko during the SNO reception

Save the Date: MCR Educational Workshop, May 16, 2017



SAVE THE DATE!

Massachusetts Cancer Registry
EDUCATIONAL WORKSHOP
Tuesday, May 16, 2017
8:00am - 4:00pm

Hosted by:
Dana-Farber Cancer Institute
Location: Dana-Farber Cancer Institute
Yawkey Building,
Conference Room 307
450 Brookline Avenue, Boston, MA 02215

It's free and will be webcast!
Agenda will follow

<http://www.naacccr.org>



North American Association of Central Cancer Registries
Working together to make every cancer count.

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