Message From the President

Jill A. MacKinnon, PhD, CTR
NAACCR President

Spring is an amazing period of renewal in nature. The plants and trees have started a new cycle and are coming alive with new growth and strength. Regardless of what winter brought, spring affirms we made it through and are ready to start all over again. This is a wonderful time of year…for those of us with allergies…not so much.

Spring is also a period of renewal within NAACCR. Our membership has just elected the new members to the Board of Directors, a number of new initiatives are in the final planning phases or are being implemented, and the *Annual Report to the Nation* was among the best ever. All of this has been possible because of strength of our members. NAACCR's membership continues to grow. Our base structure continues to broaden. Our collaborations with other disease surveillance professionals continue to mature.

As the management of cancer changes, those of us in charge of cancer surveillance must continue to move and mature with the state of the art. This is always a good thing for the cancer patients we serve. However, managing and incorporating the changing state of the art into our day-to-day systems is often challenging. I can assure you the NAACCR membership, the NAACCR leadership, and our Sponsoring Members are working very hard with the standard setters to understand, incorporate, and mitigate the effects of the change. At this point, I don't know what our new staging systems will look like but I do know that our individual and collective depth, dimension and ingenuity will keep us on track.

The NAACCR Annual Conference in Charlotte, North Carolina, is just around the corner. The Program Committee has developed another fantastic meeting. If you have not already done so, please log onto naaccr.org and register for the meeting.

My term as President comes to an end at this meeting. However, I can assure you that my commitment to NAACCR will never come to an end. NAACCR is my family and I am so proud, humbled, and honored to be part of the family.

Take care, and I look forward to seeing you in June.

Best Wishes,

Jill A. MacKinnon, PhD, CTR
President, North American Association of Central Cancer Registries

Message From the Executive Director

Betsy A. Kohler, MPH, CTR
NAACCR Executive Director

Like most of you I have lost friends and family members to cancer. Right now, one of my closest childhood friends, someone I have known since I was 9, is struggling with metastatic disease. Watching the inevitable unfold is very difficult. I grow frustrated with the progress we have made - why can't we do more for our loved

ones? I ask myself, what have we accomplished over the course of my career in this field? The answer is quite a lot. Maybe not enough, but a lot.

We know so much more about these diseases than we did 30 years ago. The cancer surveillance system is the model for all other disease surveillance systems. Through years of working together we have built a system that works; one that we can be proud of. Every state, and virtually every province, has met NAACCR certification standards at least once. Many achieve the Gold level year after year, demonstrating the quality of their data and utility for public health. We have reliable data on cancer from every corner of North America. We can demonstrate trends over time and measure our success and struggles. Through our universal data definitions, our standards and rules, through guidelines and documentation, we have confidence in the data we produce. We know that we can make comparisons and conduct valid analyses.

Working together has not always been easy. We have had many challenges, overcome setbacks, and continued to search for common ground on which to build our foundation. We don't give up. We are entering the era of "big data," where we see companies with vast resources and grandiose ideas attempting to construct meaningful cancer databases without our data. Now more than ever it is a time for us to pull together, with all of our experience and expertise to make our data stronger, better, more useful, and more competitive *vis a vis* these emerging sources.

Be assured that NAACCR management, staff, the Board, and committee members are continuously advocating for collaboration. Along with our partner agencies we are working to maintain the integrity of our data and improve operations. Despite our differences, we are all trying to work collaboratively and productively, make the right decisions, improve cancer surveillance, and ultimately serve cancer patients.

At the end of the day, we all want to "make every cancer count" and reduce the burden of cancer in North America. None of us can do it alone. We need to work together to make progress, each of us working in a coordinated way to contribute meaningfully. We owe this to our friends and family, and to cancer patients we don't even know. It's our job, it's what we do.

NAACCR Annual Conference

The 2015 NAACCR Annual Conference, *First in Flight: Launching a New Era in Cancer Surveillance*, will be held June 13-19 in Charlotte, NC. This meeting will focus on collecting and sharing data, well-coordinated cancer research activities, and enhancing registry operations to strengthen cancer surveillance and control programs throughout North America.

Chandrika Rao, PhD
Chair, NAACCR 2015 Program Committee

The host of the 2015 NAACCR Annual Conference welcomes everyone to the launching of a "New Era in Cancer Surveillance," in the Queen City of Charlotte, North Carolina, on June 13-19, 2015.

When there is news of a launch, people typically associate it with NASA launching a rocket in orbit for research purposes. This time around, it is NAACCR with its distinguished members and colleagues that are doing a few launches and just not a single launch, during the Annual Conference. However, these launches are not merely intended for cancer surveillance and research but also to further save thousands of lives and hoping to extend it eventually to saving millions of lives.

The North Carolina Central Cancer Registry Team is extremely pleased and honored to host and launch the 2015 NAACCR Annual Conference, *First in Flight: Launching a New Era in Cancer Surveillance*. This meeting will focus on collecting and sharing data, well-coordinated cancer research activities, and enhancing registry operations to strengthen cancer surveillance and control programs throughout North America.

The plenary sessions will cover a wide range of topics such as the Evolving use of Cancer Treatment a "Sequential" Process, Enabling Research, Cancer Genomics, Maximizing the Potential for Research, Virtual Pooled

Registry, Big Data, Data Consolidation, Staging, Using XML, the new Death Clearance, Survivorship Plans, Delay Adjustment Factors, Vision for Cancer Control, and much more.

In addition, there will be a great opportunity to share ideas and discuss opportunities at concurrent and breakout sessions on improving case ascertainment, data quality, linkage, cancer staging, tools available for quality improvement, and to launch a new era in surveillance of cancer treatment and outcomes.

Lastly, the Queen City offers a great variety of cultural activities, dining, and entertainment to unwind the day with your colleagues and friends.

Let's all work together to keep these launches in orbit and add more in the coming years!

Birds of a Feather

Susan T. Gershman, PhD, MS, MPH, CTR
NAACCR Treasurer/Massachusetts Cancer Registry

Rich Pinder
NAACCR Standardization and Registry Development Steering Committee/
Los Angeles County Cancer Surveillance Program

The ever-popular Birds of a Feather will be recording its eighth flight at the NAACCR Annual Conference *First in Flight: Launching a New Era in Cancer Surveillance.* Hosts Susan Gershman (Massachusetts Cancer Registry) and Rich Pinder (Los Angeles County Cancer Surveillance Program) are poised for take-off, so please grab your "cup of joe" and join us for another engaging session on Wednesday, June 17th, from 7:00 a.m to 8:00 a.m. This year, the topic is **"Using Our Registry Data – What Works and What's Next?"**

To start off the session, we pose these questions for your consideration:

- Do you have any examples of innovative data use?
- Are you linking to hospital discharge databases and all payers claims databases?
- Who are your collaborators?
- Are you working with cancer control programs?

Come join in this informal discussion so we can share thoughts, experiences, and ideas. Don't forget that there are always special treats from Los Angeles and Boston for the most creative ideas!

National Data Exchange Agreement

Susan T. Gershman, PhD, MS, MPH, CTR
NAACCR Treasurer

It's Spring, so Time to Renew Your Goals and Sign on!

Thirty-four registries have signed the modified National Data Exchange Agreement. For registries needing to re-sign and registries that are now ready to sign, visit the National Interstate Data Exchange Agreement page on the NAACCR website and 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, Connecticut, Delaware, Guam, Hawaii, Idaho, Indiana, Kentucky, Louisiana, Massachusetts, Michigan, Mississippi, Montana, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, South Carolina, Texas, Utah, Vermont, Virginia, West Virginia, Wisconsin, and Wyoming.

Join our team so you can add another important step towards efficient registry operations!

Click here to see a map of National Data Exchange participants as of March 2015.

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.

Highlights From the Program Manager of Standards

Lori A. Havener, CTR
NAACCR Program Manager of Standards

Standards Volume II, Version 16

NAACCR Standards for Cancer Registries, Volume II Data Standards and Data Dictionary, Version 16 is scheduled for release on July 1, 2015. The UDS is working on several changes and proposed new data items to accommodate CS transition. A few new data items have been added for geocoded county, which is different than reported county. There are several data items that the wording will change to make them less specific (for example, change "hospital" to "reporting facility").

Standards Volume II, Version 17

Believe it or not it is time to start thinking about *Standards Volume II*, Version 17! I know, we haven't even released Version 16!

Keep in mind the timeline below as you start thinking about Version 17:

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

NAACCR 2015 Implementation Guidelines

The *NAACCR 2015 Implementation Guidelines and Recommendations* have been revised (February 2015) and posted to the NAACCR website. The document retained the tracked changes to allow easy detection of the revisions. NOTE that the *Implementation Guidelines* are currently being updated to include changes to the SEER reportability. A NAACCR ListServ announcement will be broadcast when the second revision is posted.

The *NAACCR 2015 Implementation Guidelines and Recommendations* document has been updated with 2 new sections:

- 4.3 Prostate Grade Conversion
- 4.4 SEER Reportability Clarifications

The *Heme Conversion* document is updated to include the Prostate Conversion and, the most recent version of the Specifications for Program to Convert Records from NAACCR Record Layout Version 14 to Version 15 is posted (click here for more information).

NAACCR Education and Training Program Update

Shannon Vann, CTR
NAACCR Program Manager of Education & Training

The NAACCR Annual Conference will be presented June 13-18, 2015 in Charlotte, NC, and will again provide excellent education and training for cancer surveillance professionals. In addition to the 3 conference days, there will be pre-conference workshops. If you have already registered for the Annual Conference, it is not too late to register for a pre-conference workshop.

The National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) program has developed two Windows-based systems for analyzing cancer registry data for use in cancer surveillance and control. The first, SEER*Stat, allows for the calculation of rates (age-adjusted and crude), trends, frequencies, survival probabilities (relative and observed), and several other statistics. The second, SEER*Prep, permits a user to format databases containing individual tumor records for use in SEER*Stat. Three workshops will be presented by experts from NCI and Information Management Services, Inc. (IMS). Basic SEER*Stat will be presented on Saturday, June 13, 2015; Advanced SEER*Stat will be presented on Sunday, June 14, 2015; and SEER*Prep will be presented on Monday, June 15, 2015.

The Geocoding Operations Short Course will be presented on Sunday, June 14, 2015. The course will provide an overview of how geocoding works, outline manual pre- and post-geocoding best practices, and present geocoding resources. The course will use the NAACCR geocoder, and course participants are welcome to bring their own data and work to resolve geocoding issues with course instructors. Faculty includes Recinda Sherman, PhD; Kevin Henry, PhD; and Dan Goldberg, PhD.

The Short Review Course: Overview of Central Cancer Registries has historically been presented as a pre-conference workshop. However, the course is being revised by a task force of the Professional Development Steering Committee into a webinar series. A syllabus for the Understanding Population-Based Cancer Registries Webinar Series will be ready for distribution during the NAACCR Annual Conference.

Additional training updates:

The April 1, 2015, recording of the NAACCR Journal Club: *Annual Report to the Nation, 1975-2011, Featuring Incidence of Breast Cancer Subtypes* is accessible online here.

Registration is now open for three upcoming free webinars. You can register for all three online here.

- **May 28, 2015, Cancer Surveillance Series: SEER*Stat: Some highlights on new and existing features.** The SEER*Stat statistical software is a powerful tool to view individual cancer records and to produce statistics for studying the impact of cancer on a population. For the next installment of the NAACCR Surveillance Webinar Series, Angela Mariotto of the National Cancer Institute and Steve Scoppa of Information Movement System highlight new and existing features in SEER*Stat and demonstrate its use in the analysis of registry data. Please join us on Thursday, May 28, 2015, from 2:00-3:30 p.m. EDT for this event. Topics to be covered during this presentation include: (1) analyses of incidence rates by county-level attributes, (2) how to set up your incidence data with county-level attributes, (3) age-standardized survival, (4) new life tables including geography and socioeconomic index to estimate relative survival, (5) the Pohar Perme method to estimate Net (relative) survival, and (6) new and upcoming features in SEER*Stat.

- **June 23, 2015, Journal Club: Ovarian cancer incidence trends in relation to changing patterns of menopausal hormone therapy use in the United States.** After a report from the Women's Health Initiative (WHI) in 2002, a precipitous decline in menopausal hormonal therapy (MHT) use in the United States was linked to a decline in breast cancer incidence rates. Given that MHT use is also associated with increased ovarian cancer risk, a recent analysis in NAACCR evaluated whether ovarian cancer incidence rates changed after 2002 using age-period-cohort (APC) models. This webinar provides an overview of the ovarian cancer incidence rate changes before (1995 to 2002) and after (2003 to 2008) the WHI report and describes the age-period-cohort modeling approach.

- **August 12, 2015 Cancer Surveillance Series: Life Tables-Concepts and Methods.** This webinar will provide an overview of life tables, introduce basic concepts, and explain why they are used in cancer registry research. How to construct a life table will be explained and several smoothing methods will be discussed.

NAACCR 2015 Education and Training Calendar

APRIL 2015

4/21/15 - Session 1; CTR Exam Preparation & Review Webinar Series
4/28/15 - Session 2; CTR Exam Preparation & Review Webinar Series

MAY 2015

5/5/15 - Session 3; CTR Exam Preparation & Review Webinar Series
5/7/15 - Collecting Cancer Data: Larynx and Thyroid
5/12/15 - Session 4; CTR Exam Preparation & Review Webinar Series
5/19/15 - Session 5; CTR Exam Preparation & Review Webinar Series
5/26/15 - Session 6; CTR Exam Preparation & Review Webinar Series
5/28/15 - Cancer Surveillance Webinar Series: SEER*Stat Update

JUNE 2015

6/2/15 - Session 7; CTR Exam Preparation & Review Webinar Series
6/4/15 - Collecting Cancer Data: Pancreas
6/9/15 - Session 8; CTR Exam Preparation & Review Webinar Series

JULY 2015

7/9/15 - Survivorship Care Plans

AUGUST 2015

8/6/15 - Collecting Cancer Data: Central Nervous System
8/25/15 - Session 1; CTR Exam Preparation & Review Webinar Series

SEPTEMBER 2015

9/1/15 - Session 2; CTR Exam Preparation & Review Webinar Series
9/3/15 - Coding Pitfalls
9/8/15 - Session 3; CTR Exam Preparation & Review Webinar Series
9/15/15 - Session 4; CTR Exam Preparation & Review Webinar Series
9/22/15 - Session 5; CTR Exam Preparation & Review Webinar Series
9/29/15 - Session 6; CTR Exam Preparation & Review Webinar Series

OCTOBER 2015

10/6/15 - Session 7; CTR Exam Preparation & Review Webinar Series

10/13/15 - Session 8; CTR Exam Preparation & Review Webinar Series

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.naaccr.org); or contact Shannon Vann (svann@naaccr.org) or Jim Hofferkamp (jhofferkamp@naaccr.org).

Steering Committee Corner

Susan T. Gershman, PhD, MS, MPH, CTR
NAACCR Treasurer

Welcome to the Steering Committee Corner! This column provides brief Steering Committee updates such as new reports or projects, coding changes, new data standards, requests for Priority Area Network members for specific work groups, 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)

Chair: Annette Hurlbut

Committee highlights since the last *Narrative*:

- The CSC has been charged with developing a Communications Plan. The plan should be ready for the Board to review this spring. Best Practices for NAACCR's CSC is also under construction.
- A "Toolkit" that will provide information to registries on how to integrate the Explainer Video into their registry web site or promote the video to a specific audience is under development. This will be e-mailed to Registry Directors in a few weeks.
- The Social Media Work Group is focusing on various ways that the registry community can better utilize our social media outlets to provide important and timely information.
- The NAACCR membership will soon have a forum for timely exchange of ideas/editorials via our own NAACCR blog site.
- A membership survey will be conducted electronically in preparation for the NAACCR's Annual Conference.
- The CSC has a new intern, Benjamin Manthei. Benjamin is a senior at the University of Illinois where he is majoring in Communications. He is focusing on projects that involve assessment and improvement of both internal and external communications.
- Results from the ePoll that appeared in the last issue of the *NAACCR Narrative* indicate that NAACCR Certification provides more than one benefit to our registry members. In follow-up, three registries have provided articles to this issue of the *Narrative* sharing their experiences.

Research and Data Use Steering Committee (RDUSC)

Co-Chairs: Hannah Weir and Frank Boscoe

Committee highlights since the last *Narrative*:

Training/education:

- Journal Club: *Annual Report to the Nation, 1975-2011, Featuring Incidence of Breast Cancer Subtypes* was held on April 1, 2015.
- Journal Club: Future discussion includes *Ovarian Cancer Incidence Trends in Relation to Changing Patterns of Menopausal Hormone Therapy Use in the United States*. Be on the lookout for a NAACCR listserv announcement.
- Training Webinar: *What's new in SEER*Stat?* is scheduled for May 28, 2015, at 2:00 p.m. Eastern.

Other news to share with the NAACCR Community PAN interests:

- The Cancer Control Task Force (Co-Chairs Recinda Sherman and Susan Gershman) met on March 10, 2015, to discuss the project methods and timeline. The methodology will be Tom Tucker's index for burden of cancer (rank sum technique); major cancers will be included. Analysis is scheduled to begin July 2015.
- The Consent for Data Use Task Force will be organized in the next few months.
- If you have a suggestion for a journal club or surveillance webinar topic, please contact Hannah Weir (hweir@cdc.gov).
- If you would like to join the Research and Data Use Priority Area Network (RDU PAN) and receive notices about these and other upcoming events, please go to MyNAACCR at naaccr.org and sign up.

Professional Development Steering Committee (PDSC)

Chair: Deirdre Rogers, MS, CTR

Committee highlights since the last *Narrative*:

Training/Education:

- The Central Registries Short Course is being revised by a task force of the PDSC into a webinar series. A syllabus for the Understanding Population-Based Cancer Registries Webinar Series will be ready for distribution during the NAACCR Annual Conference.

Twitter Digest

Dan Curran, MS, CTR
Chair, NAACCR Social Media Work Group

If you had been following @NAACCR's Twitter feed you would have seen these interesting recent tweets:

@theNCI
Death rates for nearly all major types of cancer in the US decreased from 2002-2011: 1.usa.gov/1DnyfGi #ARN15

@theNCI
Have you explored the new SEER site? It has #cancer statistics, interactive tools & more 1.usa.gov/1ClsMM8 @NCICancerStats

@CDC_Cancer
Help young women learn their #BreastCancer risk. Share your story w/ #BringYourBrave campaign 1.usa.gov/1CgWELY

@NCIEpi
New CDC blog post discusses challenges of implementing a large precision medicine cohort study in the U.S. 1.usa.gov/1Cv4deI #pm101

@NAACCR
Medicare to potentially cover cancer screenings. Read one NAACCR member's thoughts http://news.naaccr.org/medicare-to-cover-annual-lung-cancer-screening-for-some-beneficiaries/

#NAACCReview

@CoC_ACS
Cancer #Registrars Thank you for data collection that supports cancer research, prevention +treatment @NCRAnews

@NAACCR
4 types of #breastcancer subtypes are mapped and described in the Annual Report to the Nation go.usa.gov/3YnFJ RT to share!

@NAACCR
CBS News story: 17th Annual Report to the Nation on the Status of Cancer ow.ly/L5kcu #ARN14

@NAACCR
Huff Post story: 17th Annual Report to the Nation on the Status of Cancer ow.ly/L5hfX #ARN14

@NAACCR
WebMD coverage of the 17th Annual Report to the Nation on the Status of Cancer ow.ly/L5gLr #ARN14

@NCICancerStats
NEW: Annual Report to the Nation on the Status of #Cancer, including special section on #BreastCancer subtypes go.usa.gov/3YnFJ #ARN15

@AJCCancer
RT @theNCI #CancerFilm Back in 2011, Dr Mukherjee spoke at NCI. You can watch excepts from the talk here: 1.usa.gov/1H6MX3S

@theNCI
Targeted #cancer therapies interfere with specific molecules involved in cancer cell growth and survival. More here: 1.usa.gov/18Yibi1

@AJCCancer
Students raise $93K for pediatric cancer research cin.ci/1C67Dro via @Enquirer

@CDC_Cancer
People with a new diagnosis of #ColorectalCancer should be offered genetic testing for Lynch syndrome go.usa.gov/3cAET

@NCIEpi
Registries are important sources of data for cancer research - see our list of national & state cancer registries 1.usa.gov/1E1EhbI

@AJCCancer
HIPAA crackdown extends beyond health care providers tnne.ws/1Bq1adL via @Tennessean

@NCIEpi
MT @DrKhouryCDC: Updated Cancer Genomics & Epidemiology Navigator with meta-analysis database http://ow.ly/LpJtc

Poll: Please Help us Better Keep You 'Connected'

NAACCR Social Media Workgroup

1. Which of the following NAACCR social media accounts do you follow? Please check as many as apply.

- ☐ ***Facebook***
- ☐ ***Twitter***
- ☐ ***Google +***

- ☐ ***Flickr***
- ☐ ***LinkedIn***
- ☐ ***None***
- ☐ ***Other*** _____

2. If you are connected with NAACCR on LinkedIn which profiles are you following?

- ☐ ***Company Page***
- ☐ ***Membership Group***
- ☐ ***Annual Conference Page***
- ☐ ***N/A***

If you have not already done so please follow our accounts

Facebook | ***Twitter*** | ***Google +*** | ***Flickr*** | ***LinkedIn***

Submit

NAACCR Annual Conference Social Media Contest

Dan Curran, MS, CTR
Chair, NAACCR Social Media Work Group

Win a $100.00 Amazon Gift Card!

Rules: Create a publicly shared blog, web page, or post to popular social media site (LinkedIn, Twitter, Pinterest, YouTube, etc.) where the main topic/emphasis is the upcoming NAACCR Annual Conference, a planned activity at the Annual Conference, or an activity occurring at the Annual Conference.

If your entry will only use Twitter, mention @NAACCR and include the hashtag #NAACCRcontest to enter the contest. If your entry will be on another site, you must use Twitter to officially enter the contest. Tweet a link to your entry with a mention of @NAACCR and the hashtag #NAACCRcontest to enter.

Entries must be received during the contest period from June 6, 2015, to June 17, 2015.

The contest is open to all NAACCR members with the exception of the judges. Please, no teams, but multiple entries per individual are welcome.

Judging: A panel of judges assembled by the NAACCR Social Media Work Group will award a $100.00 Amazon gift card for the most creative entry.

Winner Announcement: The winner of the gift card will be announced during the NAACCR Annual Conference and will be simultaneously tweeted from @NAACCR. The winner does not need to attend the conference but is welcome to be present to receive the prize and the admiration of fellow members!

2015 NAACCR Election Results

Bobbi Jo Matt, RHIT, CTR,
Chair, NAACCR Nominating Committee

The NAACCR Nominating Committee was charged with identifying qualified candidates for four elected positions to begin service at the 2015 Annual Conference: the Treasurer and three Representatives at Large.

The Committee solicited nominations from the membership and received numerous suggestions, including self-nominations.

Elected candidates are:

- **Treasurer:** Bruce Riddle, PhD (NH)
- **Representatives at Large:** Eric Durbin, DrPH, MS (KY);
  Deirdre Rogers, MS, CTR (MS); and Winny Roshala, BA, CTR (CA)

Seventy-four of 86 voting members voted (86%). The Nominating Committee would like to thank everyone who agreed to be included in the election as well as Charlie Blackburn and Dustin Dennison from the NAACCR office for their assistance.

NAACCR Nominating Committee members:
Bobbi Jo Matt, BS, RHIT, CTR
Bruce Riddle, PhD
Chandrika Rao, PhD

NAACCR Member Recognition Awards

Frances Ross, CTR
Director of Registry Operations, Kentucky Cancer Registry

NAACCR Wants to Recognize You!

It's time to add up your points for the Member Recognition awards. This award series was established by NAACCR to celebrate the active involvement and continuous efforts made by its members to support the organization and further its goals in cancer surveillance and public health research.

The Member Recognition Awards are based on a point system, in which specific activities are assigned a range of point values that may be earned by participation in any eligible activities. Eligible activities include attendance at educational meetings; making presentations; serving on NAACCR committees or on the Board of Directors; publishing relevant books, papers, or articles; and many other possibilities.

Visit the NAACCR Awards Program web page for details and online submission instructions. Please enter your accumulated points before May 4th, 2015, in order to be recognized at the NAACCR Annual Conference in Charlotte, NC, in June.

Annual Report to the Nation on the Status of Cancer

The 17th *Annual Report to the Nation on the Status of Cancer*, for which NAACCR was the lead agency, represents a collaborative effort by senior researchers from each major cancer surveillance organization in the United States to produce the up-to-date and comprehensive trends in cancer incidence and mortality. This year, the focus of the *Annual Report* is on breast cancer subtypes. You may access the journal article here.

Recinda L. Sherman, MPH, PhD, CTR
NAACCR Program Manager of Data Use & Research

On behalf of NAACCR and my co-authors from ACS, CDC, and NCI, I am pleased to present the latest *Annual Report to the Nation on the Status of Cancer*. This is our 17th *Annual Report*, and NAACCR was the lead agency. The *Annual Report* represents a collaborative effort by senior researchers from each major cancer surveillance organization in the United States to produce the up-to-date and comprehensive trends in cancer incidence and mortality.

Each year we focus on a special topic, and this year our topic is breast cancer subtypes. For the first time on a national level, we have published newly available data on breast cancer incidence rates by demographic and tumor characteristics for the four intrinsic molecular subtypes (HR+/HER-, triple negative, HR+/HER+, and HR-/HER+).We present rates for each subtype stratified by race/ethnicity and by age, stage, grade, and census tract-based poverty. We also present rates by subtype by state.

Presenting cancer statistics by molecular or histological subtypes is becoming progressively important as critical clinical treatment decisions are based on subtype for an increasing number of cancers. As medical knowledge advances, the future of cancer registries lies in our ability to accommodate this advancement. Diagnosis year 2010 marks the first year of nationally required Her2 receptor status reporting. And this year's special topic represents another success story for cancer registries and standard setters in reaching a balance among the competing demands of maintaining a reasonable burden on the registration system, preserving clarity and consistency of coding, and meeting the needs for clinical and public health research and prevention.

Additional information and resources will be made available and accessible from the NAACCR website. You may access the journal article here. Please don't hesitate to contact me (rsherman@naaccr.org) with any questions about the *Annual Report* findings or about your state's data.

Data Use and Research: Data in Action

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

Cancer registries are legislatively mandated to collect confidential data, including demographic data and tumor characteristics, to monitor cancer trends, aid in epidemiologic research, focus cancer control activities, and address public questions and concerns regarding cancer. An important element in this cancer surveillance system is the address at diagnosis fields.

The impetus for collecting address at diagnosis is that cancers and risks for cancers are not randomly disbursed across physical space. Health behaviors, positive ones like cancer screening and negative ones like smoking, vary by geography and influence cancer rates. Social factors, both mutable like community-based cancer control programs, and immutable like the distribution of a community by age or race, also vary by geography and impact cancer rates. Collecting address at diagnosis allows us to map these geographic differences to target cancer control efforts and inform epidemiologic research.

The need to collect the address at diagnosis is most obvious for cancer cluster evaluation and place-based research such as treatment or survival outcomes based on proximity to medical care. For example, NAACCR colleagues have published papers assessing the role of geographic proximity from medical facilities on stage at diagnosis (abstract here) and the receipt of optimal care (abstract here) for breast cancers. But geospatial research is a broad category of research on relationships among place and health and includes using address at diagnosis as a proxy for social measures, such as social class or the impact of regional systems. For instance, last year, NAACCR colleagues published the most detailed assessment of the association of area-based poverty on cancer to date (abstract here).

In order to conduct such studies, we require accurate collection of address at diagnosis. In addition to the address specific fields, there are a number of fields dependent upon address at diagnosis: (1) fields derived through geocoding (county, census tract, block group, and longitude/latitude), and (2) area-based measures (poverty, urban/rural status, urban/rural commuting codes). Address at diagnosis is also commonly used in linkage projects, both in linkages for improving quality of data and in cohort research linkage studies.

There are barriers to collection of accurate address at diagnosis. One problem is a homeless patient. The street address of a homeless patient should be coded as the address of the facility diagnosing the patient. It is recommended practice to enter "homeless" into the supplemental address field so that they can be handled appropriately in research studies. And address may be missing completely, although these are almost exclusively for historical cases. Missing addresses are coded "UNKNOWN" but a missing address is a rare event for an analytic case. And an address can have typographical errors.

But the largest the problem is the use of P.O. Box addresses instead of street addresses. Although a P.O. Box address can be useful in linkage studies, a P.O. Box does not represent the location where the patient lives or where area-based information was collected and can't be used in geospatial research. A P.O. Box address should only be coded as address at diagnosis as a last resort. Recommended practice is to enter the P.O. Box address into the supplemental address field and a street address into the address at diagnosis field. A rural route address should be increasingly less common as these have been phased out with 911 locator efforts. However, cases with rural routes, as well as general delivery, can generally be used in geospatial research.

How can we improve address data quality? Often geocoding and data quality assessment on address at diagnosis is done at the central registry level. For instance, most central registries correct address mistakes and typos through interactive geocoding and using online maps and telephone directories. And central registries commonly use administrative data sources like Department of Motor Vehicles, Voter Registration, Medicaid, or propriety people finders like LexisNexis, which requires a fee, to replace P.O. Box address with valid street addresses. And at least one state has implemented specific edits on address at diagnosis.

But the most effective improvements can be made at the hospital cancer registry level. Hospital registrars are closer to the source data and can review address information in a more timely fashion than the central registry can. In some hospitals, registrars work with the billing department to identify a previously unknown or incorrect address. Hospital registrars can use many of the same web-based resources available to central registries. It is recommended practice to use external resources to correct typos and replace P.O. Box addresses with street address.

Address at diagnosis is not often discussed in CTR trainings, but epidemiologists rely on these fields to map data, focus resources, and evaluate etiologic relationships. Inaccurate address information has the potential to bias study results, exclude patients from potential study participation, decrease the utility of mapped cancer rates, decrease the match rate of linkage, and decrease the usability of our data in research. Poor quality address information can undermine the utility of cancer registry data.

The following is a list of recommended address formats and practices for address at diagnosis:

- No periods or other punctuation.
- "RR" is acceptable—no RURAL ROUTE, STAR ROUTE or RURAL DELIVERY
- "HCR" is acceptable—no HC or HIGHWAY CONTRACT.
- "GENERAL DELIVERY" is acceptable.
- "UNKNOWN" is acceptable—no UNK or UK. The word "UNKNOWN' should be spelled out and should only be used when abstracting historical cases.
- "PO BOX" is acceptable—no POB or POST OFFICE BOX. However, P.O. Box should be entered in the Supplemental address field and the street address in the Address at Dx field. P.O. Box addresses should only be used if a street address is not found after reviewing chart and external data sources.
- Although people don't live at the Post Office, P.O. Box is preferred over "UNKNOWN". Using "UNKNOWN" over a P.O. Box address loses information. A P.O. Box can still be used to link to administrative databases for quality improvement linkages, research studies, and by the central registry to find a good street address.
- "HOMELESS" is not allowed; enter facility address in address at diagnosis and "HOMELESS" in supplemental address field.
- Use external data sources to correct typos and find street addresses for missing or P.O. Box addresses. Ensure that an address found by this type of investigation is appropriate for the date of diagnosis.

Enabling Interoperable Mechanisms of Data Exchange at the California Cancer Registry

The California Cancer Registry and College of American Pathologists are engaging many national and federal organizations, states, and local groups to develop and deploy new data capture standards based upon existing and emerging Office of the National Coordinator requirements. Through coordination with and sponsorship by California hospital systems, laboratories, and pathologists, they have begun a vital shift in pathology cancer reporting from unstructured, unstandardized, and narrative text data capture to one of standardized and structured data capture.

Jeremy Pine
E-Reporting Program Manager, California Cancer Registry

The California Cancer Registry (CCR), a program of the California Department of Public Health (CDPH), and the College of American Pathologists (CAP) are at the forefront of enabling interoperable mechanisms of data exchange designed to improve the health care and outcomes of California cancer patients. The CCR and CAP are engaging many national and federal organizations, states, and local groups to develop and deploy new data capture standards based upon existing and emerging Office of the National Coordinator requirements. The vision of the CCR goes well beyond the traditional role of cancer registries and, by design, includes directly impacting the care of cancer patients through improved access to interoperable, standardized, structured data suitable for automated decision support and quality assessments.

The current and prevalent use of free-form narrative text by the cancer clinical care community is arguably the single greatest barrier impeding health system interoperability within the larger cancer health care community. The CCR and CAP, via the coordination with and sponsorship by California hospital systems, laboratories, and pathologists, have begun a vital shift in pathology cancer reporting from unstructured, unstandardized, and narrative text data capture to one of standardized and structured data capture.

From February-June 2014, the CCR contracted with CAP to begin the implementation of the CAP electronic Cancer Checklists (eCC). The pilot project was intended to demonstrate that by using the eCCs, hospitals can transmit data directly from their local sites to the CCR electronically and without the need for additional manual processing. During the pilot, CAP successfully implemented the eCC templates for lung and colon cancer in Cerner CoPath Plus (CPP). Melanoma was also implemented through the CAP electronic Forms and Reporting Module (eFRM) software. From two sites, de-identified historical data was transmitted successfully to the CCR using standard NAACCR Vol V HL7 2.5.1 protocol, automatically parsing all messages into standard data fields, and converting the parsed data into NAACCR and Collaborative Stage codes to allow for structured data upload into the CCR Eureka database.

The CCR recently entered into an extended agreement with CAP to continue the coordinated effort for October 2014-June 2015. The primary goals of this project phase are to onboard and integrate three organizations inclusive of 15 facilities. As of March 27, 2015, the CCR has five facilities transmitting live, identified data to the CCR production systems using the eCC and standardized transmission protocols.

The real-time linkage and consolidation of patient diagnosis data from a structured pathology report by the CCR is the first example in the U.S. by a central cancer registry. Sponsorship of the project by California pathologists has provided the turning point in realizing the CCR/CAP achievements to date. The CCR and CAP have the long-term vision of the value of structured cancer data and the possibilities that are presented following the success of the current project, including using this “big data” for analytics to improve patient outcomes. The CCR is pursuing long-term partnerships with California health systems, laboratories, pathologists, and clinicians to further develop and expand the use of eCC to achieve these goals.

The capture of structured pathology data will provide a platform and a tangible product for a number of health care systems to approach the possibility of exchange of cancer diagnosis data in ways that have previously been impossible. The advancement of technology, and more specifically the CCR and CDPH systems themselves, has led to a realistic and tangible view of health system interoperability. CCR and CAP intend to continue to work with California pathologists in the development of technology which benefits and helps manage transitions of care and the development of accurate, real-time patient summaries for use by health professionals. Of greatest importance to the CCR, CAP, and CDPH is that our organizations have proven the California public health system can play an integral role in assisting and better meeting the current and future health care needs of all Californians.

NAACCR Certification in Maine: What it Means to Our Registry

The Maine Cancer Registry (MCR) has been Gold Certified for 11 years and looks forward to continuing this certification for its 12th year. The registry has has streamlined its processes and duties required for NAACCR Certification and is on the path to Public Health Accreditation. MCR has been conferred with extra status as a result of its NAACCR Gold Certification and is well positioned to address the documentation, data quality, completeness, and timeliness requirements for Public Health Accreditation.

Kathy Boris, CTR
Maine Cancer Registry Data Quality Manager

I am the Data Quality Manager for the Maine Cancer Registry (MCR) and have been employed at the central registry for 10 years. I previously had been employed at a hospital registry which was a COC-approved facility. Because both positions required extensive review of data to either pass survey (for COC) or to receive certification (by NAACCR), quality data has always been a priority. However, at the central registry, the data is reviewed with much more scrutiny due to submissions from multiple sources (hospitals, physicians, path labs). When discrepant data (such as dates of birth, social security numbers, treatment dates) is found on consolidation or review of subsequent primary cancers, follow-back to facilities is performed.

Although we are a very small staff at MCR (3.5 full-time employees and 3 contractors working on a part-time basis), we have a good relationship with the staff at cancer registries at our reporting facilities. The CTRs in Maine have remained fairly constant over my years in the registry, and resolution of issues is usually an e-mail or phone call away.

Through the development of our timeline for projects (such as Pathology Clearance from an in-state laboratory that services half of the hospitals in Maine, Death Clearance, Interstate Data Exchanges), our duties required for certification by NAACCR have become more streamlined. With the addition of software that is more aligned to central registry processing of data, the running of edits prior to data call has become less labor intensive. Deduplication of cases for NAACCR certification has required less time as the number of cases for review has decreased due to better data review over the years, resulting in fewer duplicate cases in our database. Our contracted epidemiologic support has remained constant by the same person for the last three years so preparing for the data call requires a simple review of the previous year's procedures.

NAACCR Gold Certification is always a welcome notification because MCR is working with limited resources, and there are limited rewards for hard work. The consistency of our staff, our contractors, and the facilities that submit data to us has been instrumental to maintaining this certification. MCR has been Gold Certified for 11 years, and we look forward to continuing this certification for our 12th year.

Within our state agency, we have been on the path to Public Health Accreditation. As such, MCR has been conferred with extra status as a result of our NAACCR Gold Certification. Through this achievement, MCR is well positioned to address the documentation, data quality, completeness, and timeliness requirements for Public Health Accreditation.

NAACCR Certification: The Rhode Island Experience

The Rhode Island Cancer Registry (RICR) has achieved NAACCR Gold Certification 16 years in a row. RICR views this as a statewide accomplishment that involves the entire cancer registration community. NAACCR Gold Certification is more than a measure of data quality, it is a symbol of cooperation and pride in the Rhode Island cancer registry community. It signifies that RICR has achieved a high level of timeliness, quality, and completeness while maintaining a positive working relationship with hospital cancer registries and administrations.

David Rousseau
Rhode Island Cancer Registry

The Rhode Island Cancer Registry (RICR) has achieved NAACCR Gold Certification 16 years in a row. However, in Rhode Island we view this as a statewide accomplishment that involves the entire cancer registration community. Upon receiving the certificate, a letter is sent to the President and the Chairs of hospital Cancer Committees, noting that this accomplishment would not be possible without the dedicated work of hospital cancer registrars. The certificates are prominently displayed on a wall in the Rhode Island Cancer Registry (RICR)

and not only represent that the RICR has achieved a high level of timeliness, quality, and completeness but also that we maintain a positive working relationship with hospital cancer registries and administrations.

In Rhode Island, the Rhode Island Department of Health contracts the Hospital Association of Rhode Island to maintain the official statewide cancer incidence database. When members of government, hospital administration, public health, emergency management, and the public attend meetings at the Hospital Association they ask, "What are all those certificates on the wall?" The President of the Hospital Association or staff leading the meeting respond by explaining that the certificates indicate that the RICR has achieved the highest standard in data collection and quality.

In Rhode Island, NAACCR Gold Certification is more than a measure of data quality, it is a symbol of cooperation and pride in the Rhode Island cancer registry community.

RICR staff, front row from right to left: Shirley Eliason, CTR; Joyce Curcio, BS; and Nancy Lebrun, CTR, AS. Back row (left to right): Lisa Garcia, CPEHR; David Rousseau, BS; and John Fulton, PhD

NAACCR Certification: The Texas Experience

Achieving NAACCR Certification is a way of demonstrating to Texas Cancer Registry staff, customers, and funders that these data are rigorously collected, maintained, and evaluated each and every year. This high standard is the way things are done in the population-based cancer registry world and everything possible should be done to preserve or achieve that level of high-quality data. The cancer community, and most importantly its patients deserve nothing less.

Melanie Williams, PhD
Branch Manager, Texas Cancer Registry

When you first walk in to the Texas Cancer Registry, a wall of framed NAACCR Certification certificates greets visitors and staff alike. Why such an overt display of years past and present achievements? Because NAACCR Certification demonstrates to others that our data are complete, accurate, and timely. Think of it as the cancer surveillance "Good Housekeeping Seal of Approval." Achieving NAACCR Certification is a way of demonstrating to our staff, customers, and funders that these data are rigorously collected, maintained, and evaluated each and every year. That investing the time, energy, dollars, and occasional tears required to produce them is judged by others as worthwhile and in accordance with international standards.

We also post these certifications as a badge of personal accomplishment. Too often, we achieved the standard by a thread. Many of us remember a time when Texas had the distinction of never having received NAACCR Certification. At that time, our leadership and customers were disappointed, but kind. And while some likened our standards to "tin foil," the registry staff remember those times as more of a "rusty nail" – a deep, black hole not only in our hearts, but also visible on a map of North America. In this spirit, we say to those who haven't met the standard, or who have missed it due to circumstances beyond their control, "don't give up!" Use the lack of certification as your rallying cry. Make sure everyone is aware that the registry must be supported, and that when supported, accomplishments are recognized and celebrated. And, when you do receive certification, proudly put it on display. Start your own wall of fame as a way to visualize not only your accomplishments, but your goals.

A wall of NAACCR Certification certificates or the absence of those certificates whether the viewer realizes it or not tells a story. That this high standard is the way things are done in the population-based cancer registry world and everything possible should be done to preserve or achieve that level of high-quality data. The cancer community, and most importantly its patients deserve nothing less.

Forming a Hospital Cancer Registry in West Africa During the Ebola Era

In September 2014, amidst fears of an impending Ebola outbreak, Rebecca Cassady and John W. Morgan traveled to Ghana, West Africa, to assist in establishing a breast cancer registry at Peace and Love Hospital. If Ebola arrives in Ghana, hospital staff will be among the first to have contact with infected patients. In spite of concerns about Ebola, staff members in this small private hospital continue to conduct tumor safaris into remote and underserved regions of Ghana, where Ebola could be lurking.

Rebecca Cassady, RHIA, CTR
Director, Region 5, Cancer Registry of Greater California

John W. Morgan, DrPH, CPH
Cancer Epidemiologist, Regions 4 & 5, Cancer Registry of Greater California

In September 2014, amidst fears of an impending Ebola outbreak, Rebecca Cassady, RHIA, CTR, Director, Region 5 of the SEER Cancer Registry of Greater California (CRGC) and John W. Morgan, DrPH, Professor of Epidemiology at Loma Linda University and Cancer Epidemiologist for Regions 4 & 5 of the CRGC, traveled to Ghana, West Africa, to assist in establishing a breast cancer registry in a private hospital (Peace and Love Hospital). The Peace and Love Hospital in Kumasi, the second largest city in Ghana, was established in October 2002 for diagnosis and treatment of breast cancer. Since it was founded, 1,301 breast cancer patients have received diagnosis or care at the Peace and Love Hospital.

Breast cancer is the leading cancer diagnosed in Ghana with an estimated 70% of cases diagnosed at advanced stages. Late diagnosis of breast cancer in Ghana is substantially the consequence of limited availability of mammographic screening and diagnostic services, limited availability to clinical breast exam technology, and limited access to fine needle aspirate (FNA) biopsy and microscopic pathology services. In addition to these barriers to breast cancer early diagnosis, widespread reliance on mystical beliefs, herbal remedies, and recent fears about contracting Ebola in hospitals also present barriers to treatment of breast cancer following diagnosis. Although no Ebola cases have been confirmed in Ghana, the tragedy of fungating (gangrenous) breast cancer resulting from ulcerating tumors is prevalent. Olfactory cues to the tragedy of gangrenous fungation permeate examination rooms where these patients receive diagnostic and palliative care.

In response to an invitation from the Director of the Peace and Love Hospital, Rebecca Cassady, RHIA, CTR travelled to Kumasi, Ghana, assisting in installation and training in the use of abstracting software (SEERAbs), with the remaining time allocated to cancer registration training sessions for the three hospital staff assigned to the fledgling cancer registry.

During the same time period, Dr. Morgan was invited to travel approximately 200 miles southeast of Kumasi with the Peace and Love Hospital team to the Volta Region of Ghana, near the border with Togo, where he served as a public health ambassador advocating the importance of breast cancer early detection and treatment. After gaining support from the Regional Tribal Chief, the Peace and Love team invited middle-age and older women to participate in breast self-examination training and to receive clinical breast exams. During this 4-day excursion, approximately 1,000 no-charge clinical breast examinations were performed by the team in this remote and underserved region of Ghana. This labor-intensive process was directed by a breast surgical oncologist and founder of the Peace and Love Hospital, Dr. Beatrice Wiafe-Addai, who was assisted by approximately 50 specially trained “nursing” staff and dozens of breast cancer survivors who served as volunteers. After evaluation by Dr. Wiafe-Addai, several dozen women having masses suspicious for breast cancer received written prescriptions for follow-up diagnostic mammograms, FNAs, or biopsies intended to identify earlier stage breast cancer. The expectation was that this process would identify between 6 and 12 patients having early stage breast cancers that would, ultimately, receive care at the Peace and Love Hospital.

Volta Region Tribal Chief (in Silver) and Dr. Beatrice Wiafe-Addai (dressed in pink) with John W. Morgan, DrPH, Cancer Epidemiologist, Regions 4 & 5 of Cancer Registry of Greater California

In addition to discovery of breast masses, this breast tumor safari identified several dozen overt breast lesions characterized by ulcerations and fungation, with these patients directed for diagnosis and follow-up care. Like this trip to the Volta Region, Peace and Love Hospital-staff conduct monthly expeditions, searching for early stage breast cancers in other remote regions of Ghana.

Cancer Registry Trained staff of Peace and Love Hospital with Rebecca Cassady, RHIA, CTR, Director, Region 5, Cancer Registry of Greater California

During the past 3 years, Peace and Love Hospital, together with two other hospitals, has collaborated in the NCI-supported Ghanaian Breast Health Study that funds breast tumor biopsy, microscopic pathology, and collection of biological specimens. This funding provides estrogen and progesterone receptor status and Her-2-Neu findings for breast biopsy specimens for patients diagnosed with breast cancer. To date, the Peace and Love Hospital has enrolled 750 (more than half) of the breast cancer patients in the Ghanaian Breast Health Study and is slated to enroll the remaining 350 patients during the next 2 years. Combined with information from the newly formed cancer registry, these data will be used by staff at Peace and Love Hospital, Loma Linda University School of Public Health and Region 5 of the CRGC to evaluate and seek to improve breast cancer control strategies in Ghana and beyond.

Every member of the Peace and Love Hospital staff is aware that if Ebola arrives in Ghana, hospital staff will be among the first to have contact with infected patients and that surgical hospital staff experience exquisitely high potential for exposure to body fluids. In spite of concerns about Ebola, staff members in this small private hospital continue to conduct tumor safaris into remote and underserved regions of Ghana, where Ebola could be lurking. In the words of Dr. Wiafe-Addai, "*The threat of Ebola is theoretical, while the opportunity to prevent deaths from breast cancer is real.*" Both Rebecca Cassady and Dr. John Morgan express their thanks for the work of Dr. Wiafe-Addai and staff at the Peace and Love Hospital, and for the opportunity to contribute to their work in breast cancer control in Ghana.

2015 Edition Base EHR Definition

Lori A. Havener, CTR
NAACCR Program Manager of Standards

The Notice of Proposed Rulemaking is introducing the 2015 Edition Health IT Certification Criteria, proposing a new 2015 Edition Base EHR definition, and proposing to modify the ONC Health IT Certification Program to make it open and accessible to more types of health IT. The NAACCR Standardization and Registry Development Steering Committee encourages the NAACCR membership to review the Cancer Sections in the ONC document and the CMS document (links below).

For consideration, comments must be received by ONC no later than 5 p.m. on May 29, 2015. In the Table of Contents, click on Addresses for the methods to submit comments.

Click here to go directly to the Cancer Section in the ONC document.

Click here to go directly to the Cancer Section in the CMS document (Measure 4 - Public Health Registry Reporting).

XML Data Exchange Standard Task Force at the NAACCR Annual Conference

Lori A. Havener, CTR
NAACCR Program Manager of Standards

The NAACCR 2015 Annual Conference will feature several presentations of an XML specification to help move NAACCR towards a new solution to build standards for data exchange of the future:

- **A plenary session** will highlight the features of the XML standard, presenting highlights of XML Data Exchange Task Force work.
- Members of the Task Force will present **an XML-themed concurrent session**, with three in-depth presentations about the new format with time for discussion.
- **A live demonstration** showing data exchange between computer systems utilizing XML data will be presented in the exhibitor area of the Conference.

A Must-Watch Movie: "Living Proof"

Taina Valone, RHIA, CTR
Cancer Registry of Greater California

[*Movie review reprinted from the March 2014 issue of the Cancer Registry of Greater California's CHATS newsletter.*]

How often do you get to watch a movie that brings to life an aspect of the cancer registrar's work in a way that is touching, well-acted and entertaining? "Living Proof" is this kind of movie. What could have been a schmaltzy Lifetime Television disease-of-the-month movie is instead an inspirational true story of the dedication of one doctor and the lives he has touched.

This movie dramatizes the efforts that Dr. Dennis Slamon, portrayed by Harry Connick,Jr., a UCLA Medical Center oncologist and researcher, took to make HER2/neu testing and Herceptin a viable option for women who have this more aggressive breast cancer. Connick nails the doctor's role with just the right amount of "nerd" to believe he's a doctor and captures the determination of Dr. Slamon's belief that he can affect the survival rates for breast cancer patients. We quickly see that Dr. Slamon is determined to prove his theory, even at the cost of lost family time, doubts in his tenacity, and political maneuvering by overzealous clinical trial over-seers.

The FDA and the drug company present challenges to Dr. Slamon's ability to get this drug to the patients. When the drug company stops funding him, he is lucky that one of his friends is Lilly Tartikoff (Angie Harmon), a well-connected philanthropist and wife of Brandon Tartikoff who at that time was head of NBC. She convinces Revlon to donate initially to keep his research going, and after that she continues generating money by putting on the annual "Fire and Ice Ball." The drug company Genentech did eventually jump back in with funding and they are the current producer of Herceptin.

As we get engrossed in Dr. Slamon's struggles to get this drug approved for clinical trials, we meet a number of women who we know are going to get the dreaded doctor talk, "you have cancer." Their stories merge with Dr. Slamon's story as they each find their way to the clinical trials. Bringing these women to life are some big names: Bernadette Peters, Swoosie Kurtz, Trudie Styler, Regina King and Jennifer Coolidge. Each actress gives a personal touch to her character and makes the viewing audience care about each and every one. The saddest story is the young mother who is in the mouse trials but can't continue on to the clinical trial because she doesn't meet the protocol criteria. When her mother (Swoosie Kurtz) begs Dr. Slamon to give her daughter more Herceptin because of positive results, it is heart breaking to see him have to tell her "no." Later on, the compassionate care clause is added to the protocols to help these kinds of situations.

The most uplifting story involves Bernadette Peters' character, Barbara. She is fed up with chemotherapy and she is on her way to Mexico to try some last-ditch nutrition therapy. Dr. Slamon originally calls her to ask her to be on the trial and she refuses. He becomes convinced that the Herceptin can help her and calls her *again* in the middle of the night before her trip. Yes, this is the kind of doctor you want on your side. He convinces her to postpone her trip so she can join the trial. She ends up having a measureable response as her metastatic neck tumor shrinks and she is eventually deemed cancer free.

Other characters don't fare as well, but their stories add human faces to the breast cancer statistics. Trudie Styler plays a quirky hippie lady who is into natural remedies who isn't so lucky to move on to the next clinical trial. Jennifer Coolidge plays the humorous patient who makes the other patients laugh. The other positive story is based on Regina King's character that inconveniently has her breast cancer diagnosis recur around the same time that she meets the man of her dreams. She breaks it off with him because she feels she is going to die and she doesn't want him to suffer. She ends up finding out about the clinical trials. After she has spent weeks trying to get through massive paper work and bad luck to get on the third clinical trial, she is told by a nurse that she is too early as the trial is starting the next week. She explains to the nurse—with the truth of those close to death—how hard it is to wait for people who aren't ready for her because she is *dying* and death waits for no one. This quote will stay with me for a long time. The nurse calls Dr. Slamon and he hooks her up as the first patient to start the third trial. We later see her getting married and, we hope, disease free.

The FDA approved Herceptin in 1998. This movie was released in 2008. Today, the full impact of getting Herceptin to all the women who need it is reflected in this movie's Amazon reviews from patients who are the "living proof." The patient played by Bernadette Peters is still alive and living in the Northwest. For you readers, the movie is an adaption of the book Her-2: The Making of Herceptin, a Revolutionary Treatment for Breast Cancer by Robert Bazell. Dr. Slamon is still working in cancer research and his immense biography is here if you want to read more about this incredible human being who never gave up.

I highly recommend "Living Proof."

Job Opportunity at the Kentucky Cancer Registry

Frances Ross, CTR
Director of Registry Operations, Kentucky Cancer Registry

The Kentucky Cancer Registry is recruiting for the position of:

QA Manager for Abstracting and Training

Requisition # RE02917
Kentucky Cancer Registry

This person will oversee the data quality assurance program at KCR by performing audits on data, developing and conducting training programs, and taking an active leadership role in national cancer registration organizations. Experience with cancer registries, cancer care, or cancer data collection is essential.

The QA Manager for Abstracting and Training at Kentucky Cancer Registry (KCR) will supervise four Regional Abstractors who collect cancer patient data from 50-60 small hospital and non-hospital facilities.

To apply for job #RE02917, submit a UK Online Application at www.uky.edu/ukjobs. If you have any questions, contact HR/Employment, phone (859) 257-9555 press 2.

The application deadline is May 17, 2015.

The University of Kentucky is an equal opportunity employer and encourages applications from minorities and women.

NAACCR Training Specialist/Project Coordinator Job Opening

Narrative Staff

Join the NAACCR Team!

NAACCR is seeking a hardworking, innovative cancer registry professional who works well independently. Duties include developing, coordinating, and providing training for NAACCR members and the cancer registry community. In addition to training activities, this individual will be responsible for managing and providing professional support for various NAACCR activities. This would include support for NAACCR committees and a variety of NAACCR projects.

Working experience in both a central cancer registry and hospital cancer registry is desired. Candidates must be a CTR and have experience developing and coordinating training activities. The ability to work independently is essential and managing multiple large-scale projects is required. Experience working with a learning management system is a plus. Creative use of technology and social media to deliver content is also desired. NAACCR offers a competitive salary, superior health benefits package, 401k with match, and a full-time 37.5 hour work week. The candidate may be able to work remotely. Some travel required.

If interested please send a resume to Jim Hofferkamp at jhofferkamp@naaccr.org.

To view the job posting, please click here.

http://www.naaccr.org

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

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