MESSAGE FROM THE PRESIDENT

Fall 2018 NAACCR Narrative

Antoinette Stroup, PhD
NAACCR President
nan.stroup@rutgers.edu

Hafa Adai[1]

Kids are back in school, leaves are strewn all over my driveway, there’s a brisk chill in the air, and Halloween decorations are everywhere...it must be fall. This fall season also brought the 2018 Implementation Guidelines, the NAACCR Call for Data, encouraging registries to submit using NAACCR XML, and, last but not least, some of our NAACCR members, including me, are heading for Arequipa, Peru for the International Association of Cancer Registries (IACR) conference (November 13-15, 2018).

I will be joining Betsy Kohler, NAACCR Executive Director, who will be giving a talk on advancing cancer surveillance efforts in the Caribbean; making good on one of NAACCR’s “Wow!” initiatives from the Strategic Management Plan and made possible through a successful collaboration with the National Cancer Institute, CDC, the Caribbean Public Health Agency (CARPHA), and IACR. I’m also looking forward to a Keynote address on Day 2 (Wednesday, November 14) by one of our NAACCR colleagues, Dr. Guillermo Tortolero Luna from the Registro Central de Cancer de Puerto Rico (or the Central Registry of Cancer of Puerto Rico), who will be speaking about the use of cancer registry data in Puerto Rico.

I would be remiss if I didn’t mention our planned excursion to Machu Picchu, which is an Inca citadel (or fortress) built in 1450 high atop a 7,970 ft. mountain range near Cusco and the Sacred Valley in southern Peru. My hiking boots are packed. I’ve taken all the CDC-recommended vaccinations, and I’m ready for my very first trip to South America! Estoy Listo! Vamonos!

Don’t forget to follow us on social media platforms on Facebook and Twitter @NAACCR, Inc. – be sure to like and follow us. You can also follow me @nan_cxreggeek...who knows what you might see from our Peruvian adventure!

[1] “Hafa Adai” is pronounced ha-fa-day and means “Hello” in my native Chamorro language.
REMEmBERING DR. GILBERT H. FRIEDELL

Fall 2018 NAACCR Narrative

Remembering Dr. Gilbert H. Friedell
By: Thomas Tucker, PhD, MPH; Frances Ross, CTR; and Eric Durbin, DrPH, MS

Dr. Gilbert H. Friedell, affectionately known as “Gil”, passed away peacefully on September 23, 2018, at the age of 91. Gil was a passionate and tireless advocate for cancer control and cancer surveillance. He was the first Director of the Markey Cancer Center at the University of Kentucky (UK). During his tenure at UK, Gil helped to form the Kentucky Cancer Registry (KCR). As a direct result of his advocacy, in 1990 state legislation was passed making KCR the official population-based cancer surveillance program for the Commonwealth. Gil firmly believed that complete, accurate and timely population-based cancer data was essential. He believed that without this critical information it would not be possible to determine where the cancer burden was high, and it would not be possible to measure the impact of our cancer prevention and control interventions aimed at reducing the cancer burden.

Dr. Friedell’s influence reached well beyond the borders of Kentucky. He was one of the original founding members of the North American Association of Central Cancer Registries (NAACCR) and he was one of the first people to receive NAACCR’s prestigious Calum Muir award for his contributions to cancer surveillance. Gil was instrumental in helping to get federal legislation passed that established the National Program of Cancer Registries (NPCR). This federal program provides funding that makes it possible for all states to have a population-based cancer registry and Gil played a key role in seeing that this program was placed at the Centers for Disease Control and Prevention (CDC).

Above all else, Gil was devoted to helping the most vulnerable people, those with fewer resources and less education. He was a passionate advocate for the people of Appalachia, and he worked tirelessly to develop and implement programs that both provided critical education about and access to cancer screening and treatment. He was a friend and a mentor to many in the cancer community. His tenacity, his wisdom, his leadership, his humor, his kindness and most of all his friendship will be greatly missed.

HIGHLIGHTS FROM THE PROGRAM MANAGER OF STANDARDS

Fall 2018 NAACCR Narrative

Lori Havener, CTR
NAACCR Program Manager of Standards
lhavener@naaccr.org

DATA STANDARDS AND DATA DICTIONARY DATABASE MANAGEMENT SYSTEM UPDATE

NAACCR plans to update the current management system that houses the data standards and data dictionary. The data standards and data dictionary is primarily used for data transmission; however, there are a variety of users with a variety of needs. If you have contacted Monica or me in the past with a request or have thought of a utility you would like added to the management system send your wish list to Monica Thornton (mthornton@naaccr.org).
The NAACCR Data Standards and Data Dictionary, Version 18 was released March 2, 2018. There have been several changes since the initial release of the Data Standards and Data Dictionary, Version 18. **NOTE:** All of the changes since the Version 18 release are documented in the change log that is available on the same website as the Data Standards and Data Dictionary. The change log identifies the date of the change, the data item number, data item name, the field that was changed, the change that was made and a column for notes.

**XML DATA EXCHANGE STANDARD IMPLEMENTATION BY 2020**

The NAACCR Board approved changing its Standards Volume II data exchange format from fixed-width to an Extensible Markup Language file format (XML) by 2020. The NAACCR Plan to Implement XML is posted on the NAACCR website. The XML Data Exchange Standards website includes the NAACCR XML Data Exchange Standard Implementation Guide Version 1.3, XML dictionaries, XML webinars, software tools, etc.

**DATA STANDARDS AND DATA DICTIONARY (VOLUME II), VERSION 20 TIMELINE:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>NAACCR Deadlines</th>
<th>Considerations/suggestions to meet NAACCR deadlines</th>
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<tbody>
<tr>
<td>Proposed requests-for-change (new and changed data items) submitted to the Mid-Level Tactical Group (previously Change Management Board (CMB))</td>
<td>October 1, 2018</td>
<td>1. Complete request-for-change forms for new and changed data items; submit to the Mid-Level Tactical Group (previously CMB) by October 1, 2018.</td>
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<td>Requests-for-change final review/approval by Mid-Level Tactical Group and other groups as needed (e.g., UDS)</td>
<td>December 31, 2018</td>
<td>1. Coordinate with Mid-Level Tactical Group to ensure communication with stakeholders. 2. Final requests are submitted to the UDS WG by January 1, 2019 for review and inclusion in to Standards Volume II.</td>
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<td>Convene NAACCR 2019 Implementation Guidelines Task Force</td>
<td>April 1, 2019</td>
<td>1. Materials for NAACCR Data Standards and Data Dictionary (Volume II) must be in final format for the Task Force to develop the implementation guidelines. 2. Final versions of mapping and/or conversions.</td>
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<tr>
<td>UDS Work Group reviews and updates the Data Standards and Data Dictionary (Volume II) (Jan – April)</td>
<td>May 2019</td>
<td>1. Assumes completion of all requests for changes to existing data items and requests of new data items.</td>
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Finalize the Data Standards and Data Dictionary (Volume II) and submit to NAACCR Board for review/approval

<table>
<thead>
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<th>NAACCR Data Standards and Data Dictionary Released</th>
<th>June 1, 2019</th>
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<tr>
<td>NAACCR 2019 Implementation Guidelines Released</td>
<td>August 1, 2019</td>
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<td>EDITS metafile release</td>
<td>September 1, 2019</td>
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<td>Education and training</td>
<td>Ongoing as material becomes available</td>
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<td>Implementation</td>
<td>January 1, 2020</td>
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**NAACCR RESEARCH AND DATA USE UPDATE**

Fall 2018 NAACCR Narrative

Recinda Sherman, MPH, PhD, CTR
NAACCR Program Manager of Data Use and Research
rsherman@naaccr.org

As the Fall colors fade and the leaves drop (at least for those of you who live in areas with distinct seasons!), we have limited time for reflection as we are furiously working to ensure the multiple submission are high quality and completed on time.

To this end, you will notice some improvements to the Call for Data (CFD) site this year. This year, you are able to electronically sign the data agreement as well as the consent forms for annually approved projects. If you are unable to sign electronically, you can still print, sign, scan, and upload the same as last year. We will also accept the signed documents by fax or email, but we encourage you to sign electronically or upload.

Another change to the site is the RRID6 and the CDC IRB Assistance information collection systems have now been merged into the CoRRI database. More information about CoRRI is included in a separate section of this edition of the Narrative.

And CFD again includes the consent for the Public Use Datasets, ACS Facts & Figures, Medulary Thyroid Research, CINAPlus in SEER™Stat, and Delay Adjustment with no changes. The consent for NAACCR Synthetic
Dataset has been updated to allow the training dataset to be larger (from 10,000 synthetic cases to 500,000) and to allow the Synthetic data to be used in NAACCR Trainings without additional consent. We also have a new project with the American Lung Association that is included in the CFD consents.

Please note, NAACCR CInA data is covered by a Certificate of Confidentiality (CoC) from NIH. Because NIH no longer provides CoC documentation, please contact me if your organization needs additional information. We hope this helps central registries increase data use participation while complying with local policies and regulation.

And once Call for Data is complete, we of course barrel on through to the Annual Conference—and the period between Call for Data and the Annual Conference seems shorter every year. What is not shorter, thankfully, is the length of time for submitting an abstract to our combined NAACCR/IACR Annual Conference in Vancouver, Canada. Abstracts for both student and professional presentations and posters are due on Friday, February 15, 2019—for both international and North American presenters. This year, we have a fully automated abstract submission, review, and scheduling process. Most of the improvements will not be noticeable to abstract submitters, but we welcome your feedback on our new system. Online submission will be open in a few weeks. We are excited to see you all in Vancouver!

Another area of restructuring is the NAACCR IRB. In response to the changes in the Federal Policy known as the Common Rule, we are simplifying the NAACCR IRB requirements for CInA Data Requests. At the April NAACCR IRB Meeting, we will finalize and approve these changes. I look forward to providing the specifics then.

NAACCR EDUCATION AND TRAINING PROGRAM UPDATE

Fall 2018 NAACCR Narrative

Jim Hoefferkamp, BA, CTR  
NAACCR Program Manager of Education & Training  
jhoefferkamp@naaccr.org

Have you had a chance to see all of the free webinars available from NAACCR on topics that are new or changed for 2018? If not, check out our 2018 Implementation page on the NAACCR learning management system (LMS): https://www.naaccr.org/2018-implementation/

We currently have recordings on the following topics and expect to add to the list over the next year:

- New Grade Coding Rules for 2018
- 2018 Radiation Coding Rules
- Solid Tumor Rules (Intro, breast, lung, colon, CNS)
- Summary Stage 2018

The 2018-2019 webinar series started on October 4. The topic of our first webinar was lung and the second is pharynx. My co-host for these three webinars is Wilson Apollo, MS, CTR, RTT. Wilson is a CTR, radiation therapist, and an accomplished educator. Wilson and I discussed the new solid tumor rules, staging (AJCC, EOD, Summary Stage 2018, and SSD1s) and the new radiation codes. Response to these first two webinars of our new season has been outstanding! I’m looking forward to working with Wilson on the December webinar covering Breast.

Our January webinar is on Testis. Denise Harrison and Louanne Currence will be hosting this webinar. If you have not been to a training presented by Denise and Louanne, you are in for a treat!
For more information on upcoming NAACCR webinars or to subscribe for the 2018-2019 NAACCR webinar series see our website at: https://www.naaccr.org/cancer-registry-surveillance-webinar-series/.

We are currently gearing up for another CTR Prep and Review Webinar Series. The 2019 CTR exam will include changes implemented in 2018. We are updating all of the CTR Prep materials to reflect these changes! Our first session will be the second week of January. We will open registration soon!

For more information see the NAACCR CTR Prep and review page at: https://www.naaccr.org/ctr-exam-preparation-review/.

Keep your eye out for information on upcoming NAACCR Prep Talks! We are working on a robust schedule for 2019. NAACCR Talks are free webinars on topics that concern the NAACCR membership. These are usually topics related to research and data use, analytic tools, and central registry functions. More information on upcoming NAACCR Talks and recordings of previous NAACCR talks are available at: https://education.naaccr.org/freewebrinars

If you have any questions about upcoming training events, please contact Angela Martin or myself!

Angela Martin
amartin@naaccr.org

Jim Hofferkamp
jhofferkamp@naaccr.org

NAACCR 2018 EDUCATION AND TRAINING CALENDAR

Fall 2018 NAACCR Narrative

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VIRTUAL POOLED REGISTRY UPDATE

Fall 2018 NAACCR Narrative

Castine Clerkin, MS, CTR
NAACCR Program Manager of Virtual Pooled Registry
cclerkin@naaccr.org

Fall is my favorite time of year here in New Hampshire! It’s not only beautiful, but it’s also a time to prioritize activities to tackle before the snow flies at the end of the year. Even my boys are helping!

In terms of the Virtual Pooled Registry Cancer Linkage System (VPR-CLS), we are wrapping up our first pilot test of the Phase I functionality to support the initial registry linkage and release of aggregate match counts. We were fortunate to have 35 registries volunteer to participate in the linkage with the Childhood Cancer Survivor Study cohort. During the allotted two-week timeframe, 30 registries completed the linkage using Match*Pro and a pre-defined configuration file. The resulting match count reports were uploaded to the VPR-CLS and shared with the study investigators. 21 of these registries also manually reviewed the match results to help us assess software performance. While we received minor suggestions for software tweaks, by far the best feedback received was this:

“Of all linkages I have completed in the past 3 years, the VPR-CLS set-up has been by far the easiest and smoothest linkage I have done.”

We are now focusing our attention on Phase II of the VPR-CLS functionality, which will streamline the submission and tracking of registry/IRB requests for release of individual-level data on matched cases. Registries previously responded to a survey about whether they could use the Templated IRB/Registry Application (in lieu of their state-specific forms) and/or the NCI Central IRB for review of minimal risk linkage studies (in lieu of their local/state/university IRB). Currently, 75% of respondents are able to use one of these options to simplify the application and review process. This will significantly reduce the time and resources that registries, IRBs, and researchers dedicate to completing and reviewing such requests. We aim to have the Phase II functionality completed by year’s end and then embark on the system testing.
As we prepare to launch the VPR-CLS in 2019, we thought it would be helpful to provide U.S. registries with a comprehensive VPR-CLS Fact Sheet. This fact sheet, which will be shared soon, provides information on the main features of the VPR-CLS, how it works, and the benefits of registry participation. To date, the level of support for, and participation in, the pilot testing has been incredible and we look forward to increased participation once the VPR-CLS goes live.

As always, I’m happy to hear from registries with any comments, questions, or concerns!

NAACCR INTRODUCES THE CARRI DATABASE

Fall 2018 NAACCR Narrative

NAACCR is proud to introduce you to CaRRI, the newest addition to our family! The Cancer Registry Researcher Information (CaRRI) database is designed to collect pertinent information on registry and IRB processes and requirements for requesting, releasing, and using registry data. The CaRRI database captures up-to-date, detailed information on the following:

- Registry, IRB, and VPR contact information
- Data years available and registry participation in various types of studies
- IRB and registry application and review process (with URLs)
- Requirements for data destruction, publication review, DUA, and progress reports
- Requirements for physician and patient consent
- Summary of registry and IRB fees

The CaRRI database consolidates information previously collected within CDC’s IRB Assistance site and NAACCR’s Researcher Registry Information Database. When designing the new database, NAACCR worked closely with IMS, Inc. to develop a user-friendly system that eliminated redundancies between the two systems, minimized narrative text, provided standard drop-down responses, and incorporated other key data items of interest to researchers and the Virtual Pooled Registry (VPR).

All registries, including the Canadian Provinces, are asked to populate the CaRRI database as a part of the NAACCR Call for Data process. Data should be entered between December 1, 2018, and January 31, 2019, after data submissions are complete. However, registries may begin entering data as early as November 1,
2018, when the CaRRI database is made available alongside the NAACCR Call for Data Submission Site (see screenshot below). Active users with an assigned role of ‘Registry Administrator’ for the Call for Data Submission can access the CaRRI database using their MyNAACCR login credentials.

After registry responses have been reviewed, data will be made publicly available for query and report generation. The CaRRI database will benefit both researchers and registries alike. Not only will it eliminate the need for researchers to contact each individual registry, it will also allow the registry to maintain, and refer researchers to, a single location that summarizes requirements for data requests.

Questions about the CaRRI database can be addressed to Recinda Sherman (rsherman@naaccr.org).

STEERING COMMITTEE CORNER

Fall 2018 NAACCR Narrative

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.

PROFESSIONAL DEVELOPMENT STEERING COMMITTEE (PDSC)

Co-Chairs: Frances Ross and Mignon Dryden

Committee Highlights since last Narrative:

The Board of Directors have tasked the Professional Development Steering Committee with new charges. Recruitment for NAACCR members to join Task Forces or Work Groups has started for the projects listed below.

New Committee Charges:

1. Framework for Higher Education
2. Best Practices for Recruitment & Retention
3. Best Practices for Telecommuting
5. CDC Cooperative Agreement
6. Work with RDU on education in LMS for NDI linkage and Match*Pro
7. Get continuous use items in LMS – work with other committees

If you are interested in working with Professional Development on these important projects or would like more information, please contact Frances Ross far@kcr.ukv.edu; or Mignon Dryden mdryden@crcc-cancer.org.
RESEARCH AND DATA USE STEERING COMMITTEE (RDUSC)
Co-Chairs: Hannah Weir and Susan Gershman

Training/Education:

- Next Webinar Producing Cancer Statistics at the Census Tract Level: A Louisiana Story scheduled for November 14, 2018, 2:00pm – 3:30pm ET.
- SEER Tools webinar to be scheduled.

Committee Highlights since last Narrative:

- Advocacy Cancer Fact Sheets: NAACCR will distribute ACS CAN state specific and summary fact sheets when reports become available early next year.
- Virtual Pooled Registry Update: Childhood cancer survivors study cohort is ready for linkage with volunteer registries. This will help test overall system, Match*Pro software, and manual review component.
- If you have a suggestion for a journal club or surveillance webinar topics, please contact Hannah Weir (hweir@cdc.gov) or Susan Gershman (gershman@state.ma.us).

STANDORIZATION & REGISTRY DEVELOPMENT (S&RD)
Co-Chairs: Winny Roshala and Lori Koch

Committee Highlights since last Narrative:

- The 2018 Implementation Guidelines and Recommendations are posted to the NAACCR website: https://www.naaccr.org/implementation-guidelines/

Note: In Appendix B, 2018 Source References, the TNM 8th Edition Staging Library hyperlink will be added when available.

- New and Emerging Data Sources Task Force – Inventory central registries to identify new data sources to categorize and assess their value to the central registry and/or cancer surveillance. Determine how to evaluate the value of the new reporting source.
- Interstate Data Exchange Task Force – Review and update the NAACCR Interstate Data Exchange Guidelines document.
- Timeliness Task Force – Assess specific issues identified by the original ACCR-TRS task force. Design a survey for central registries to understand the following:
  - Identify customers of surveillance data
  - Identify requestors of timely data and their intended use of it
  - Identify any legislative issues
- Determine if the ACCR TRS TF data set is sufficient to define as the minimal data set for incidence data.
- Characterize cases not submitted in a timely manner by type of reporting source including the reason behind the non-timely reports. Some cases that are considered not timely are by design e.g., path-only cases are not added to the registry until the end.
- Recommend an optimal time frame for a timeliness standard.

Individuals interested in participating in these new task forces are encouraged to contact Lori Havener for more information at: lhavener@naaccr.org.

Susan T. Gershman
Massachusetts Cancer Registry
Greetings to All NAACCR Members! In this whirlwind time of change and advancement in the cancer surveillance community, strong and diverse leadership are more essential than ever. The NAACCR Board has served that role for more than 30 years, but we can’t do it without the help of dedicated volunteers like you! The NAACCR Nominating Committee is seeking nominees to run for election in four key leadership roles in 2019: Treasurer and three (3) openings for Representative-At-Large. NAACCR has been a unique and innovative partner in the cancer registry world for over three decades, and volunteers have been the cornerstone of our organization’s success. Serving as a member of the Board is a rare opportunity for members like you to help drive the decisions of this esteemed international association. Through guiding existing programs and identifying future opportunities, Board members play a pivotal role in governing NAACCR affairs and moving the organization forward. NAACCR recognizes that it is fortunate to have knowledgeable, dedicated, and progressive members who volunteer each year to serve on the Board. These members of the NAACCR community generously contribute their time and expertise, allowing NAACCR to make significant, valuable contributions to cancer surveillance. Please consider recommending a qualified colleague for one of the four 2019 vacancies. Or, nominate yourself! For additional information on duties and eligibility and to nominate someone, please click here. The deadline for receipt of nomination forms is 5:00 PM, Friday, December 7, 2018.

Nominating Committee Members:

Jetty Alverson, Chair  
Michigan Cancer Surveillance Program  
alversong@michigan.gov

April Austin  
New York State Cancer Registry  
april.austin@health.ny.gov

Stephanie Hill  
New Jersey State Cancer Registry  
stephanie.hill@doh.nj.gov

Sarah Nash  
Alaska Native Tumor Registry  
shnash@anthc.org

Kyle Ziegler  
Cancer Registry of Greater California  
kziegler@crgc-cancer.org
WHAT'S HAPPENING IN OUR REGISTRY?

Fall 2018 NAACCR Narrative

MidMichigan Health-Tumor Registry Oncology Services
Submitted by: Sara Morel, CTR
Edited: by Ginger Greenwood, CTR

From left to right: Michelle Keyes, RHIT, CTR; Tara Talaski, CTR; Sara Morel, CTR-Lead Registrar; Ginger Greenwood, RHIT, CTR; Maggie Nelson, CTR; Wendy Johnson, RHIT, CTR-Lead Coordinator; Joan Herbert, Pharm.D.-Director, Oncology Service Line

The best is yet to come:

As we prepare for the finalization of the many changes for 2018, our registry has been taking it day by day, coming together to bring our very best work to meet the challenges. Even though the changes seem quite impossible at times, we all know that in the end, once everything is settled, future cancer patients will benefit from better data collection. We’ve all experienced cancer up close and personal with our loved ones, and the work we do every day is in their honor and memory. When you are on the other side of cancer, it’s a life changing experience and for me, I have dedicated my life to the cancer registry now since the passing of my father to cancer six years ago at the age of 48. Everyone has a purpose, and I feel so very fortunate to have been given this opportunity to become a CTR. Even through the changes, we all remain positive and focused on the greatness that will come with the new guidelines and rules. We just have to take a step forward and hope for the future that we can stop cancer! What we’ve learned in all this is that change is good even when it’s hard. I am so impressed by how many CTRs have come together over the last year and as we unite, we know anything is possible. We will never back down from a challenge in the battle against cancer. We got this, we are CTRs!!

What’s happening in our registry?

Here are some tips and tricks we are doing in our registry to help with the changes.

Cancer Conference Agendas: We have blank templates for each specialty cancer conference in a Word document that allows us to easily add a case. We also copy and paste and send this to staff to fill out and send back. These templated forms allow for physicians to add additional information when presenting a case and also to meet the requirements for the Commission on Cancer standards. Each specialty group wants to look at certain site-specific information on each case, so having a fluent template really helps. We can update or revise the template at any time, based on provider feedback and changes in requirements. We are also sending cancer conference agendas in EPIC now and our physicians like how each cancer conference agenda is right at their fingertips. This also saves time since we do less e-mailing and faxing.

Abstracting: We have begun abstracting 2018 cases making sure to fill in each text field with all elements so that when we go back we can abstract right from the notepad. We have created an abstracting guide that breaks down each required item by site and how to code and text it. Staff can review this abstracting guide for any clarification for every required item. We give every case two hours to be completed with the new changes and this will ensure quality. We have worked very hard for one year now, and we are abstracting concurrently for every cancer site for our five facilities. We started with our top five sites and each month we
added all from that site and just kept plugging away. This was no easy task but it’s great now that we are current so we can run current data in our reports for administration. I am very proud of our team for working so hard and realizing the benefit of concurrent abstracting for all cancer sites.

Case-finding: We have EPIC and have had a wonderful EPIC team that has built many case-finding reports for the cancer registry including the following: EPIC staging logs, head and brain imaging, distress screening scores, completed survivorship care plans, MDI, infusion center/chemotherapy patients with a new treatment plan, all cancer patients by stage and site. We also created a shared drive where we assign work on a monthly basis. There is a shared folder for each case-finding list and every month each CTR is responsible to get their assigned work done. This has helped tremendously with the new changes to keep everyone organized in one central shared location.

Cancer committee: We have many templated forms, one for each standard that help us track all Commission on Cancer required items. This templated system provides many benefits including consistent documentation for our cancer committee meetings, keeping meeting minutes that are organized and consistent, as well as consistent year-to-year reporting to ensure that we are meeting all standards.

Teamwork: We all couldn’t make it without our supportive leadership and our CTR team. This is our team at MidMichigan Health:

Michelle Keyes, RHT, CTR; Tara Talaski, CTR; Sara Morel, CTR-Lead Registrar; Ginger Greenwood, RHT, CTR; Maggie Nelson, CTR; Wendy Johnson, RHT, CTR-Lead Coordinator; Joan Herbert, Pharm.D.-Director, Oncology Service Line (photo at top of page).

NJSCR COMMEMORATES 40 YEARS OF CANCER SURVEILLANCE

Fall 2018 NAACCR Narrative

Submitted by: Antoinette (Nan) Stroup, PhD, Director, New Jersey State Cancer Registry
Contributing authors: Stephanie Hill, MPH, CTR, Program Manager, New Jersey State Cancer Registry and Betsy Kohler, Executive Director, NAACCR and former Director of the New Jersey State Cancer Registry.

Caption: New Jersey State Cancer Registry Staff, Trenton, NJ, September 2018

The New Jersey State Cancer Registry (NJSCR) is celebrating its 40th anniversary this October 2018. The launch of the New Jersey State Cancer Registry on October 1, 1978, was in response to the first national cancer mortality atlas published by the National Cancer Institute, which showed that New Jersey had one of
the highest cancer mortality rates in the country from 1950-1969. This was especially true for male bladder cancer, as 18 of New Jersey’s 21 counties had significantly higher bladder cancer mortality rates than the U.S. overall. As a result, New Jersey became known as “Cancer Alley” throughout the 70s and 80s.

There have been many milestones over the last four decades, but with advances in data collection, information systems, and a more coordinated surveillance system between central registries, hospitals, federal agencies, and, of course, NAACCR, New Jersey continues to meet the highest standards for complete, accurate, and timely data. Indeed, maintaining an up-to-date registry of all newly diagnosed cancers has fundamentally improved public health, providing essential data to guide prevention efforts and reduce mortality. In fact, today, New Jersey cancer mortality rates have improved to 13th lowest in the nation.

To commemorate 40 years of quality data and innovative research, we

- Celebrated alongside our hospital registrars at the Oncology Registrars Association of New Jersey (ORANJ) Annual Meeting in Atlantic City, NJ (October 4-5, 2018).
- Held a reception for current and former NJSCR staff on October 10.
- Took our message to the State Capitol, providing information about the Registry to legislators, staff, and visitors at the New Jersey State Capitol Annex the week of October 15-19, 2018.

Plan to raise awareness of the value of the registry among cancer researchers by displaying posters and providing information at the Rutgers Cancer Institute of New Jersey on Wednesday, October 24, 2018.

Caption (Left): NJSCR celebrating its 40th Anniversary with local hospital registrars at the ORANJ Annual Meeting, October 4, 2018, Atlantic City, NJ. “40 Years of Public Health Cancer Surveillance and Research and the Implications of Quality Data” presentation by Antoinette (Nan) Stroup, PhD, Director of NJSCR and Dr. Christina Tan, MD, MPH, Assistant Commissioner/State Epidemiologist, New Jersey Department of Health.

Caption (Right): NJSCR at the New Jersey State Capitol Annex, October 15, 2018, Trenton, NJ. (Left to Right) Stasia Burger, MS, CTR, Jessica Diamond, CTR, Antoinette (Nan) Stroup, PhD, Director, NJSCR, and Stephanie Hill, MPH, CTR, Program Manager, NJSCR.
IN MEMORIAM PAUL FEARNS

Fall 2018 NAACCR Narrative

It was with tremendous sadness that the Surveillance Research Program learned of the loss of our friend and colleague, Paul Fearn. Paul began his work at NIH in February 2015 as a consultant while still working as the Director of Biomedical Informatics at Fred Hutch Cancer Research Center. In August 2016, he became Chief of the newly formed Surveillance Informatics Branch in SRP. During his time at SRP, Paul facilitated collaboration across NCI and NIH and encouraged the advancement of informatics tools, approaches, and architectures for the SEER Program.

As technical lead of the NCI-Department of Energy (DOE) Pilot 3 collaboration, he spearheaded efforts to advance scalable clinical data processing for cancer registries using natural language processing and machine learning techniques, and he fostered collaborative relationships with computational experts at the DOE Labs. Especially because of his desire to create structure and foster transparency, Paul was instrumental in the development of the Data Acquisitions and Linkages Initiative by supporting the team in the thoughtful consideration of new data linkages and related topics such as data provenance, data integration, and data security. While a consultant for NIH, he led a comprehensive evaluation of the SEER Data Management System (SEER*DMS) with four other informatics experts. This work was pivotal in providing a roadmap to critical system enhancements. In the past two years Paul's vision, guidance, and steadfast support has seen the SEER*DMS community implement new mechanisms for collaborative work, redefining IT governance for a complex network of stakeholders, driving a comprehensive usability evaluation on SEER*DMS, and fostering new relationships to thoughtfully redefine the infrastructure of SEER*DMS.
Paul received his MBA at New York University and his PhD in Biomedical and Health Informatics at the University of Washington. Throughout his career, he worked to advance biomedical informatics at Baylor College of Medicine, Memorial Sloan-Kettering Cancer Center, and Fred Hutchinson Cancer Research Center. Paul focused on building teams and collaborations and creating thoughtful strategies, rather than solely providing short-term solutions. He was also deliberate in making time for trainees and fellows, continually focusing on training and building others to meet them where they were. His true talent was making every person feel valued.

Paul is remembered for his unparalleled ability to connect researchers across NIH and throughout the informatics community, his innovative approaches and openness to new ideas, his calm advice, and his genuine laugh. Creativity is intelligence having fun. There is not a person who exhibited this more than Paul. He will be sorely missed.

IN MEMORIAM DONALD AUSTIN

Fall 2018 NAACCR Narrative

It is with a heavy heart that we acknowledge the passing of Dr. Donald Austin (November 1, 1937, to October 21, 2018), due to ALS. Donald F. Austin, MD, MS (OHSU), MPH (UC Berkeley) was an Emeritus professor in the OHSU-PSU School of Public Health, in Portland, Oregon.

He spent three decades in state and federal health agencies conducting disease surveillance and analysis, disease investigations and research. He co-authored *Causal Inference in Epidemiology: A Practical Approach*, with John Stull, William Lambert and David Buckley. Epidemiologic research included the effect of industrial air pollution on lung cancer risk, the exposures responsible for an excess of malignant melanoma in a nuclear energy research facility, the effect of drinking and smoking on oral cancer and the characteristics of an epidemic of uterine cancer in postmenopausal women.

As adjunct faculty of the Epidemiology and Biostatistics program at Univ. of Calif. Berkeley, he helped design the first course on the use of epidemiology in the assessment of causation. In 1993, he helped design and teach the epidemiology curriculum for the Oregon MPH Program. He taught the epidemiology course on causation at both UCB and OHSU for over 20 years. In addition, Dr. Austin consulted and testified as an expert in many lawsuits on the issue of causation.

Much of his professional career was involved in the design, operation and use of central cancer registries. He designed and implemented the statewide cancer reporting system in California, advised on the Kentucky and Vermont registries, and was the “father” of OSCaR, the Oregon cancer registry. He was the founding President of NAACCR—back when it was only AACCR, and the Canadian registries were included in our organization in the 2nd year of his leadership. He also worked to draft the federal legislation establishing NPCR.

Don is remembered for making the work a better place as a public health “Rockstar,” professor. He was also a curious pioneer, dancer, songwriter, and poet. And for so many of us in the cancer surveillance community, he was a mentor and a friend.
For several months before Don’s death, he was able to celebrate his life with colleagues, friends and family. Donations to the ALS Association Oregon and SW Washington Chapter would be appreciated. Don will continue to teach having donated his body to the OHSU body donation program.

There will be a Celebration of Life for Don March 24, 2019.
Please sign the online guest book at www.oregonlive.com/obits