



2007 NAACCR Gold Certified Registries

For a complete list of Gold and Silver Certified Registries go to www.naaccr.org/registrycertification.



NAACCR
2007 Annual
Conference
 Photos and Stories Inside.



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Message from the President

Once again, we celebrate the completion of another successful conference! I extend my thanks to the Metropolitan Detroit Cancer Surveillance System for their hospitality. It doesn't seem possible that NAACCR has been around for twenty years, does it?

For those of you who were unable to attend, I'd like to share with you some of my thoughts from my President's Address.

In 1991, a year after becoming Director of the Massachusetts Cancer Registry (MCR), I attended my first NAACCR Conference in Bethesda, Maryland. It was at my own expense – luckily I could stay with my cousin, who lived outside of Bethesda. I did a presentation on *Case Ascertainment in Population-Based Cancer Registries*, using transparencies. During one of my practice sessions, my cousin's husband fell asleep. I like to think that things have changed since then!

As a new central cancer registry director, I knew I had a lot to learn – and NAACCR was there for me. One of NAACCR's greatest strengths is the willingness of its members to share what they have learned and help other members. It is through networking at NAACCR Annual Conferences that I have been able to greatly improve Massachusetts Cancer Registry operations. Some examples include:

- During the early 1990s, while attending a NAACCR Annual Conference, I arranged for a NAACCR quality control audit. This documented the MCR's underreporting, which led to additional completeness efforts.
- Dale Herman, former Director of the North Carolina Central Cancer Registry, sent me a ten-page letter on the death clearance process. The MCR followed his instructions and we were awarded our first gold certificate for diagnosis year 1997.
- Tom Tucker, Frances Ross, and Eric Durban of the Kentucky Cancer Registry gave MCR staff a two-day review of their operations. This led to improvements in our data management system.

By working together and helping each other, we have the opportunity to build a powerful cancer surveillance system that has the potential to play a major role in reducing the burden of cancer.



**Susan T. Gershman,
MS, MPH, PhD, CTR**

I look forward to the opportunity to lead NAACCR over the next two years. During my tenure as President of NAACCR, I plan to focus on four areas:

1. Electronic Transmission: Whether we like it or not, this is the wave of the future, so we need to be onboard. NAACCR has established the Interoperability Ad Hoc Committee, which will move the NAACCR standards to be consistent with national standards.
2. Data Use: We must promote the use of cancer incidence data in cancer control efforts for epidemiological research, biomedical research, and program evaluation.
3. Collaboration: We must collaborate with all our sponsoring organizations, as unity brings strength, efficiency, and effectiveness.
4. Globalization: We must reach beyond our borders, as cancer is not unique to North America.

I urge you to do your work with passion and compassion: *passion* to insure that cancer surveillance data are timely, complete, and high quality, and *compassion* to always remember that each case is a real person - a family member, a friend, or a colleague - who has been diagnosed with a serious disease.

I am honored to be starting my term as President, and I thank Betsy Kohler for her leadership during the past two years. I look forward to working with you all. Here is to the next twenty years of NAACCR!

- *Susan T. Gershman, MS, MPH, PhD, CTR*
President

In the Lincoln-Douglas debates, Stephen A. Douglas accused Abraham Lincoln of being two-faced.

"I leave it you, my friends," Lincoln retorted, turning toward his audience. "If I had two faces, would I be wearing this one?"

- from *The Wit & Wisdom of Abraham Lincoln—A Treasury of Quotations, Anecdotes, and Observations*

Message from the Executive Director

Great Circle Distance (GCD) is Meaningless – NOT!

The Great Circle Distance (GCD) is an algorithm to compute the distance between two points. The distance is a straight line indicator that takes into consideration the curvature of the earth in the calculation. Last year, we asked NAACCR members to submit the GCD for the distance between a patient residence at the time of diagnosis and up to five facilities from where cancer data were submitted, presumably with some association to cancer care. Only four states submitted GCD data. Many thought that the sole purpose of the GCD algorithm was to compute distance to treatment. We have learned that our facility definitions are not well standardized, consolidation of data is not consistent across registries, and without such standard definitions, these computations will have varying meaning across registries and depending on local registry operations and system software, may not be meaningful at all. This is a problem we would like to understand better. If access to care and quality cancer care are priority questions of the day, and they are, we would like to use cancer registry data and population-based data sets to help advance our understanding of these issues. To have registry data be more helpful to health services research, we may want to consider developing better standards and definitions for our facility variables.

Further, the algorithm works on calculating distance between any two points of interest. The patient address file is only one of the points. Imagine, as many of your colleagues have already done, interest in the distance of cancer patients to an environmental point source of exposure, like smoke stack emissions, nuclear reactor accidents, or poorly contained superfund waste sites, landfills or other potential sources of exposure that concern the public and our policymakers. When I started in this field, we used protractors to draw concentric circles around a point source of concern and captured all the cases within rings of various distances. Clearly, a GCD indicator

improves this early technique, especially when multiple-variable analyses can also take into consideration wind direction, surface water run-offs, or other important variables that improve the precision of exposure.



Holly L. Howe, PhD

Two presentations at the NAACCR Annual Conference demonstrated how important a distance measure can be in epidemiologic research. First, Myles Cockburn of USC included a distance measure in his study of prostate cancer risk related to ambient exposures to pesticide applications. This type of study was not possible when I began my career. With GIS applications and tools, and measures of actual distance, wind dispersion patterns, and other effect modifiers, Myles demonstrated how they were able to more precisely measure exposure and as a result, observed stronger risk estimates for prostate cancer.

Scarlett Gomez of the Greater Bay Cancer Registry described a study of physical activity and breast cancer risk. In her study, an effect modifier was the “walkability” of the neighborhood, or proximity to a high crime area, as well as distance to neighborhood services, both desirable and undesirable (e.g., supermarkets and fast food establishments).

For the 2008 Call for Data, please take a few moments to run the GCD SAS program. It is a tool we want to evaluate and it will also help in the NAACCR project funded by the Komen for the Cure grant to develop a road network distance calculation tool.

*- Holly L. Howe, PhD
Executive Director*

A ranking official of the Post Office died and the next day a job applicant waylaid President Lincoln in the White House.

“Mr. President, did you know that the Chief Postal Inspector just died. Can I take his place?”
“Well,” drawled Lincoln, “it’s all right with me if it’s all right with the undertaker.”

- from The Wit & Wisdom of Abraham Lincoln—A Treasury of Quotations, Anecdotes, and Observations

Surveillance & Research Uses of NAACCR Submissions

CINA Monograph

This year marks the 17th release of the annual publication of *Cancer in North America (CINA)*. The 2007 monograph includes data from 65 central population-based registries: 52 from the United States (92% population coverage) and 13 from Canada (100% population coverage). Combined statistics are created from registries with high quality incidence data for all years, 2000-2004 and more than 61% of the Canadian population and 82% of the U.S. population are covered in the combined statistics.

The *CINA* monograph is comprised of four volumes:

- Volume One presents cancer incidence data for NAACCR-member, population-based central cancer registries in Canada and the United States who have agreed to participate in the *CINA* monograph.
- Volume Two presents cancer mortality data for states and provinces and for Canada and the United States as a whole.
- Volume Three presents cancer incidence data that have been combined from registries that meet at least the NAACCR silver standard for high quality incidence data at the time of data submission.
- Volume Four presents registry specific cancer incidence data for the Hispanic/Latino populations. Inclusion criteria for Volume Four are the same as for comparable tables included in both Volumes One and Three.

CINA in SAS

All the data published in the *CINA* Monograph are available in a SAS dataset, which can be downloaded from the NAACCR website.

New NPCR Staff

Dr. Christie Ehemann has accepted the position of Acting Chief, CSB and Karen Ledford, RHIA, CTR has accepted the position of Team Leader for the Operations Research and Technical Assistance Team, CSB.

Dr. Ehemann received her B.S. in applied biology from the Georgia Institute of Technology; as well as a masters degree in health physics from the same institution. She subsequently received a Ph.D. in epidemiology from Emory University. Christie has held a number of positions as health physicist, or epidemiologist, at the CDC, and she has been Team Leader, Epidemiology Section, in DCPC's Epidemiology and Applied Research Branch since 2002. She has published extensively on disease-related findings, as well as the development of new statistical methods and strategies.

CINA+ Online

CINA+ Online is an online, public, interactive, query system available on the NAACCR website that can be used to obtain cancer statistics from the NAACCR data submissions. Tables, maps, and graphs are generated from the data. The available queries are limited, but provide basic cancer incidence counts and rates for national and state or province geographies by age, sex, year, race, and ethnicity. Small numbers are suppressed when necessary to preserve confidentiality.

CINA Plus in SEER*Stat

This data analysis tool includes all the data from *CINA+* Online, except that the data are available in SEER*Stat software to enable more flexible queries that can include statistical testing. Access to this data set is discretionary and only requests from NAACCR members will be considered. An application form to access the file must be submitted.

CINA Deluxe

A multi-registry aggregated database is compiled from all NAACCR member registries that meet the inclusion criteria of data quality. This data file is released under controlled conditions to NAACCR member researchers who are interested in using the data for cancer surveillance research. All investigators must submit a proposal, obtain approval from the Research Proposal Review Subcommittee and the NAACCR IRB, and sign confidentiality agreements.

- Holly L. Howe, PhD
Executive Director

Ms. Ledford is a Certified Tumor Registrar and has been a program consultant for the National Program of Cancer Registries for the past four years. Ms. Ledford has a B.S. in Health Information Management and 10 years of experience in hospital health information management. Before joining CDC, she spent 11 years working for the Atlanta Metropolitan SEER Registry and the Georgia Comprehensive Cancer Registry. Ms. Ledford has extensive experience in cancer data collection, quality assurance, training, and registry operations management. She is an active member of the National Cancer Registrars Association and the American Health Information Management Association.

- LaDora Woods
NPCR

Education and Training Calendar 2007

AUGUST

GIS Applications

August 16, 2007; Central Registry Webinar

CTR Exam Readiness Webinar Series

August 1, 2007: Session 2

August 7, 2007: Session 3

August 8, 2007: Session 3

August 14, 2007: Session 4

August 15, 2007: Session 4

August 21, 2007: Session 5

August 22, 2007: Session 5

August 28, 2007: Session 6

August 29, 2007: Session 6

SEPTEMBER

CTR Exam Readiness Webinar Series

September 4, 2007: Session 7

September 5, 2007: Session 7

September 11, 2007: Session 8

September 12, 2007: Session 8

Abstracting Breast Cancer Incidence and Treatment Data

September 13, 2007; Hospital Tumor Reporting Webinar

Statistical Techniques Used to Analyze Surveillance Data:

Trend Analysis

September 20, 2007; Central Registry Webinar

NAACCR 2007 Toolkit Workshop

September 10-12, 2007; Charleston, SC

OCTOBER

Abstracting Melanoma Cancer Incidence and Treatment Data

October 11, 2007; Hospital Registry Webinar

Coding Pitfalls: Collaborative Staging; Multiple Primary/Histology

October 25, 2007; Central Registry Webinar

NOVEMBER

Abstracting Gynecologic Cancer Incidence and Treatment Data

November 8, 2007; Hospital Registry Webinar

Colon/Rectum Cancer Surveillance Data Collection

November 15, 2007; Central Registry Webinar

DECEMBER

Hospital Cancer Registry Operations

December 6, 2007; Hospital Registry Webinar

Cancer Surveillance Data Use and Release

December 13, 2007; Central Registry Webinar

Registration forms and course descriptions are available on the NAACCR website, www.naaccr.org/training. Contact the Program Manager of Education and Training, Shannon Vann, svann@naaccr.org or (315) 682-6543, for further information about NAACCR training programs.

Join the NAACCR Walkers!

Ramp up your summer exercise program and help raise money for cancer research! On September 16th, a group of NAACCR members will be walking the Boston Marathon route to benefit the Dana-Farber Cancer Institute. All NAACCR members, friends, and family are welcome to join the NAACCR team. Our group plans to do the 13 mile half-marathon. Please join us if you can!

If you can not join the team, please consider sponsoring one or more of our members on the walk. We are trying to have as many walkers as possible reach the *Pacesetter* level, so we encourage you to make your donation to the walker who is closest to reaching the

\$1,000 level rather than using the category for a general team donation. Because many NAACCR colleagues know several of the team members, a donation to any of us will be considered a donation to us all.

Please visit our webpage at <http://www.jimmyfundwalk.org/naaccr> to join our team or sponsor a walker. Any questions can be sent to team captain Jane Braun at jane.braun@health.state.mn.us.

Thanks for your support!

- Jane Braun

Percy Award for Distinguished Service to Ken Gerlach

Ken has provided excellent leadership and vision to NAACCR and the committees that he chairs. He has been active in many aspects of NAACCR including Uniform Data Standards, Information Technology and our new Ad Hoc Interoperability Committee. He was instrumental in the expanding and clarifying NAACCR's adoption of HL7 for pathology and laboratory reporting. Having accomplished that goal, he has taken on the formidable task of mapping the NAACCR full case abstract for transmission in HL7. Moving to an HL7 format while retaining NAACCR data items requires vast technical and clinical knowledge. Fortunately for all of us in the NAACCR community, Ken understands the need for us to get in step with the broader health information technology world and his actions and dedication to the greater good underscore his commitment to cancer surveillance.

Ken is a hardworking visionary who wears these many hats well.

- *Betsy A. Kohler, MPH, CTR*
Past President



Calum S. Muir Memorial Award to Lilia O'Connor

Lilia O'Connor has served the cancer surveillance community for over thirty years. Her experience includes many years as a director of registry operations and a subject matter expert on many aspects of cancer registry operations. She has managed the data collection for several quality of care studies and has led a section for developing the protocol for data collection for a CDC-funded study in collaboration with European colleagues in EUROCARE.

Lilia has served on numerous NAACCR committees such as Registry Operations, Education, and the Program Committee. Recently she was a member of the workgroup that revised *Volume III: Standards for Completeness, Quality, Analysis, and Management of Data*. She has served as faculty for the NAACCR short course at the Annual Conference, Program Chair of the 1995 NAACCR Annual Conference in California, and treasurer of NAACCR for the past four years. Lilia's expertise in business and accounting has been invaluable to the NAACCR Board of Directors. Over the years she has been a mentor to many NAACCR members in all aspects of cancer registry operations. Her expertise in management has constantly brought new ideas and solutions to the NAACCR community. Her dedication, commitment and superb management and educational skills have been a true asset to the cancer surveillance community.

This is the woman who raised a son who climbed Mount Everest. The apple does not fall far from the tree.

- *Betsy A. Kohler, MPH, CTR*
Past President



NAACCR Education & Training Program Update

As I reflect on the 20th anniversary of NAACCR, I realize that including the 2007 conference I have attended 12 of the 20 NAACCR Annual Conferences, the last three as a member of the NAACCR staff. When I worked at state cancer registries, I looked forward to the opportunity to attend sessions that gave me useful processes, procedures, and ideas to use in the registry where I worked as well as an opportunity to network with people who became my friends. As a member of the NAACCR staff and the program committee, I have been impressed by the massive contributions of members to ensure that the annual conference is a first-rate educational conference. Now besides learning and networking, I am able to identify educational needs NAACCR members want the organization to address.

I encourage all of you to volunteer for NAACCR committees. My NAACCR staff activities include participating in the education, registry operations, and program committees. At this year's conference at the NAACCR 101 concurrent session, I encouraged participants to volunteer in their area of interest. Don't think you need to have been around forever, or don't think it's too late to get involved. The organization is looking for input and ideas from everyone!

As Program Manager of Education and Training, I coordinate the annual conference pre- and post-workshops. In 2007 we had pre- and post-workshops that were positively evaluated. It has been suggested that we include more workshops on data analysis in the future. We are planning a conference workshop on survival analysis in 2008.

The 2007 Toolkit Workshop will focus on data analysis. Topics addressed include the NAACCR Call for Data, the NAACCR Asian/Pacific Islander Identification Algorithm (NAPIIA), great circle distance calculation, using SAS for analysis of cancer surveillance data, and multi-level modeling. The workshop will be held September 10-12, 2007 in Charleston, South Carolina. Registration information is on the education page of the NAACCR website: <http://www.naacccr.org/educationandtraining>

- *Shannon Vann, CTR*
Program Manager, Education and Training

Sisters Sought for Research Tracking Breast Cancer

Reproduced from KETV.com

Letters have gone out to over 3,500 women in Nebraska who have been diagnosed with breast cancer, asking them to ask their sisters to participate in a national study. The study will try to discover how environment and genes affect the chances of getting breast cancer.

The Sister Study is a research effort sponsored by the National Institute for Environmental Health of the U.S. Department of Health and Human Services. The study will involve sisters of women who have had breast cancer, but who do not have it themselves.

"Breast cancer is the second leading cause of death of women in Nebraska and the cause of significant fear and concern. As a woman, and as a physician, I know the importance of research about the disease," said Dr. Joann Schaefer, the state's chief medical officer, in a news release. "The study results will be used to help prevent breast cancer and promote good health for women."

The national study team has asked the Nebraska Health and Human Services System to help locate women in Nebraska who have had breast cancer, who could then locate sisters who may volunteer. The sisters are not required to be Nebraska residents. Assistance with the study is voluntary.

This mailing is being sent to women whose names are currently on the Nebraska Cancer Registry. The Health and Human Services System manages the Nebraska Cancer Registry, which is recognized nationally for the quality of its data. Physicians and individuals report information to the registry. Nebraska law protects individual privacy, and the System will not release names, or personal or medical information to the study.

For more information about the study, contact the national Sister Study, toll free, at 877-474-7837 or go to SisterStudy.org.

NAACCR Webinar Series

In 2006-2007 the North American Association of Central Cancer Registries (NAACCR) presented its first webinar series. Through this series, NAACCR has filled a need for good educational programs at a reasonable cost that is easily accessible to staff and data submitters. We are now accepting subscriptions for both the 2008 Central Registry and 2008 Hospital Registry Webinar Series. Subscribers can view each four-hour presentation, participate in quizzes and exercises, ask questions, and get answers in real time from the comfort of their own work space! The cost, time, and stress of travel is not necessary for most people to attend! The 2008 series will begin October 2007. The feedback from the first series has been extremely positive, as you can deduce from the selected comments below.

"The lymphoma webinar was one of the best in-services I have ever attended - thank you. I wish I could have had the advantage of all of these webinars when I first started abstracting."

"We are so glad that we subscribed and participated with the Webinar series this past year. Our staff members have found them to be very informative, useful and very well presented. Thanks for doing such a great job! We on the front lines of registry data management really appreciate the opportunity to participate in such a quality educational program in a convenient, cost effective manner. Kudos to all!!"

"As you know, I sponsored (paid) for this year's sessions. Then asked all the TR's [tumor registrars] in the state to please join me, free. No charge plus the drug reps have sponsored our lunches for free,

and my hospital has given them free valet parking, not something hospital employees get every day. I asked the State Association if they would pay for the next year of sessions at the Spring meeting. Before we could complete the discussion, the Manager of the State Central Registry offered to pay for the entire 8 sessions. I will continue to get the drug reps to provide lunch and my hospital will again provide valet parking and the facility. All free to any registrar that wishes to attend. I am so excited that the sessions are so informative and well received by the people who attend. I usually have about 20 people sign up for each session. One registrar drives over 3 hours through mountain passes to attend even in the worst winter weather. Thanks so much for this opportunity. I know how much effort you put into each session and I know we all learn from them."

"I have attended your webinars locally, and they are great! Keep up the good work!"

Session descriptions, schedule, and a registration form can be found on the NAACCR website, <http://www.naaccr.org/educationandtraining>. Please forward information about this training opportunity to your data submitters.

If you have questions, please contact us.

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Shown here are attendees at the NAACCR Cancer Registry Data Collection and Management Institute hosted by the Massachusetts Cancer Registry at the John Hancock Conference Center in Boston, MA on May 22-23, 2007.

MP/H Coding Rules Implementation: An Overview

There are three distinct phases of support that must be in place to ensure successful implementation of a new coding system: Phase I: Initial training; Phase II: Ongoing support while using the rules; and Phase III: Re-evaluation of documentation and evaluation-based revisions.

Phase I: Initial Training

Initial training on the 2007 multiple primary and histology coding rules took place before the rules went into effect. The initial training goal was to provide training to the majority of users on all of the rule sets and the new data items. To accomplish this goal, the Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute (NCI) and the National Program of Cancer Registries (NPCR), Centers for Disease Control (CDC) identified a group of individuals who participated in two Train-the-Trainers (TTT) sessions held in 2005 and 2006. The 99 individuals who completed the TTT sessions had access to a training portal website from which they could download Power Point presentations, speaker's notes, practicums with real de-identified cases, and additional teaching aides. By the end of June 2007, these trainers reported conducting a total of 188 trainings with greater than 7,300 participants. The trainings have taken place in 49 states, and have included Veterans Administration (VA) and Department of Defense (DoD) registrars. Internationally, trainings have been held in 10 Canadian provinces, Guam, Palau, Puerto Rico, South Korea, and Taiwan.

Both SEER and the North American Association of Central Cancer Registries (NAACCR) developed and conducted on-line training sessions that included instructions on the site-specific Multiple Primary and Histology (MP/H) coding rules and the new data items. It is not possible to calculate the number of people trained by these on-line sessions.

A list of trainers and an MP/H training calendar are available on the SEER website (www.seer.cancer.gov). Meeting planners can use the list to identify and contact speakers for future educational meetings. The MP/H training calendar allows registrars to view scheduled trainings throughout the United States and Canada. The meeting facilitator's contact information is given so the registrar may request additional information or register for the meeting.

Phase II: Continued Support

Ongoing, real-time support is needed when the rules are actually being used in the registry. Not only do

the questions differ from those in Phase I but help is also needed with difficult cases.

The on-line web-based trainings developed by NCI-SEER were recorded for use in both Phase I and Phase II. The lectures, practicums, transcripts and certificates for continuing educational credits are available on the SEER website (www.seer.cancer.gov). The registrar is able to use these sessions when they want a refresher course before starting to use the rules. Registrars may also use these recorded sessions for clarification on the rules for a certain site or while working on a difficult case. The recorded sessions have been accessed 12,268 times between the months of January and June 2007.

A new series of lectures and practicums called "Beyond the Basics," has been added to the SEER web site. This advanced series answers questions raised by registrars who have started to use the rules. Advanced educational modules added in July 2007 include presentations on general or overall rules and lung, colon, and urinary sites. Practice cases and rationale are available for all site-specific presentations. Continuing education credits are available for completing the recorded educational modules and for working the cases.

An introduction to the MP/H Rules has been added to the SEER web-based training website (<http://training.seer.cancer.gov>). Continuing education credit is available from NCRA after completion of this module.

The frequently asked questions regarding the MP/H rules have been added to the SEER Inquiry System (SINQ). SINQ can be accessed from the SEER website (seer.cancer.gov) and is available to all registrars. The Commission on Cancer's Inquiry and Response (I&R) system is another source available for MP/H questions and answers (www.facs.org/cancer).

Phase III: Re-evaluation of Documentation followed by Evaluation-Based Revisions

The reliability study mechanism, used extensively during the development and final revision of the rules, is designed to identify documentation that needs improvement and to target educational needs. Prior to implementation of the MP/H rules, reliability study participants had no training or experience using the rules, which resulted in the most stringent testing of the rules prior to their implementation. The testing phases were followed by an evaluation-based revision to the coding rules.

(Continued on page 10)

MP/H Coding Rules Implementation: An Overview

(Continued from page 9)

In 2008, NCI-SEER will conduct another web-based reliability study. By the time of the study, participants will have not only had training, but also experience, using the rules. This reliability study involving trained and experienced participants will provide new and deeper insight into the usability of the rules and the clarity of the instructions. As before, the study will be followed by an evaluation-based revision to the coding rules. The study will be used to help target educational needs. MP/H educational efforts thus far have been geared toward broad coverage of all of the rules. Future educational sessions will be specific to the needs of registrars using the 2007 MP/H rules. The results of this reliability study will also reveal where clarification is needed in the MP/H instructions and documentation. Revisions to these

materials based on the outcome of the study will improve the ability of registrars to apply the rules in a consistent manner.

Conclusion

The 2007 MP/H rules are an important new initiative in the cancer registry arena. A three-phase approach to support of this initiative is essential to ensure successful implementation.

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NAACCR 2007 Photo Album—Detroit, MI



Twenty Years of NAACCR 1987-2007

Twenty Years of NAACCR, 1987-2007	
1987	First discussion with representatives from NCI, ACoS, AACI, and ACS to maximize data utility among all U.S. central cancer registries
Mar-88	First organizational meeting
Apr-89	Adopted Bylaws and Standing Rules
1991	CDC provided funds to the California Public Health Foundation to explore quality and use of registry data for cancer control
1992	Incorporated the American Association of Central Cancer Registries in California First released statistical monograph, Cancer Incidence in the U.S.A, 1988
1994	Changed name to the North American Association of Central Cancer Registries, Inc. Released the first volumes of Standards for Central Cancer Registries that included Data Exchange layout (Vol. I); Data Standards and Data Dictionary (Vol. II); and Completeness, Quality, Analysis, and Management . Expanded the statistical monograph to include Canadian data, Cancer in North America, 1988-1990
1995	National Coordinating Council for Cancer Surveillance established and NAACCR joins this consortium Under leadership of President Dee West, NAACCR initiated a management-by-objectives approach to direct the focus and organization of activities
1996	Released first Volume IV of the Standards for Central Cancer Registries, Data Edits
1997	Initiated the annual Registry Certification Program, the only accreditation program for Central Cancer Registries
1998	NAACCR, Inc. began to operate as its own fiscal agent with receipt of a Cooperative Agreement from CDC
1999	Hired first employee, the Executive Director, Holly L. Howe, PhD and opened an Executive Office in Springfield, Illinois
2000	Support for NAACCR continues to grow with a contract from NCI for Technical Support for Cancer Surveillance
2003	Released first annual bibliography of research publications using the NAACCR CINA Deluxe datasets.
2005	Board initiates an Annual Conference Scholarship Program with support by the ACoS, AJCC, and NAACCR contributions. Released first Volume V of the Standards for Central Cancer Registries, Pathology Lab Electronic Reporting
2006	Launched the NAACCR Training Program; fully supported by registrations and expansion in distance learning for both hospital and central registry staff using Webinars
2007	Celebrated NAACCR's 20 Year Anniversary at the Annual Conference in Detroit, Michigan

I am sure that many of you could contribute significant events to this timeline of Twenty Years of NAACCR. Please send any items to Holly L. Howe at hhowe@naaccr.org.

The highest compliment you can pay me during the brief half-hour as I conclude is by observing a strict silence; I'd rather be heard rather than be applauded.

- Abraham Lincoln

Gifts, Donations, and Bequest Program

If you attended the business meeting in June, you know that NAACCR has engaged a professional fundraising firm, Community Counseling Services (CCS), to conduct a feasibility study on NAACCR's ability to secure donations from corporations and foundations. This four-month study will be completed in July with a final report delivered to the Board in August 2007. Some of our members have been interviewed by representatives of CCS and we thank you for your time. The report will summarize the results of the pilot study and provide direction and some recommended next steps if NAACCR should decide to proceed with a major fundraising campaign to secure major gifts from corporations. More information on the status of the pilot study will be available in the Fall 2007 newsletter.

Separate from this large scale effort, NAACCR continues to look for and appreciates contributions by our membership. These do make a difference. If 50% of the NAACCR membership would give \$25, we would have

raise more than \$6,800. These monies could support critical committee projects, printing of a NAACCR publication or one scholarship to have a developing registry send a representative to the NAACCR Annual Conference. You could make a donation yourself or partner with a co-worker to make a donation. Please consider what a nominal contribution would do for the organization. You can now make a donation on-line at www.naacccr.org, by accessing a secure transaction mechanism from the donation box on our home page.

More specific information is available about Gifts, Donations, and Bequest Program at <http://www.naacccr.org/donations>. I hope that you will consider donating. Please contact Charlie Blackburn, at 217-698-0800 Ext. 4 for more information.

- *Charlie Blackburn*
Director of Administration

Communications Corner

The Communications Committee, working with Josh Whitley of the NAACCR staff, developed procedures and a web page last year to feature NAACCR press releases. Our objective is to highlight NAACCR's accomplishments and work products for our colleagues in the medical field and also the general public. We hope this will be an educational effort to explain what we do, who we are, and hopefully, foster lead to greater recognition and support of cancer registries and cancer surveillance. A press release may end up published *verbatim* in a newsletter, traditional print media, or web news service, or it may spur interest by a medical writer to develop an article.

As part of our regular activities the Communications Committee will actively develop press release topics. We also welcome press release ideas and content from our members and committees. We ask that all committee

members read the Press Release Tips document linked on our committee page, www.naacccr.org/committees/communications and consider publicizing your work through a press release.

Press releases are posted on the NAACCR media page, www.naacccr.org/media. Future plans may include developing an RSS (newsreader) feed for the media page, and budget permitting, a subscription to a newswire service. We will work this year to develop working relationships with medical writers and columnists. Who knows, you might see NAACCR featured on a television news story one day! Paging Dr. Gupta?

- *Dan Curran*
Chair, Communications Committee

Decline in Breast Cancer

A [Morbidity and Mortality Weekly Report \(MMWR\)](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5622a1.htm) article published June 8, 2007 on the decline in breast cancer incidence by Sherri Stewart, Sue Sabatino, Stephanie Foster, and Lisa Richardson is receiving wide media coverage. The article is based on 1999-2003 NPCR and SEER data covering 86% of the U.S. population. This article can be found at: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5622a1.htm>.

- *LaDora Woods*
NPCR

Registry Spotlight: New Jersey Knits & Walks for Cancer

We would like to launch a new series for our newsletter that gives our members the opportunity to share with all NAACCR colleagues the non-surveillance volunteer activities that are conducted by the registry staff to help cancer patients and cancer survivors. The first is submitted from the New Jersey State Cancer Registry.

The New Jersey State Cancer Registry (NJSCR) is helping cancer patients around the state by doing more than just tracking cancer incidence. Once a week some of the staff meet in a conference room at lunch time, and pull out their knitting. The NJSCR has been knitting “chemo caps” for local hospitals for about six months now. The staff make all sizes and colors, for men, women and children. Linda Johnson, CTR, doesn’t knit, but specializes in making flowers and other decorations that can be stitched on once the hats are completed.

When the large plastic bin is full, Susan Van Loon, RN, CTR, Program Manager, loads them into her van and takes them to a hospital in inner-city Trenton. “We looked for several places that would be willing to take donations,” Susan said. “We spoke to the staff at Mercer Medical Center about what the patients would like the best, and how many we could donate. We had special requests for very soft, light weight hats so that they are comfortable and not too hot. The patients are thrilled with them and touched that someone they do not even know is thinking about them. It also gives our staff a feeling of being connected to cancer patients in a way beyond our every day work.”

The NJSCR staff also participate in a team effort every year for the Susan G. Komen Race for the Cure event in New Jersey. We have participated in every race held in New Jersey, over thirteen years. John Murphy, CTR, who lost his first wife to breast cancer when his daughter was a toddler, energizes the staff each year for the Race. “We all walk together during the Race. Some years it has been very hot, and other years we have had torrential rain and even snow. But we all come out to support the cause. Most of us wear the names of loved ones we have lost, or the names of friends, family and co-workers who are survivors pinned to our backs.”

Does the staff in your Registry go beyond the call of duty to support the cancer community in other ways besides doing their nine to five jobs? We would like to hear about it! Each newsletter this year will profile a registry that goes a step beyond, whether it’s for cancer or another worthy cause. If you would like to share a description of what staff from your registry volunteer to do for the faces behind our statistics, please submit it to Dan Curran, dcurran@ccr.ca.gov, to include in future issues of the *NAACCR Narrative*.

And, if you have unused yarn from unfinished projects, the NJSCR will take donations! Please contact Susan Van Loon at Susan.Vanloon@doh.state.nj.us.

- *Betsy Kohler*
Director, New Jersey State Cancer Registry



Left to right: Pei-Yi Chu, Vivien Chen, Jim Martin, and Ya-Fen Liang. Pei-Yi and Ya-Fen are a pathologist and CTR from Taiwan.

Standards Update

NAACCR Interoperability Activities

The Interoperability Ad Hoc Committee held its first meeting at the NAACCR Annual Conference in Detroit on June 4, 2007. There was discussion on the work plan, goals and objectives, the process of adding new data items and the relationship of the Interoperability Ad Hoc Committee to the Uniform Data Standards (UDS) Committee. The Interoperability Ad Hoc Committee will work closely with UDS to clarify the process for adding new data items and to develop a flow diagram and to clarify the relationship between the two committees. At our next meeting this group will be busy finalizing goals and objectives, developing a budget, updating the interoperability work plan, clarifying relationship with UDS, and developing a flow diagram for new data items.

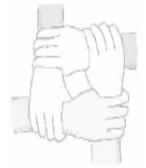
Standards for Cancer Registries, Volume V

Standards for Cancer Registries, Volume V, Pathology Laboratory Electronic Reporting, Version 2.0 documents the recommended message or format standards for electronic transmission of reports (pathology, cytology, and hematology) from pathology laboratories to central cancer registries. The Pathology Data Work Group is currently updating this document to Version 2.1 and plans to release an electronic copy by September 2007. The *Standards Volume V, Version 2.0* revisions include issues identified by implementers and the HL7 Messaging Workbench that have been resolved by the Pathology Data Work Group.

- *Lori A. Havener, CTR*
Program Manager of Standards



NAACCR Mentor Fellowship Program



Provide an opportunity for a one-on-one, in-depth, onsite and interactive learning experience in cancer registry operations.

Strengthen cancer registries and their staff throughout North America.

NAACCR Members Mentoring Each Other...

Fellowship Awards include, but are not limited to the following operations:

- Data Collection
- Data Processing
- Data Quality Evaluation
- Data Use

Closing Dates

March 31, June 30, September 30, December 31

*Go to www.naaccr.org for more information and application forms or
Contact: Shannon Vann - **Email:** svann@naaccr.org **Phone:** (315) 682-6543*

This project has been funded by the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Contract No. HHSN261200444001C and ADB No. N02-PC-44401 to NAACCR.

Trip Report to the NAACCR Annual Conference

Attendance at the NAACCR conference in Detroit, USA in June, 2007.

With the honor of receiving a NAACCR fellowship to attend this organization's annual conference held in Detroit on Jun 2-9, 2007, I started from Ho Chi Minh City, Vietnam on May 30, 2007. Leaving the warm sunny small land in the South East Asia on my own in a long trip, I was a little worried and I expected the weather to be colder in the US. Contrary to my thoughts, I indeed felt the warmth and the peacefulness due to the enthusiastic and hearty welcome of every NAACCR members.

Because the cancer registration in my city is at the early stage, we need the necessary knowledge to orient its development. As the supervisor of the cancer registry of Ho Chi Minh City, I consider it my duty to train myself and get more chances to follow the international requirements. Thanks to the generous help of NAACCR, I had an opportunity to get this knowledge on this trip. I registered to attend the pre-conference short course with the topic "Central Cancer Registries: Design, Management and Use," the main conference, as well as the post-conference course "Privacy, Confidentiality and the Protection of Health Data: A Statistical Prospective on Data Sharing."

In the pre-conference course, I learned about the design and management of a central registry step by step. Every aspect was raised and instructed in the course, from the type and characteristics of the central registry in order to build and to aim its operation, to its daily activities such as budgeting, staffing, collecting and ensuring the quality of the data and using the data for cancer research and control. Some special topics were also mentioned such as ethics and confidentiality; recruiting and training staff, which are very useful to a newly-established registry.

It was the first time I learned about NAACCR. And in this first time I knew about the strength and the growth of NAACCR when I was in the conference with hundreds of delegates representing many registries all over the US and Canada. During the conference, I learned about the development of NAACCR after 20 years of building and expanding. In many concurrent sessions that came afterwards, many activities of cancer registration were introduced. I followed the reports of population-based scientific research, screening, cancer control and interventions. With the presentations from many registries, I was able to draw some experiences in setting up these activities in my registry in the future.

I also had the chance to attend the post-conference course with the topic of data sharing and confidentiality. I realized that the condition in my country was not the same that of the US. Therefore, this problem was not seriously considered in my country. Anyway, we will take it into consideration in the data sharing process in the future.

I would like to thank NAACCR for a very nice and useful trip. I hope not only the registry in Ho Chi Minh City but also the cancer registration in Vietnam will benefit from the help of NAACCR in the future. I also hope that it is the first step in the collaboration and help from NAACCR to the newly-established cancer registry in Ho Chi Minh City. Once again, please send my special thanks to every NAACCR member for their warm hospitality and precious help.

- *Bui Duc Tung*
Ho Chi Minh City Cancer Registry, Vietnam

Members Receiving Honors

Cheryll Cardinez was awarded the Matthew Lee Girvin Award. The Matthew Lee Girvin Award is presented to a recent graduate of the Rollins School of Public Health who exemplifies Matthew's selfless dedication to the field of public health and who has made significant contributions toward improving the lives and health of others.

- *LaDora Woods*
NPCR

I cannot claim that I am free from error in all the opinions that I advance.

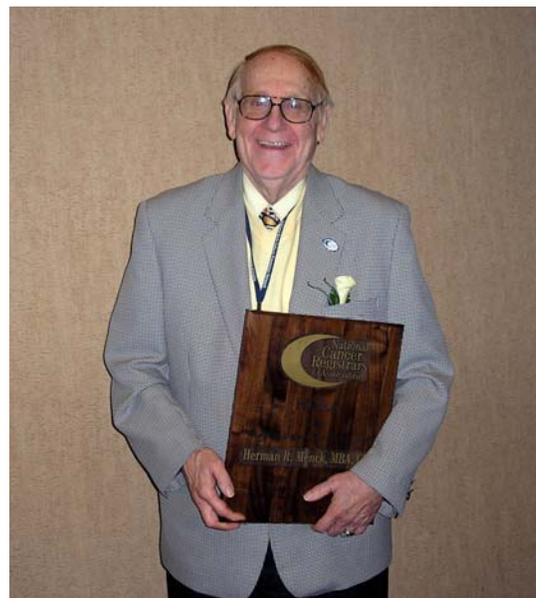
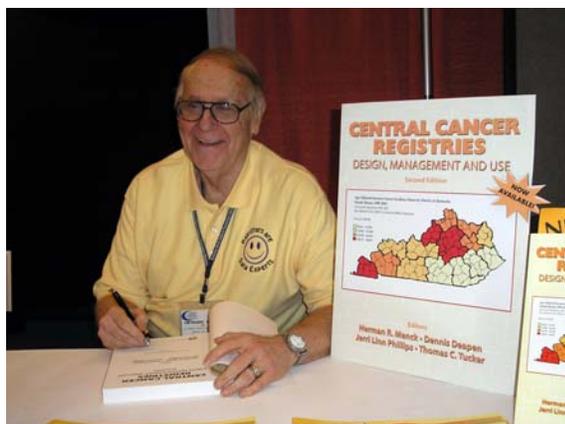
- Abraham Lincoln

NCRA Distinguished Member Award

Herman Menck received the NCRA Distinguished Member Award this year for his many accomplishments to the cancer registration field. Among them were noted:

- A founding member of NAACCR and Board of Directors member for three years.
- President of both the Southern California and the California Cancer Registrars Associations.
- An NCRA officer and board member for 3 years.
- The developer of a PC-based data base management system, for central registries in developing countries, which is in operation today.
- Workshop faculty member at NCRA's annual conference and has written more than 150 articles on cancer and cancer registries that have been published in such prestigious journals, as *Cancer* and *CA, a journal for clinicians*.
- Teacher of the short course on central cancer registry for more than 10 years, and is a co-author of the text *Central Cancer Registries, Design, Management, and Use*.
- Co-editor of NCRA'S textbook, the 2nd edition of *Cancer Registry Management Principles and Practices*.
- Developer and leader of the National Cancer Data Base for 10 years.
- JRM Editor for four years.
- Chair of NCRA's Work Load Management Task Force.
- A tireless worker to support and promote the field for 35 years.

- Amy Fremgen, PhD, CTR
Past NCRA President



Herman Menck, MBA, CPD, signs a copy of *Central Cancer Registries: Design, Management, and Use, Second Edition*, at the NCRA annual meeting. He is one of the editors that include Dennis Deapen, Jerri Linn Phillips, MA, CTR; Thomas C. Tucker PhD, MPH. A link to the publisher's web site can be found at <http://www.ncra-usa.org/store/index.htm>.

After a Cabinet officer complained to Lincoln of a political favor he had just given to a Democrat, a visitor to the White House asked the President, "What is your definition of a friend?" Lincoln stroked his beard reflectively before he answered, "One who has the same enemies you have."

- from *The Wit & Wisdom of Abraham Lincoln—A Treasury of Quotations, Anecdotes, and Observations*

How Well Do You Know the 2007 MP/H Rules?

1. A 94 year old patient presents for a routine colonoscopy and is found to have a single polyp in the sigmoid colon. The polyp is removed and the pathology report indicates there is mucinous adenocarcinoma within the head of the polyp. What histology should be coded?

2. Pathology from a nephrectomy shows a 2cm renal cell carcinoma, papillary and clear cell type. What histology should be coded?

3. Prostate, right side needle biopsies: Infiltrating moderately differentiated acinar adenocarcinoma. What histology should be coded?

4. A CT of the chest shows a single malignant appearing tumor in the left upper lobe and a second malignant appearing tumor in the right upper lobe. A biopsy of the tumor in the left upper lobe reveals squamous cell carcinoma. No further information is available. How many primaries are present?

5. A patient with a history of astrocytoma in the parietal lobe was initially diagnosed in 2001 and was treated with surgery and radiation. He has had no apparent tumor since that time. In February of 2007 a new tumor is found in the frontal lobe. A biopsy of this tumor shows glioblastoma multiforme. Is this a subsequent primary?

See answers below.

Need help with the new MP/H rules? Contact the NAACCR Education and Training staff to schedule a training workshop or webinar for your group or staff!

- *Jim Hofferkamp, BA, CTR
Trainer*

Answers: 1. 8210/3 Adenocarcinoma in an adenomatous polyp 2. 8255/3 Adenocarcinoma with Mixed Subtypes
3. 8140/3 Adenocarcinoma, NOS 4. Two 5. No



NAACCR Process Improvement Program



Are you planning your state or province association annual workshop?

Then add the Process Improvement Program to your workshop agenda. The Process Improvement half day workshop is designed to enhance data quality through improved collaboration, more effective communication, and strengthening the relations between central cancer registry staff and local cancer registrars/reporters. Visit the NAACCR web to complete an application.

Closing Dates

January 1, April 1, July 1, October 1

Go to www.naaccr.org for more information and application forms or
Contact: Shannon Vann - **Email:** svann@naaccr.org **Phone:** (315) 682-6543

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- American College of Surgeons
- American Joint Committee on Cancer
- Canadian Association of Provincial Cancer Agencies
- Centers for Disease Control and Prevention
- College of American Pathologists
- Public Health Agency of Canada
- National Cancer Institute
- National Cancer Registrars Association

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