

RR Registrar Review

Vol. 3, No. 3

Quarterly Newsletter of the Virginia Cancer Registry

December 1999

Welcome to the December 1999 edition of the REGISTRAR REVIEW (RR), the quarterly newsletter of the Virginia Cancer Registry (VCR). We remind all readers of our aim that the content of this newsletter address current and changing needs of cancer control and prevention stakeholders in Virginia. Therefore, we welcome any and all comments, criticisms and suggestions on how the RR can continue to meet the dynamic needs of Virginia's cancer reporting system. If you have comments, please do not hesitate to let us know by contacting the VCR at:

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Virginia Cancer Registry
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1500 East Main Street
Richmond, VA 23218

(804) 786-1668 phone
(804) 371-4061 fax



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www.vdh.state.va.us

Y2K Last Minute Checklist

The Virginia Cancer Registry software, Rocky Mountain Cancer Data System (RMCDS), and all of our computers and equipment are Y2K compliant. We will be testing the system just before and just after the New Year to ensure that key functions are still operable. Please notify us if you get zapped and are unable to report your cases. Hold on tight, the ride may get bumpy!!

So you hope your data system is ready. How is your HOUSEHOLD? Matthew Ryan, Senior Policy Director of the U.S. Subcommittee on Government Management, Information, and Technology, provided the following checklist during his presentation at the October VCRA meeting:

- 3-day to 1-week supply of non-perishable food for each person
- 3-day to 1-week supply of water for each person - fill your bathtub on December 31st
- Flashlights, batteries, radios, and candles
- Prescriptions and cars – fill them up!
- Do not forget the needs of the kids, elderly, disabled, and pets!

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VCU/MCV Cancer Surveillance Study

Many of you are aware of a study being conducted by researchers from Virginia Commonwealth University/Medical College of Virginia (VCU/MCV). This study will evaluate the benefit of complementing the VCR database with other potential sources of cancer surveillance data, including the statewide discharge database and Medicare claims. The study can benefit the VCR by helping us try to capture some of the estimated 13% of all cancer currently going unreported in Virginia. The study is funded through the National Cancer Institute, and the State Health Commissioner has approved it.

An integral part of the study involves review of patient medical records to evaluate the validity of information found in the numerous data sources. Although the VCR has worked to have the study cause minimal burden on hospitals and on hospital registrars, there have been some issues as the work progresses. Ultimately, however, hospitals hold the key to understanding the case information, so we appreciate your patience and willingness to contribute.

Any questions or concerns about the study details should be directed to Lynne Penberthy, MD, MPH, the Principal Investigator for MCV (804-828-6938), or Dawn Parker (1-800-566-0405 or 804-828-0577). The Virginia Cancer Registry has not been involved in the daily operations of the study, but please feel free to call Amy Pugh (804-786-1668) if you have any questions about legal access or the study in general.

Calling all Prostate Cancers!

The Virginia Cancer Registry has been awarded one-time funding through CDC for the enhanced surveillance of prostate cancers in Virginia. We will be hiring a contractor to provide CTRs to identify additional sources of prostate cancer (such as urology clinics and independent pathologists), perform baseline casefinding, and work with the new facilities on casefinding and reporting procedures. The VCR estimates that over 1,200 prostate cases go unreported each year. You may be hearing from these folks as they try to network across the state to find these cases, so please be thinking of possible sources in your area.

Through this prostate cancer-related funding, the VCR also is producing an incidence study specifically on prostate cancer. The study should be ready for distribution in mid-2000.

Stamps Aid the Fight Against Cancer

The U.S. Postal Service offers two stamps whose purchase and use can help raise awareness and funding for cancer research.

The Breast Cancer Stamp bears the logo “Fund the Fight, Find a Cure,” and costs \$0.40. Proceeds above the cost of postage go to the National Institutes of Health and the Medical Research Program of the Department of Defense, which both conduct cancer research. Designed by a breast cancer survivor, this stamp allows the nation’s public to contribute every day to the war on cancer. The breast cancer postage stamps have raised over \$5 million dollars for breast cancer research.

A second stamp aims to raise awareness for prostate cancer and the need for annual checkups and tests. The Postal Service hopes the stamp’s dissemination into homes across America will help spread the word among men young and old about the disease and the need to talk with their doctors.



VCR Grows

The Virginia Cancer Registry continues to change and grow. Welcome to four new permanent staff:

- Jayne Arline, CTR, Cancer Surveillance Specialist
- Dianne Collins, CTR, Cancer Surveillance Specialist
- Nancy VanVoorhis, ???, MPH, Statistical Analyst, Sr.
- Dawn Hawkins, MS, Statistical Analyst, Sr.

Congratulations to Sarah Norris and Nancy VanVoorhis, who each recently completed her Master’s in Public Health at VCU/MCV. The VCR also is proud of Bonnie Perry, who recently was elected as Vice-President of VCRA. WAY TO GO!

Reporter's Corner

Case Finding and Data Quality Reviews

Accurate and complete cancer registry data are required in order to draw correct conclusions about the burden of cancer in Virginia. It is important to routinely measure the completeness of a population-based registry. It is also important to verify that facilities required to report cancer cases report all of their cases. Registry data that are used for decision making such as cancer control must be of the highest possible quality and it is the central registry's responsibility to assess these data.

In order to maintain high data quality, the Virginia Cancer Registry (VCR) staff has resumed doing case finding and data quality reviews. The VCR staff has visited five facilities to conduct case finding reviews. At three of the five facilities, data quality reviews were also conducted. The staff reviewed a variety of case finding sources for a time period of two to six months, based on the 1997 caseload for the facilities. The reviews identified 298 cases as not having been reported to VCR. The data quality reviews consisted of reabstracting certain data fields which included date of birth, race, diagnosis date, laterality, site, histology including behavior code and grade, stage, sequence number and state of residence at diagnosis. These reviews identified 20 discrepancies in the reabstracted data compared to the hospital-reported data.

These reviews are a learning experience for the central registry as well as for the hospital registrar. They will assist the VCR staff in developing better methods for tracking electronic reporting. The data quality reviews will assist the staff in meeting the educational needs of the hospital registrars as well as identifying educational topics for our annual seminar. Unless you choose otherwise, VCR staff will not contact other hospital departments or personnel in conducting or reporting results of these reviews.

In the coming year, the VCR staff will be visiting facilities across the Commonwealth conducting the case finding and data quality reviews. The following table lists the steps followed by both hospital and VCR staff to prepare for, complete, and reconcile the reviews.

Before the visit, the VCR will:

- Identify facilities for the case finding and data quality reviews by random selection based on caseload.
- Contact registrars by phone to establish a mutually agreed upon date for the reviews.
- Forward a letter to the hospital registrar outlining exactly what the registrar needs to do to prepare for the review:

?	Copies of case finding resources needed
?	Medical record charts that need to be made available
?	A quiet space to work with electrical outlets

- Call the day before the reviews to confirm readiness for the reviews

After the visit:

- The VCR staff will notify the hospital registrar of any cases identified by the Case Finding Review as not having been reported.
- The registry either reports the case or provides reason case is not reportable.
- The registrar will be notified of any discrepancies identified in the Data Quality Review of the medical records.

Remember:

- The Case Finding Review may be used as a request for use of data for the Commission on Cancer Survey.
- The Data Quality Review may be used as a quality assurance procedure for the Commission on Cancer Survey.
- The VCR staff will be glad to meet with the cancer committee chairman or the hospital administrator.
- The reviewers will sign confidentiality statements if requested by the registrar or by hospital administration.
- These reviews are in accordance with the Code of Virginia.

Reporter's Corner

Arlington Welcomes VCRA for Its 20th Anniversary



The Virginia Cancer Registry Association's outgoing president, Beverly Hodge, and her co-worker and program chairman, Barbara Ryan, deserve a round of applause for all the work they put into the VCRA's 20th anniversary annual conference. The meeting was

held at the Holiday Inn Arlington at Ballston on October 14 and 15, 1999; and although the number of members attending was relatively small, the conference schedule was full.

Speakers' topics ranged widely—from annual reports as marketing tools, to U.S. Congress Senior Policy Director's observations and warnings about Y2K, to clinical subjects such as prostate cancer treatment options, breast cancer and HER2-NEU/C, and an ovarian cancer profile. A presenter that we will all remember was a breast cancer survivor who reported on her experiences using yoga to complement her medical and surgical therapy; she ended her presentation with an amazing demonstration of yoga exercises.

While a delicious luncheon was served, on the first day of the conference, the annual business meeting was held. At its conclusion Colleen Bennett was sworn in as VCRA President for the years 2000-2001. Other 2000-2001 officers sworn in were Bonnie Bowman, President Elect; Bonnie Perry, Vice-President; Becky Davis, Secretary; and Renee Robertson, Treasurer.

There were many door prizes awarded and laughs shared; and, as always, a lot of good times were enjoyed during breaks and meals when friends and colleagues got together to solve problems, to catch up on family news, and to remember other occasions when we were together. It was a good celebration of VCRA's 20th! We missed all of you who could not attend this year's conference and hope we'll meet again before another year goes by!

The VCRA & VCR: Continued Collaboration

In October, representatives from the Virginia Cancer Registrars Association and the Virginia Cancer Registry met in Baltimore with other partners in cancer registration and control at the American Cancer Society's Second Annual Mid-Atlantic Conference on Regional Collaboration for Better Cancer Control. One focus was brainstorming on ways to help the VCR prepare for its upcoming application for the next five-year funding cycle of the Centers for Disease Control and Prevention's National Program of Cancer Registries. Beverly Hodge, then VCRA President, suggested that VCRA and its members could contribute through:

- (1) an organizational letter of support,
- (2) submission of data in a timely manner (working toward the standard of six months after diagnosis), and
- (3) running CDC/NAACCR Edits software so data are clean when reported to the VCR.

VCRA on the Web!

At the October meeting of the VCRA, the board accepted the offer by the Virginia Cancer Registry to post VCRA information and events on its web site (www.vdh.state.va.us/epi/vcr.htm). The VCR web pages will be revamped this spring, so look for the new additions.

Email submissions

?? Those facilities submitting data through encrypted email should note a change in submission address. Please send your data directly to Bonita Bryant, CTR, QA Coordinator, at bbryant@vdh.state.va.us. **As always, be sure to compress ("zip") and password-protect the file to prevent unauthorized access.**

Reporter's Corner

Laboratory Cases

The VCR has developed a Physician-Laboratory Agreement form to help clarify reporting responsibility between private physicians and independent laboratories. Physicians complete one form for each laboratory source used for pathology readings and provide contact information. The VCR then sends the form to the lab to sign-off that they currently report cases for that physician, they have not but will report those cases, or that they do not believe they should be responsible for the reporting.

If you have physicians asking you about their reporting responsibility under §32.1-70, please contact the VCR (804-786-1668) and we can either provide you with forms or send them directly to the physicians.

Physician Reporting

The decision by the American College of Surgeons Commission on Cancer not to require the collection of physician office cases has let everyone breathe a sigh of relief. At the VCR 1999 conference we learned that generally physician case information cannot be maintained in a hospital registry without patient consent. If you currently are collecting these cases, please consult your hospital attorney to determine ownership of the medical information. For instance, if the physicians are practicing in a hospital-affiliated clinic, the legalities of that clinic-hospital relationship can determine your registry's right to the information. BE SAFE – CHECK IT OUT!

Certified Examination Results for the Cancer Registrars of Virginia

Congratulations to the following Virginia cancer registrars recently passing the CTR exam:

Lisa Clubb
Ingrid Hawley

Mary Dianne Collins
Glynis Marsh

More Data on the Way

Statewide incidence data for the 1995 and 1996 diagnosis years will be published on the VCR web site by the end of the month, and the hardcopy annual report (which also will include 1997) should be out by March 2000. For the first time, statistics will be presented for more detailed race/ethnicity groups and at a greater geographic detail.

Physician reporting diagram

The following diagram is available in a revised version of "What Every Physician Should Know about Cancer Reporting in Virginia" released in November 1999. This orange flyer replaces the pink one distributed earlier and clarifies the reporting responsibility of physicians, clinics, and independent pathology laboratories. An important highlight is that hospital pathologists reading on contract and reporting results directly to private physicians are considered independent pathology laboratories under current regulations. Please contact the VCR if you would like copies of the new flyer.

Mark Your Calendar



Year 2000

January 10-12 & June 19-21

Advanced Cancer Registry Training Program, Atlanta, GA; registration fee \$400.00: This intensive and comprehensive training program is taught by a staff of recognized experts in cancer registration, surveillance, and control. This Advanced Cancer Registry Training Program will specifically address: abstracting, staging, and coding really difficult cancer cases; bizarre, rare, and unusual cancer cases; calculating incidence, prevalence, age-adjusted, survival, and other rates; using registry data (preparation, analysis, annual reports, etc.); and using the Internet to locate comparable data and useful cancer information and resources. Participants must have attended the [Principles and Practice training program](#) prior to registering for this advanced training (or have at least one year of experience working in a cancer registry). For more information contact Steven Roffers, PA, CTR at (404) 727-4535, fax (404) 727-7261 or e-mail sroffer@sph.emory.edu.

March 6-10, August 14-18 & November 6-10

Principles and Practice of Cancer Registration, Surveillance and Control, Atlanta, GA; registration fee \$800.00. This program will be held on the campus of Emory University. This program is suitable for all oncology healthcare personnel, especially oncology program (hospital-based and central registry-based) employees with minimal knowledge of cancer anatomy, physiology and medical terminology. Cancer registrars, statistical staff and epidemiological staff who utilize cancer registry data would benefit most from this program. Complete details are available via their web site at <http://cancer.sph.emory.edu> or contact Steven Roffers, PA, CTR at (404) 727-4535.

March 6 - 10

Commission on Cancer, Basic Cancer Registry Data Collection Workshop, Chicago, Illinois, Registration fee \$400 includes course materials only. The objective of this workshop is to provide students with the basic tools necessary to collect data as an integral part of a Commission on Cancer-approved program. This intensive training course will include eight-hour class days and homework assignments. **Future basic training workshops are scheduled for September 2000 and March 2001.** For more information call (312) 202-5085.

March 13 - 14

Pediatric Cancer Registry Training Program, Atlanta, GA; registration fee \$200.00: This program is suitable for oncology program (hospital-based and central registry-based) employees with minimal knowledge of cancer, anatomy, physiology, and medical terminology. Cancer registrars with less than one year of experience or statistical and epidemiological staff who utilize cancer registry data would benefit most from this program. This training program will focus on pediatric cancer histologies and sites. For more information contact Steven Roffers, PA, CTR at (404) 727-4535, fax (404) 727-7261 or email at sroffer@sph.emory.edu.

March 30 - 31

The 2000 Virginia Cancer Registry Annual Training Conference will be held Thursday and Friday, March 30-31. The same hotel will host the meeting this year, the Holiday Inn Crossroads in Richmond, Virginia. More details will be provided soon. If you have questions or speaker recommendations, please contact the Registry at 804-786-1668.

May 2000

Working Together for Better Data is a ground-breaking workshop co-sponsored by NAACCR and NCRA and planned for the annual meeting at NCRA in New Mexico **next spring**. This workshop will target both hospital and central registrars to sharpen abstracting skills and develop a sense of how data are evaluated on the hospital and central registry levels for accuracy and completeness.

April 18-20

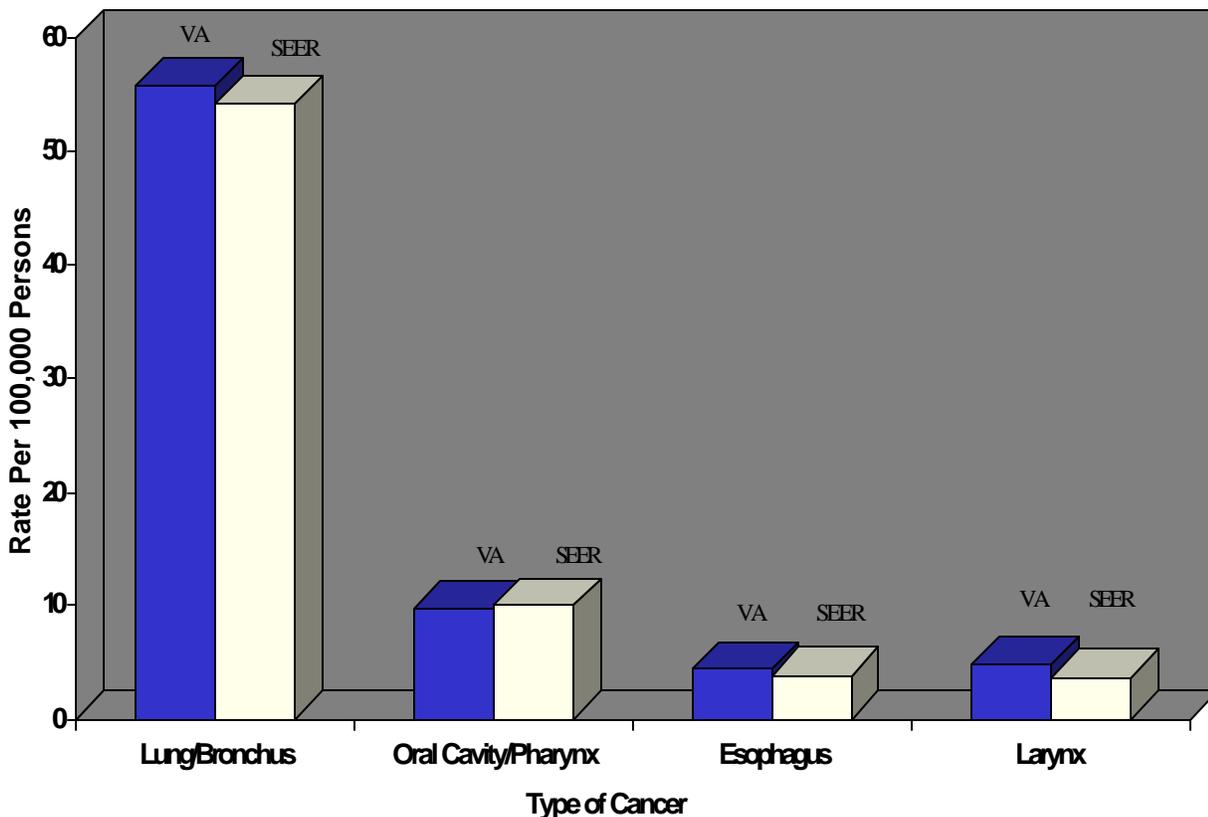
The NAACCR Annual Conference will be held at the Hilton Riverwalk in the "Crescent City," New Orleans, Louisiana. The theme is "The Challenges of Cancer Surveillance in the New Millennium: Uniformity and Diversity," There will be workshops the weekend prior to the conference.

Tobacco-Related Cancers

Smoking is the most preventable cause of cancer in our society. Tobacco use and/or exposure is responsible for most cancer diagnosed in the following four sites: lung and bronchus, oral cavity and pharynx, larynx, and esophagus. Tobacco use also increases the risk of other cancers, including cancers of the pancreas, kidney, urinary bladder, and cervix. The ACS estimates that at least 30% of all cancer deaths are caused to tobacco use, and that smokers die an average of seven years earlier than non-smokers. In 1996, 5,301 Virginians were diagnosed with one of the four cancers most often linked to tobacco use, while 4,254 Virginians died from one of these four cancers. As shown in the following graph, Virginia rates exceed national rates (based on the NCI SEER program) for all invasive tobacco-related cancers except oral cavity/pharynx. Quitting smoking reduces the risk of developing cancer, as well as coronary heart disease and cardiovascular disease. For more information on tobacco-related cancer or smoking cessation, call the American Cancer Society at 1-800-ACS-2345 or go to the website at www.cancer.org.

Graph of the Quarter

Tobacco Related Cancers Age-adjusted Incidence Rates Virginia and SEER Registries, 1996



Data exclude in situ carcinomas. Rates are adjusted to the 1970 standard US population. Virginia Cancer Registry, 1999. SEER Cancer Incidence Public-Use Database, 1973-1996; August 1998 Submission.