



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene
201 W. Preston Street • Baltimore, Maryland 21201

Martin O'Malley, Governor – Anthony G. Brown, Lt. Governor – John M. Colmers, Secretary

OCT 21 2010

The Honorable Martin O'Malley
Governor
State of Maryland
Annapolis, MD 21401-1991

The Honorable Thomas V. Mike Miller, Jr.
President of the Senate
H-107 State House
Annapolis, MD 21401-1991

The Honorable Michael E. Busch
Speaker of the House
H-101 State House
Annapolis, MD 21401-1991

RE: HB 636 (Ch. 251) of the Acts of 2001 and Health-General Article §18-204(b)(6)
2010 Legislative Report of the Maryland Cancer Registry

Dear Governor O'Malley, President Miller and Speaker Busch:

Pursuant to Health-General Article, §18-204(b)(6), Annotated Code of Maryland, the Department of Health and Mental Hygiene is directed to submit this annual legislative report on the activities of the Maryland Cancer Registry.

If you have any questions about this report, please contact Ms. Wynnee Hawk, Director of Governmental Affairs, at 410-767-6481.

Sincerely,



John M. Colmers
Secretary

Enclosure

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Maryland Department of Health and Mental Hygiene

ANNUAL REPORT

Maryland Cancer Registry

Fiscal Year 2010

Martin O'Malley
Governor

Anthony G. Brown
Lieutenant Governor

John M. Colmers
Secretary

October 2010



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1. INTRODUCTION

This report contains the Maryland Cancer Registry's Annual Fiscal Year Report for the period July 1, 2009 through June 30, 2010 (FY10).

The Maryland Cancer Registry (MCR) is a cancer incidence data system maintained under the direction of the Department of Health and Mental Hygiene (DHMH). Data in the registry are used to monitor trends in cancer incidence; identify differences in cancer incidence by age, sex, race, and geographic location; plan and evaluate cancer prevention and control programs in the State; and provide a valuable resource for cancer research.

The Maryland Cancer Reporting law, enacted in 1991, requires the electronic submission of all new cases of cancer diagnosed or treated in Maryland to the MCR by hospitals, radiation therapy centers, laboratories and freestanding ambulatory care facilities. The reporting law was amended in 1996 to require reporting by physicians whose non-hospitalized cancer patients are not otherwise reported. The law was later amended to require the reporting of benign brain and central nervous system (CNS) tumors to the MCR, beginning October 1, 2001.

DHMH subcontracts the database collection, data management, and quality assurance activities of the MCR to an outside entity. The current contractor, Westat, Incorporated (Westat), assumed responsibility for providing quality assurance and database management services to the MCR on February 1, 2008.

2. MCR MISSION STATEMENT

The Maryland Cancer Registry Advisory Committee (CRAC) adopted the following mission statements for MCR:

1. Oversight of activities that implement Health-General Article, §18-203 and §18-204, Annotated Code of Maryland, and COMAR 10.14.01 (cancer reporting statutes and regulations);
2. Timely, cost-effective, complete, and accurate ascertainment of new cases of cancer and benign central nervous system tumors among Maryland residents;
3. Computerization of cancer reports to facilitate ready availability, accessibility, and analysis; and
4. Preparation and dissemination of reports on the incidence and stage of cancer at diagnosis, which provide information on site, county of residence, and date of diagnosis.

3. FY10 ACTIVITIES

3.1 ADMINISTRATIVE ACTIVITIES

During Fiscal Year 2010, the MCR-Quality Assurance/Data Management (QA/DM) team at Westat met with MCR staff at least monthly to discuss progress and plans. The MCR-QA/DM contractor continued its quality assurance and data management activities during the fiscal year. Data were exchanged twice with the 12 states and the District of Columbia cancer registries that have interstate data exchange agreements with the MCR.

3.1.1 Cancer Registry Advisory Committee (CRAC)

During FY10, the CRAC met two times. Discussion topics included MCR-QA/DM activities, data use and dissemination, data submission, data use policy and procedures, MCR regulations, and cancer research and surveillance activities. Dr. Katherine Farrell stepped down as Chairperson for the Cancer Registry Advisory Committee on January 12, 2010. Dr. Kathy Helzlsouer is the Interim Chairperson. Dr. Helzlsouer is the Chair of the Maryland State Council on Cancer Control, has a sound epidemiological background, and has an interest in the MCR and its operations.

3.1.2 Administrative Activities – MCR Headquarters

The MCR is charged with administrative and custodial oversight of all MCR operations and data. The MCR monitors reporting compliance, processes data requests, reviews research requests prior to Institutional Review Board (IRB) submission, and analyzes data for DHMH program planning and for fulfilling requests. Administrative highlights during FY10 included:

1. *NAACCR Gold Certification*
The MCR submitted 2007 incidence data for evaluation and confidential feedback from the North American Association of Central Cancer Registries (NAACCR) and received “Gold” certification on completeness of case ascertainment; completeness of information recorded; percent of death certificate only cases; duplicate primary cases; passing EDITS; and timeliness.
2. *United States Cancer Statistics Publication*
During FY 10, the MCR data for incidence years 1996 through 2007 met the requirements for inclusion in the United States Cancer Statistics Publication Standard for the National Program of Cancer Registries (NPCR). MCR data are available on the national Web site: www.statecancerprofiles.cancer.gov.
3. *NPCR AUDIT*
As a requirement for receiving Federal funds from the Centers for Disease Control and Prevention (CDC) NPCR, MCR data is audited by the NPCR every five years. The MCR prepared for the audit in FY10 and the auditors began the

MCR audit in Maryland in July, 2010. NPCR auditors are visiting select facilities and will compare the data at the facilities to data within the database.

4. *MCR Hosts NAACCR Webinars*
During FY 10, the MCR hosted a series of Web seminars (Webinars) for Abstracting Cancer Incidence and Treatment Data for Hospital Tumor Reporting and Cancer Surveillance Data Collection by Central Cancer Registries. Each Webinar session was presented by the NAACCR and Certified Tumor Registrars (CTRs) who attended these sessions received Continuing Education Units.
5. *MCR Quarterly Reporters' Teleconference*
The MCR hosted quarterly reporters' teleconferences during FY 10 for all reporters from facilities (hospitals, freestanding ambulatory care facilities, radiation facilities, doctors' offices, laboratories) who report data to the MCR. The purpose of the teleconferences is to provide an opportunity for the MCR central office staff, the MCR-QA/DM contractor, and reporters to come together for information sharing, updates, and training.
6. *NAACCR Version 12 Update*
During FY10, there was a large change in the format and content of cancer registry databases in the US and Canada. NAACCR Version 12 expanded the size, number of fields, and coding of information in the cancer registries. The MCR began the process to change to NAACCR Version 12, a process that will be completed in FY11.
7. *Revised MCR Code of Maryland Regulations*
The MCR revised its Code of Maryland Regulations to reflect federal requirements and changes in reportable conditions from national organizations.
8. *Guidelines for the Management of Inquiries Related to Cancer Concerns or Suspected Cancer Clusters*
The MCR revised the formerly entitled *Guidelines for the Investigation of Suspected Cancer Clusters* in partnership with the Environmental Health Coordination Program at DHMH to include guidelines on the handling of a report of a cancer concern by a local health department and establishing clear lines of leadership and communication. Due to these changes, the guidelines were renamed *Guidelines for the Management of Inquiries Related to Cancer Concerns or Suspected Cancer Clusters*. The guidelines were presented at the Health Officers' Policy Roundtable on January 10, 2010.

3.1.3 Quality Assurance and Data Management (QA/DM) Activities

Westat performs QA/DM activities for the MCR. Activities conducted by Westat during FY10 included: collection of cancer reports from facilities; case finding and quality assurance/quality control of data submitted; and submission of data to NAACCR and NPCR.

Westat completed the following during FY10:

- Completed data submissions to NAACCR and NPCR in December 2009 through Diagnosis Year 2007;
- Assured data quality:
 - Reviewed incoming abstracts for accuracy and completeness and consolidated abstracts;
 - Completed de-duplication by SSN, First and Last Name, and Date of Birth for years 1996-2007 (over 1,100 possible duplicates);
 - Began planning and programming for MCR database conversions from NAACCR layout Version 11 to Version 12 and tested the converted data in anticipation of CRS Plus migration to the upgraded NAACCR Version 12 format;
 - Installed new data server to host the Registry Plus applications; and
 - Completed the latest derived Hispanic ethnicity algorithm.

3.2 ROUTINE DATA PROCESSING

3.2.1 MCR Facility Audits

Westat conducted 10 facility audits between July 2009 and June 2010. Each facility submitted a list of potential reportable cancer cases. Westat performed a review of each case to determine if it was reported, and if not, whether it should have been reported. CTRs employed by Westat visited the facilities and completed a re-abstraction of data on 25 cases each. The re-abstraction information was compared to the case information submitted by the facility.

Audit findings were presented in reconciliation records that were prepared for the reporting hospitals and final reports were prepared for the hospital and DHMH. These audits help the MCR determine the quality of the data submitted by the facilities and directs the type of training the MCR provides.

3.2.2 Death Matching and Clearance

During FY10, the MCR and Westat followed the 2010 Death Clearance Procedures recently developed by NAACCR. Westat used its Follow-back Tracking application for following deaths and for creating new case reports on tumors that had not been previously reported.

3.2.3 Case Abstracts Received and Consolidated

Westat received 38,770 facility abstracts in FY10 which they processed into consolidated, newly diagnosed tumor records (see Table 3.4.1).

3.2.4 Interstate Data Exchange

The MCR has active reciprocal reporting agreements with central registries in the District of Columbia and the 12 state cancer registries (Alabama, Delaware, Florida, Georgia, New Jersey, New York, North Carolina, Pennsylvania, South Carolina, Texas, Virginia, and West Virginia). Westat completed interstate data exchange with all 13 central cancer registries in FY10.

3.2.5 Technical Assistance and Training

Westat continues to maintain its dedicated MCR Help Line to provide technical assistance to callers. During FY10, Westat provided technical help and continues to provide abstracting/coding expertise to Maryland cancer case reporters. Westat staff also provided training during the quarterly reporter teleconferences and the Tumor Registrars Association of Maryland (TRAM) meetings.

3.2.6 Other Activities

Westat began planning and submitting required documents and data for the NPCR audit (3.1.2.3) mentioned previously.

3.3 ACTIVITIES TO IMPROVE MCR-QA/DM

Westat continues to make recommendations for improving the MCR QA/DM system. These recommendations include:

- Convert the MCR database to NAACCR version 12;
- Update edits to version 12;
- Perform a systematic review of case reporting sources to identify sources who do not identify and report to the MCR;
- Perform a systematic review of other missing or unknown data values across key data fields;
- Extend the global edits fixes to edit and correct all reportable data elements; and
- Develop and automate the production of feedback reports to the facilities who report data to the MCR.

3.3.1 Data Quality and Completeness

Several presentations were made to those who report data to the MCR about the need for submission of quality data. These presentations have not only focused on coding but also included the need for submitting correct text in order for the MCR to verify coded data and for correct address information for the MCR to be able to geocode the data.

MCR staff continued to access the Maryland Motor Vehicle Administration (MVA) Direct Access Record System (DARS). Through DARS, MCR staff have been able to locate race information for patients with unknown race in the database and to update race in the MCR, leading to higher quality data.

3.3.2 Other Activities

The MCR Director and key Westat staff attended the following conferences that are required by NPCR:

- The NAACCR annual conference;
- The collaborative National Programs for Cancer Registries/NPCR conference; and
- The National Cancer Registrar Association annual conference.

In addition, key MCR staff at Westat attended the following meetings:

- The NAACCR leadership meeting and
- The American College of Surgeons Commission on Cancer.

3.4 REPORTS AND CASES ADDED DURING FY10

Table 3.4.1 shows the number of tumor abstracts reported in FY10 from all reporting facilities by year of diagnosis and state of residence. The MCR received 38,770 tumor reports during FY10.

**Table 3.4.1 Number of Tumor Abstracts Received in FY10 by Diagnosis Year and Diagnosis State
Received between July 1, 2009 to June 30, 2010**

Diagnosis Year	Diagnosis State	
	Maryland	Non-Maryland
2009	24,282	3,172
2008	6,428	941
2007	2,451	124
2006	695	102
2005	170	6
2004	83	4
2003	130	5
2002	46	0
2001	21	1
2000	16	0
1999	12	0
1998	8	0
1997	6	0
1996	11	0
1995	10	0
1994	4	0
1993	4	0
1992	1	0
1991	3	0
1990	3	1
1989	4	0
1988	1	0
1987	3	1
1986	1	0
1985	1	0
Before 1985	8	0
Unknown	11	1
Total	34,412	4,358

Data Source: Westat, Inc.

Because cases diagnosed in calendar year 2010 are not required to be submitted until September 2010, and because 2010 cases are required to be submitted in NAACCR version 12, there are no 2010 cases currently reflected in Table 3.4.1, Table 3.4.2, and Table 3.4.3 for diagnosis year 2010.

Table 3.4.2 presents the number of newly diagnosed benign brain and central nervous system tumors in the MCR, by year of diagnosis as of July 1, 2010. A total of 6,456 consolidated cases are in the MCR.

Table 3.4.2

**Total Number of Benign and Borderline
Brain and Central Nervous System Tumors*
by the Diagnosis Year and by Tumor Behavior ICD-O-3 (benign and borderline)
in the Maryland Cancer Registry Database****

Diagnosis Year	Behavior ICD-O-3	
	Benign	Borderline
2009	612	63
2008	747	54
2007	701	83
2006	652	61
2005	625	68
2004	598	66
2003	499	64
2002	398	42
2001	220	18
2000	51	5
Before 2000	741	88
Total	5,844	612

*Data Source: MCR Registry PRD database, Medicalsum table, as of 08/25/2010.

**Brain and Central Nervous System Tumors defined by the ICD-O-3 primary site (C70.0-C70.9, C71.0-C71.9, C72.0-C72.9, C75.1-C75.3).

The following primary site codes with a behavior code of 0 or 1 were included:

- Meninges (C70.0–C70.9)
- Brain (C71.0–C71.9)
- Spinal cord (C72.0)
- Cauda equina (C72.1)
- Cranial nerves (C72.2–C72.5)
- Other CNS (C72.8–C72.9)
- Pituitary gland (C75.1)
- Craniopharyngeal duct (C75.2)
- Pineal gland (C75.3)

Table 3.4.3 presents the number of newly diagnosed Myelodysplastic Syndrome tumors in the MCR, by year of diagnosis as of July 1, 2010. A total of 1,141 cases had been reported with diagnosis year 1992 through 2009.

Table 3.4.3

**Total Number of Malignant Myelodysplastic Syndrome* Tumors
by Diagnosis Year and by Diagnosis State
in the Maryland Cancer Registry Database****

Diagnosis Year	Diagnosis State	
	Maryland	Non-Maryland
2009	84	10
2008	109	16
2007	133	22
2006	108	24
2005	102	14
2004	95	17
2003	106	27
2002	118	21
2001	82	18
2000	16	4
1999	4	0
before 1999	9	2
Total	966	175

**MCR consolidated data as of 07/01/2010.

*The following ICD-O-3 diagnosis codes with malignant behavior were included:

- 9980 – Refractory anemia
- 9982 – Refractory anemia with ringed sideroblasts
- 9983 – Refractory anemia with excess blasts
- 9984 – Refractory anemia with excess blasts in transformation
- 9985 – Refractory cytopenia with multilineage dysplasia
- 9986 – Myelodysplastic syndrome with 5q deletion syndrome
- 9987 – Therapy-related myelodysplastic syndrome, not otherwise specified
- 9989 – Myelodysplastic syndrome, not otherwise specified

3.5 DATA REQUESTS

Table 3.5 shows the number of requests for data that the MCR received and processed in FY10.

Table 3.5

Data Requests Requiring MCR Analysis That Were Received and Processed in FY10

Type of Request	Number of Requests Pending as of July 1, 2009 (start of FY10)	Number of Requests Received FY10	Number of Requests Processed by June 30, 2010 (end of FY10)
Research/Special Studies	5	8	10
Reporting Facilities Requesting their own Information	0	2	1
Health Services Planning	1	11	12
Public Request for Information	2	21	19
DHMH Use	0	2	2
Total	8	44	44

4. CONCLUSION

The MCR is a valuable resource for Maryland to track and evaluate cancer statistics and to compare its rates to other states in the US. By collecting and analyzing MCR data, Maryland can better focus its cancer prevention and control efforts and can evaluate its cancer programs. The MCR will continue collecting, analyzing, and disseminating data in its efforts to further the goal of a healthier Maryland.