



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 01 2009

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

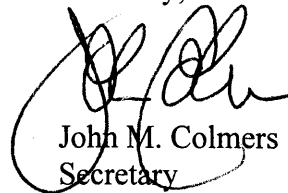
RE: HB 636 (Ch. 251) of the Acts of 2001 –
2009 Legislative Report of the Maryland Cancer Registry

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. Anne Hubbard, Director of Governmental Affairs, at 410-767-6481.

Sincerely,



John M. Colmers
Secretary

Enclosure

cc: Ms. Sarah Albert, MSAR# 5544
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Maryland Department of Health
and Mental Hygiene

ANNUAL REPORT

Maryland Cancer Registry

Fiscal Year 2009

Martin O'Malley
Governor

Anthony G. Brown
Lieutenant Governor

John M. Colmers
Secretary

October 2009



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1. INTRODUCTION

This report contains the Maryland Cancer Registry's Annual Fiscal Year Report for the period July 1, 2008 through June 30, 2009 (FY09).

The Maryland Cancer Registry (MCR) is a computer-based 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. Westat, Incorporated 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. FY09 ACTIVITIES

3.1. ADMINISTRATIVE ACTIVITIES

During Fiscal Year 2009, the MCR-Quality Assurance/Data Management (QA/DM) team at Westat, Inc. met with DHMH 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 FY09, the CRAC met four 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. During FY09, the committee assisted with the Surveillance Chapter of the new Maryland Comprehensive Cancer Control Plan.

3.1.2. Administrative Activities – MCR Headquarters

The MCR Headquarters, located in the DHMH office complex, is charged with administrative and custodial oversight of 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 FY09 included:

1. *NAACCR Webinars for Central and Hospital Certified Tumor Registrar (CTR) Training-*
During FY09, 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 North American Association of Central Cancer Registries (NAACCR) and included a presentation by an instructor using the Web-based seminar. The sessions were hosted both at DHMH and at Westat, Inc. Continuing Education Units were received by CTRs who attended a full session.
2. *United States Cancer Statistics Publication-*
During FY09, the MCR data for incidence years 2002 through 2006 met the requirements for inclusion in the United States Cancer Statistics Publication Standard for the National Program of Cancer Registries (NPCR).

3. *MCR Web site* (http://fha.maryland.gov/cancer/mcr_home.cfm)-
The MCR continues to regularly update its Web site to better serve the needs of the public, reporting facilities, and data requesters. During FY09, the MCR updated several links to assist reporters including the MCR “Announcements, Training, and Dates to Remember” Web page and the “Information for Facilities Reporting to the MCR” Reporters’ Web page.
4. *MCR Speaker Series*-
The MCR provides cancer data to researchers, local and state governmental entities, and others. The MCR developed a Cancer Data Speakers Series to provide an opportunity for DHMH staff to learn more about studies and projects that use MCR data. Topics during FY09 included: Linking Cancer Screening Data to MCR Data to Capture Screening Outcomes; Uses of Data at the Local Level: Perspectives from Baltimore City; Linking Breast and Cervical Cancer Data with the MCR Data; Reducing Disparities in Surveillance, Symptom Care, and Prevention among Breast Cancer Survivors; Implementing the 2006 Institute of Medicine Guidelines; Assessing Evidence Based Provider Practices of HPV Testing in Cervical Cancer Screening; HIV, Smoking, and Cancer in Baltimore; Geocoding; and Cancer Risks from Air Toxics in Maryland Counties.
5. *MCR Quarterly Reporters’ Teleconference*-
The MCR hosted quarterly reporters’ teleconferences during FY09 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. *MCR Regulations Updated*-
The MCR regulations, COMAR 10.14.01, are in the process of being updated to incorporate the following changes: 1) defining the cancer control goals of the State and updating the reportable diagnosis; 2) adding nursing homes and assisted living facilities as groups who will report to the MCR if asked for additional information by the MCR as a part of death follow-back procedure; 3) making modifications to the diseases that are reported to the MCR to comply with national standards; and 4) specifying how persons interested in MCR data may request confidential and non-confidential data and outlining how the data may be used.
7. *CDC Site Visit*-
The Centers for Disease Control and Prevention (CDC) NPCR conducted a site visit at the MCR on September 15-16, 2008. The primary purpose of the site visit was to:
 - Increase understanding of the MCR and its progress, successes, challenges and context;

- Assess the MCR's progress toward implementing a Statewide, population-based central cancer registry and meeting NPCR program standards;
- Identify program gaps and barriers that impede progress;
- Discuss MCR policies and procedures; and
- Discuss the MCR's education and training strategies, quality assurance activities, use of and/or participation in data utilization, collaborative relationships, and advanced activities.

Recognition of Registry Activities-

- The MCR was commended for their data remediation efforts for the last several years;
- The MCR has a great foundation of electronic reporting from hospitals as well as numerous non-hospital sources;
- The MCR links with hospital disease indices to ensure complete reporting;
- The MCR holds quarterly conference calls with reporting facilities; and
- The MCR has implemented a new Data Release Policy and Procedure to encourage appropriate data use.

3.1.3. Quality Assurance and Data Management Activities

Westat, Inc. performs QA/DM activities for the MCR. Activities conducted during FY09 included: collection of cancer reports from facilities; case finding and quality assurance/quality control of data submitted; completion of data submissions through 2007 to NAACCR and NPCR; and an update of electronic reporting software.

Westat, Inc. completed the following during FY09:

- Completed data submissions through diagnosis year 2007 to NPCR and 2006 data to the North American Association of Central Cancer Registries (NAACCR);
- Assured data quality:
 - Reviewed and removed Social Security Number duplicates (1,700 possible duplicates);
 - Completed 2002-2006 edit corrections;
 - Applied CDC patches to Registry Plus software for Collaborative Staging;
 - Developed and ran 10 SQL global edits to correct data;
 - Continued to develop internal QA including peer-to-peer oversight, supervision by director, and monthly, quarterly and annual management reports to identify anomalies in data; and
- Completed Hispanic algorithm run and write-back to master file for entire database.

3.2. ROUTINE DATA PROCESSING

3.2.1. MCR Facility Audits

Westat, Inc. completed 2007 facility audits on seven facilities between October 2008 and January 2009. Each facility submitted a list of potential reportable cancer cases to the MCR vendor-Westat, Inc. Westat, Inc. performed a review of each case to determine if it should have been reported. Westat, Inc. CTRs visited the facilities and completed a re-abstraction of data on 25 cases each. The reabstraction information was compared to the case information submitted by the facility. The audits assist the MCR to determine the quality of the data submitted by the facilities and direct the type of training the MCR provides.

3.2.2. Death Matching and Clearance

Westat, Inc. implemented a tracking system for cases reported on death certificates not previously reported to the MCR, facility disease indices, and cases reported with unknown race. Westat, Inc. used the tracking system to complete death certificate follow back for the 2006 death certificates. DHMH completed the death certificate follow back on the 2004 and 2005 death certificate cases not previously reported to the MCR and Westat, Inc. used the tracking system for uploading the data.

3.2.3. Case Consolidation

Westat, Inc. received 55,727 facility abstracts which they processed into consolidated, newly diagnosed tumor records in FY09 (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, Inc. completed interstate data exchange with all 13 central cancer registries in FY 09.

3.2.5. Technical Assistance and Training

Westat, Inc. continues to maintain its dedicated Help Line to provide technical assistance to callers. During FY09, Westat, Inc. provided technical help and abstracting/coding expertise to Maryland cancer case reporters. Westat, Inc. has made a presentation to a group of ambulatory surgery center providers explaining how to report to the MCR. They have also provided training during the quarterly reporter teleconference and the Tumor Registrars Association of Maryland (TRAM) meetings.

3.2.6. Other Activities

During FY09, Westat, Inc. hired a new Project Manager, Dr. Serban Negoita. Dr. Negoita came from the New York Cancer Registry and has a wealth of knowledge and experience in registry operations and epidemiology.

3.3. ACTIVITIES TO IMPROVE MCR-QA/DM

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

- Systematic review of case reporting sources to identify where primary cases are not being reported to the MCR;
- Systematic review of unknown race and other missing or unknown data values in key data fields (such as county of residence, cancer stage at diagnosis, first course of treatment);
- Update database to the latest NAACCR data standard;
- Update collaborative staging algorithm to new version;
- Update edits to current version;
- Implement global edits to update database on a regular basis; and
- Clarify the rules for collection of Class of Case 3 tumors.

3.3.1. Data Quality and Completeness

Numerous presentations were made to reporters about the need for submission of quality data. These presentations have not only focused on coding but also included the need for 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.

DHMH staff received permission to access the Maryland Motor Vehicle Administration (MVA) Direct Access Record System (DARS) system. Through the DARS system, DHMH staff have been able locate race information for over 5,000 patients with unknown race in the database and to update race in the MCR, leading to higher quality data.

3.4. REPORTS AND CASES ADDED DURING FY09

The MCR received 55,727 tumor reports during FY09. Table 3.4.1. data shows the number of tumor abstracts reported from all facilities reporting in FY09 by year of diagnosis and state of residence at diagnosis.

**Table 3.4.1. Number of Tumor Abstracts Received in FY09 by Diagnosis Year and
Diagnosis State
Received between July 1, 2008 to June 30, 2009**

Diagnosis Year	Diagnosis State	
	Maryland	Non-Maryland
2009	1,785*	311*
2008	26,978	4,649
2007	12,692	1,869
2006	4,175	176
2005	1,209	24
2004	1,039	35
2003	328	16
2002	90	7
2001	44	2
2000	34	1
1999	19	0
1998	11	0
1997	14	0
1996	6	1
1995	9	0
1994	3	1
1993	3	1
1992	4	2
1991	5	0
1990	7	0
1989	3	0
1988	0	0
1987	3	0
1986	1	0
1985	2	0
Before 1985	6	1
Unknown	149	12
Total	48,619	7,108

Data Source: Westat, Inc.

* 2009 cases are not required to be submitted until September 2009, which accounts for the temporarily small number of reported cases currently reflected in Table 3.4.1, Table 3.4.2, and Table 3.4.4 for diagnosis year 2009.

Table 3.4.2. presents the provisional number of newly diagnosed benign brain and central nervous system tumors in the MCR, by year of diagnosis as of June 30, 2009. A total of 5,436 consolidated cases had been reported to 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*****

Year of Diagnosis	Tumor Behavior ICD-O-3	
	Benign	Borderline Malignant
2009	4*	1*
2008	518	39
2007	639	74
2006	631	59
2005	618	68
2004	594	65
2003	499	64
2002	398	42
2001	220	18
2000	51	5
Before 2000	741	88
Total	4,913	523

***Data Source: Westat, Inc. MCR Registry database as of 06/30/2009.

**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 Myelodysplastic Syndrome tumors in the MCR, by year of diagnosis as of June 30, 2009. A total of 888 cases had been reported with diagnosis year 1992 to 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	2*	0*
2008	65	9
2007	86	20
2006	85	23
2005	96	14
2004	83	16
2003	101	27
2002	111	21
2001	78	18
2000	15	4
1999	4	0
Before 1999	8	2
Total	734	154

***MCR consolidated data as of 06/30/2009.

**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

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 FY09 that required analysis.

Table 3.5.

Data Requests Requiring MCR Analysis That Were Received and Processed in FY09

Type of Request	Number of Prior Requests Pending at the Start of July 1, 2008 (FY09)	Number of Requests Received FY09	Number of Requests Processed FY09
Research/Special Studies	3	13	12
Reporting Facilities Requesting their own Information	0	2	2
Health Services Planning	1	20	21
Public Request for Information	0	16	15
Media Requests*	0	0	0
Total	4	51	50

*Some media requests were received but were handled by providing already published data and these requests did not require any special processing so are not separately counted.

4. CONCLUSION

The MCR is a valuable resource used by DHMH in its efforts to further the cancer control goals of the State; namely, to reduce cancer incidence and mortality and to eliminate cancer disparities. The MCR collects and analyzes data and provides appropriate access to researchers, State and local governmental entities, and others who request data. Such efforts enable the State to evaluate the burden of cancer, to target its cancer prevention and control efforts, and to evaluate its cancer control programs. Outside researchers also use the data to examine trends in cancer and specific types of cancer in particular regions or jurisdictions to enhance the understanding of cancer. The MCR will continue its efforts to advance the goal of a healthier Maryland.