



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 – Joshua M. Sharfstein, M.D., Secretary

October 8, 2013

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 HG §18-204(b)(6)
2013 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. Marie L. Grant, Director of Governmental Affairs, at 410-767-6481.

Sincerely,

Joshua M. Sharfstein, M.D.
Secretary

Enclosure

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Maryland Department of Health
and Mental Hygiene

ANNUAL REPORT

Maryland Cancer Registry

HG §18-204(b)(6)

Fiscal Year 2013

Martin O'Malley,
Governor

Anthony G. Brown,
Lieutenant Governor

Joshua M. Sharfstein, MD
Secretary

OCTOBER 2013



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1. INTRODUCTION

This report required by HG §18-204(b)(6) contains the Maryland Cancer Registry's Annual Fiscal Year Report for the period July 1, 2012 through June 30, 2013 (FY 13). 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 1992, 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.

During FY 13, the MCR released its Request for Proposals (RFP) for vendor selection for the database management and quality assurance of the Registry. Westat was selected through the state procurement process as the vendor for the Maryland Cancer Registry for the next 5 years, July 1, 2013 through June 30, 2018.

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. FISCAL YEAR 2013 ACTIVITIES

3.1. ADMINISTRATIVE ACTIVITIES

During FY 13, 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 FY13, 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. A new Chairperson for the Cancer Registry Advisory Committee was appointed: Lisa Gallicchio, Ph.D., a cancer epidemiologist at the Mercy Medical Center Prevention and Research Center and member of the Maryland State Council on Cancer Control.

3.1.2. Administrative Activities

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 data requests from the public, facilities who report, local health departments, researchers, and the media. Administrative highlights during FY13 included:

1. *National Program of Cancer Registries*
The National Program of Cancer Registries (NPCR) has certified that the MCR data has met the National Data Quality and Completeness Program standards, the highest standards set by this federal program.
2. *NAACCR Gold Certification*
The MCR submitted 2010 incidence data for evaluation and confidential feedback from the North American Association of Central Cancer Registries (NAACCR) and received “Gold” certification in these areas: completeness of case ascertainment, completeness of information recorded, percentage of “death certificate only” cases, duplicate primary cases, passing edits, and

timeliness. The MCR also submitted 1996-2010 data that will be included in the publication “Cancer in North America.”

3. *Social Security Death Index and National Death Index Linkage*

The MCR linked the Maryland data with the Social Security Death Index and the National Death Index during FY13 to obtain more complete death information on cases in the MCR. The MCR is also participating with the Kentucky Cancer Registry and other Appalachian state registries on a study of cancer in Appalachia. Two MCR epidemiologists attended trainings at the Kentucky Cancer Registry to learn to develop and complete life tables.

4. *Enforcing Stronger Passwords*

During FY13, the MCR transitioned to enforcing stronger passwords for facilities reporting data electronically to the MCR. On April 1, 2013, all passwords were changed and the development of stronger passcodes was required.

5. *Colorectal Cancer Disparities in Maryland Published by the Center for Cancer Prevention and Control*

Data were obtained from the MCR for analysis and published in “Colorectal Cancer Disparities in Maryland.” Highlights from the report included:

- Incidence and mortality rates for colorectal cancer (CRC) have decreased in Maryland in every jurisdiction between the periods 1999—2003 and 2004—2008.
- Age groups 35-64: Black males have the highest age specific rates; black females and white males have similar age-specific rates; white females have the lowest rates of these four race-gender groups.
- Between 2002 and 2008: The percent of unstaged cases has decreased; the percent of localized cases has risen; black Marylanders continue to have a higher percent of their CRC diagnosed at the distant stage than white Marylanders.

6. *Linkage with Breast and Cervical Cancer Program Database*

During FY13, the MCR linked the MCR database with the Breast and Cervical Cancer Program (BCCP) database of cancer cases diagnosed from 2004-2009. There were 13 cases that were non-matches. The MCR will link with the BCCP database annually to assist in case finding and as part of requirements of the Centers for Disease Control and Prevention’s (CDC) BCCP funding.

7. *NAACCR Conversion of MCR database from v12.2 to v13*

The MCR began the process of converting its data and programs from the NAACCR version 12.2 to 13 format during FY13. The changes to the database were minor, involving geographic location and birth country codes.

8. *MCR Hosts Training Webinars*
During FY13, the MCR hosted a series of online seminars (Webinars) for abstracting cancer incidence and treatment data by hospital tumor registrars and for cancer surveillance data collection by central cancer registries. Each webinar session was presented by NAACCR. Certified Tumor Registrars (CTRs) attending the sessions received Continuing Education Units.
9. *National Cancer Registrars Week (April 8-12, 2013)*
During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland Certified Tumor Registrars (CTRs) who submit quarterly data to the MCR. A Governor's Proclamation was issued recognizing CTRs and a letter was sent to each reporter expressing appreciation for their dedication.
10. *Motor Vehicle Administration (MVA) Unknown Race Lookup*
To identify the race of people reported to the MCR with Unknown race, the MCR staff resolved over 1,800 "race unknowns" by looking up the names in the MVA database.

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

Westat performs QA/DM activities for the MCR. Activities conducted by Westat during FY13 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 FY 13:

- Completed data submissions to NAACCR and NPCR;
- Assured data quality:
 - Received and processed reports to the MCR (see Table 3.4.1.).
 - Completed conversion of the MCR database from NAACCR version 12.1 to 12.2.
 - Completed de-duplication by Social Security Number, First and Last Name, and Date of Birth for years 2002-2009 (over 2,300 possible duplicates).
 - Continued to perform internal QA including: peer-to-peer oversight; supervision by director; and monthly, quarterly, and annual management reports to review trends and identify anomalies in data.
 - Developed, installed, and maintained the MCR edits metafile, which consists of the consolidated tumor edit set and the abstracts edit set.
 - Completed the latest derived Hispanic and Asian/Pacific Islander ethnicity algorithm run and wrote back the results to the master file for incidence year 2010.
 - Completed seven audits of hospital reporting facilities with feedback reports to the facilities.

3.2. ROUTINE DATA PROCESSING

3.2.1. MCR Facility Audits

Westat conducted seven facility audits between July 2012 and June 2013. Findings were presented as a component of the reconciliation records prepared for reporting hospitals. Each facility submitted a list of potential reportable cancer cases to Westat. Westat performed a review of each case to determine: 1) if the cancer case should have been reported, and 2) if so, whether the case had been reported. In addition, Westat re-abstracted a number of cases to determine if the coding provided by the facility was correct. The audits assist the MCR in determining the quality of the data submitted by the facilities and in directing the type of training the MCR provides to facilities.

3.2.2. Death Case Finding and Updating Death Information

Westat continued to improve the death case finding procedures and the Westat follow-back tracking tool. During FY13, Westat developed a SAS-based algorithm for conducting the tumor comparison step of the death case finding process. Westat staff reviewed death certificates to confirm case reportability and to estimate the date of diagnosis for tumors not reported by other sources. Additionally, the MCR identifies people with cancer reported to the registry and matches them to the Vital Statistics Administration deaths in order to identify cause of death and date of death; Westat then writes that information to the MCR database.

3.2.3. Case Consolidation

Westat received 52,327 facility abstracts in FY13 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 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 12 states and the District of Columbia.

3.2.5. Technical Assistance and Training

Westat maintained its dedicated Help Line to provide technical assistance to callers. During FY13, Westat provided technical help and abstracting/coding expertise to Maryland cancer case abstractors and reporters. Westat also provided training during the Tumor Registrars Association of Maryland (TRAM) meetings.

3.3. ACTIVITIES TO IMPROVE MCR-QA/DM

Westat made recommendations to DHMH for improving the MCR QA/DM system. These recommendations include:

- Convert the MCR database to NAACCR version 13.

- Install the eMaRC application for processing physician reports as a result of meaningful use stage 2.
- Review systematically the cases by reporting source(s) to identify where cases are not being identified for submission and reporting to the MCR.
- Update edit sets to version 13A.
- Maintain global edits to update database on a regular basis.
- Develop WebEx training session for non-hospital reporters to utilize when additional training is necessary.
- Develop an e-newsletter as an avenue for educating reporters on changes regarding central cancer registry requirements.
- Develop a system to identify and alert the data acquisition manager on gaps in the accession numbers as a tool to improve case completeness.
- Upgrade the WesEdits application to the requirements of the NAACCR v13 data standards.

The DHMH agrees with the recommendations and has had discussions with Westat regarding Westat’s implementation of these recommendations for improvement. Implementation by Westat is expected to be completed during FY14.

3.3.1. Data Quality and Completeness

Westat staff provided several presentations and one-on-one instruction for new users of Web Plus, the online software for reporting cases of cancer to Westat. The instruction included review of how to find cancer cases that require a report and how to “abstract” the record, instruction in online Web Plus, and follow-up inquiries. One-on-one instruction is needed to improve the quality of data submitted.

3.3.2. Other Activities

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

- 2012 CDC National Cancer Conference: Uniting Systems, Policy and Practice in Cancer Prevention and Control;
- The NAACCR annual conference; and
- The National Cancer Registrar Association annual conference.

3.4. TUMOR ABSTRACTS RECEIVED DURING FY13 AND NUMBER OF BRAIN/CNS AND MYELODYSPLASIA CASES IN THE MCR

Table 3.4.1. shows the number of tumor abstracts received in FY13 from all facilities reporting, by year of tumor diagnosis and state of residence at diagnosis. Tumor abstracts are reportable to the MCR within 6 months of the date of diagnosis and are reported to the MCR quarterly.

During FY13, 52,327 tumors were reported from in-state and out of state reporters. Tumors diagnosed predominantly in calendar year 2011 were reported (35,847); however, during FY13 some abstracts were received on tumors diagnosed in 2010 and before (11,119), and in 2012 or 2013 (5,361).

Two tables, Table 3.4.2. and Table 3.4.3., present data from the MCR, by year of diagnosis, on conditions of special interest: benign and borderline malignant brain and central nervous system tumors, and malignant myelodysplastic syndrome tumors.

Table 3.4.2. presents the number of benign and borderline malignant brain and central nervous system tumors, by year of diagnosis that have been reported and entered into the MCR as of June 30, 2013. As noted in the footnote of the table, on June 30, 2013, reporting and processing of cases diagnosed in 2011 and 2012 is not yet final, so the total numbers are lower than the finalized case numbers diagnosed in prior years.

Table 3.4.3. presents the number of malignant myelodysplastic syndrome tumors that have been reported in Maryland residents by year of diagnosis and entered into the MCR as of June 30, 2013. As noted in the footnote of the table, reporting and processing of cases diagnosed in 2011 and 2012 is not yet final on June 30, 2013, so the total numbers for those two years are lower than the finalized case numbers diagnosed in 2010 and before.

**Table 3.4.1. Number of Tumor Abstracts Received in FY13
by Year of Tumor Diagnosis and State of Residence at Diagnosis**

Received between July 1, 2012 to June 30, 2013

Year of Tumor Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2013	1	0	1
2012	4,485	875	5,360
2011	31,546	4,301	35,847
2010	7,935	872	8,807
2009	841	509	1350
2008	220	63	283
2007	147	59	206
2006	156	28	184
2005	79	11	90
2004	37	5	42
2003	33	9	42
2002	14	4	18
2001	19	3	22
2000	17	7	24
1999	8	2	10
1998	6	2	8
1997	5	0	5
1996	3	1	4
1995	5	1	6
1994	1	0	1
1993	0	0	0
1992	0	0	0
1991	1	1	2
1990	3	1	4
1989	1	0	1
1988	2	0	2
1987	1	0	1
1986	1	1	2
1985	0	0	0
Before 1985	3	2	5
Total*	45,570	6,757	52,327

Data Source: Westat from the MCR abstract database as of June 30, 2013

* 24 Abstracts missing (Diagnosis Date or Year of Diagnosis)

Table does not include voided abstracts that are not included in the MCR database because they are duplicate reports or are determined to be non-reportable conditions.

Table 3.4.2.

Total Number of Benign and Borderline Brain and Central Nervous System Tumors* in the Maryland Cancer Registry Residing in Maryland or Other States at Diagnosis as of June 30, 2013 by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)**

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2012 [^]	64	25
2011 [^]	645	71
2010	950	86
2009	830	117
2008	820	90
2007	731	84
2006	663	62
2005	632	67
2004	604	67
2003	498	63
2002	398	41
2001	220	18
2000	51	5
Before 2000	741	88
Total***	7,847	884

*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).

**Data Source: Westat from the MCR consolidated database of finalized cases as of June 30, 2013.

***Two cases with missing year of diagnosis and not included.

[^] As of June 30, 2013, the MCR is still completing its data for submission for the 2011 incidence year and has just begun gathering cases diagnosed in 2012, therefore the data are incomplete; see text on page 10.

Table 3.4.3.

**Total Number of Malignant Myelodysplastic Syndrome* Tumors
Diagnosed in Maryland Residents as of June 30, 2013**
by Year of Diagnosis**

Year of Diagnosis	Number of Cases
2012[^]	11
2011[^]	148
2010	201
2009	180
2008	182
2007	146
2006	111
2005	108
2004	96
2003	107
2002	117
2001	81
2000	17
1999	6
Before 1999	11
Total	1,522

**Data Source: Westat from the MCR consolidated database as of June 30, 2013.

*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

[^] As of June 30, 2013, the MCR is still completing its data for submission for the 2011 incidence year and has just begun gathering cases diagnosed in 2012, therefore the data are incomplete; see text on page 10.

3.5. DATA REQUESTS

Table 3.5. shows the number of requests for data that the MCR received and processed in FY13.

Table 3.5.

Data Requests Requiring MCR Analysis That Were Received and Processed in FY13

Type of Request	Number of Requests Pending as of July 1, 2012 (start of FY13)	Number of Requests Received FY13	Number of Requests Processed by June 30, 2013 (end of FY13)
Research/Special Studies	2	11	12
Reporting Facilities Requesting their own Information	0	3	3
Health Services Planning	2	15	15
Public Request for Information	0	12	12
DHMH Use	0	2	2
Totals	4	43	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 United States. 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.