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

September 29, 2014

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)
2014 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. Allison Taylor, Director of Governmental Affairs, at 410-767-6481.

Sincerely,

Joshua M. Sharfstein, M.D.
Secretary

Enclosure

cc: Allison Taylor, Director, Office of Governmental Affairs
Laura Herrera, Deputy Secretary, Public Health Services
Michelle Spencer, Director, Prevention and Health Promotion Administration
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Maryland Department of Health
and Mental Hygiene

ANNUAL REPORT
Maryland Cancer Registry

Health-General § 18-204(b)(6)
Fiscal Year 2014

Martin O'Malley
Governor

Anthony G. Brown
Lieutenant Governor

Joshua M. Sharfstein, MD
Secretary

OCTOBER 2014

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The Maryland Cancer Registry is supported by Maryland General Funds, the Maryland Cigarette Restitution Fund, and by contract number U55/CCU321894 from the Centers for Disease Control and Prevention, National Program of Central Registries.

1. INTRODUCTION

This report required by Section 18-204(b)(6) of the Health-General Article contains the Maryland Cancer Registry's Annual Fiscal Year Report for the period July 1, 2013 through June 30, 2014 (FY 14). 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 MCR 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.

Sections 18-203 and 18-204 of the Health – General Article, enacted in 1992, require 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 amended in 2000 to require the reporting of benign brain and central nervous system (CNS) tumors to the MCR starting October 1, 2001.

DHMH subcontracts the database collection, data management, and quality assurance activities of the MCR to an outside entity. Westat, Incorporated (Westat), assumed responsibility for providing quality assurance and database management services to the MCR on February 1, 2008. Westat was selected through the state procurement process as the vendor for the Maryland Cancer Registry for the period of five years, July 1, 2013 through June 30, 2018, and continues to provide quality assurance and database management services to the MCR.

2. MCR MISSION STATEMENT

The Maryland Cancer Registry Advisory Committee (CRAC) adopted the following mission statements for the 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 status 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 2014 ACTIVITIES

3.1. ADMINISTRATIVE ACTIVITIES

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)

The CRAC met three 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.

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 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 FY 14 included:

1. *Staff Changes*:

   Medical Director
   Dr. Diane Dwyer, Medical Director for the Center for Cancer Prevention and Control (CCPC), retired. In her role as the Medical Director, Dr. Dwyer provided oversight to the Maryland Cancer Registry.

   Epidemiology Director
   Shalini Parekh, MPH, was appointed Director of Epidemiology. In the past, she served as an Epidemiologist and Program Manager at the Centers for Disease Control and Prevention (CDC), National Cancer Institute, and the American Psychological Association, and has substantial background in cancer epidemiology and health disparities reduction. Ms. Parekh now provides oversight for the Maryland Cancer Registry.

2. *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.

3. *North American Association of Central Cancer Registries Gold Certification:*
   The MCR submitted 2011 incidence data for evaluation and confidential feedback from the North American Association of Central Cancer Registries (NAACCR) and received "Gold" certification. The certification includes review of the following areas: completeness of case ascertainment, completeness of information recorded, percentage of "death certificate only" cases, duplicate primary cases, passing edits, and timeliness.

4. *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 FY 14 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.

5. *Linkage with Breast and Cervical Cancer Program Database:*
   The MCR linked the MCR database with the CCPC's Breast and Cervical Cancer Program (BCCP) database of cancer cases diagnosed from 2004-2010, resulting in a 100% case match across both files. The MCR links with the BCCP database annually to assist in case finding, and as a requirement of CDC BCCP funding.

6. *NAACCR Conversion of MCR database from version 12.2 to 13, and 13 to 14:*
   The MCR converted its data and programs from NAACCR version 12.2 to version 13 in September 2013 and to version 14 in June 2014. The conversion process went smoothly. The changes included a change in the place of birth field coding and many internal edit changes.

7. *MCR Hosts Training Webinars*:
   During FY 14, the MCR hosted a series of NAACCR-presented online seminars (webinars) at DHMH headquarters on topics that included abstracting cancer incidence and treatment data by hospital tumor registrars, and cancer surveillance data collection by central cancer registries. Certified Tumor Registrars (CTRs) attending the sessions received Continuing Education Units.

8. *National Cancer Registrars Week (April 7–11, 2014):*
   During National Cancer Registrars Week, through a Governor's Proclamation, the MCR recognized the dedicated work of Maryland CTRs who submit quarterly data to the MCR. Additionally, the MCR Program Manager sent a letter to each CTR expressing appreciation for their dedication and service.

9. *MCR Electronic Update:*
   The MCR developed a quarterly Electronic Update that was sent to all reporting facilities and included information on coding issues, upcoming NAACCR webinars, updated information from the Tumor Registrars Association, and updates from the Central Registry (Westat).

10. *CONCORD Study:*

The MCR accepted an invitation to join and provided data to the CONCORD 2 Study, a global surveillance of cancer survival that provides survival rates by cancer types in Europe, the United States, and Canada.

11. *Meaningful Use Stage 2 Update*:

The MCR worked with the DHMH Meaningful Use Group, which supports the implementation of the Maryland Electronic Health Records (EHR) Incentive Program. In June 2013, DHMH began accepting electronic transmissions for Stage 2 Meaningful Use, which includes physicians that diagnose and treat cancer. DHMH is now registering participating physicians.

12. *Department of Motor Vehicle Unknown Race Look-Up:*

To identify the race of individuals reported with Unknown Race in the MCR, the MCR staff searched over 1,480 names in the Motor Vehicle Administration database for this missing race information.

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

Westat performed QA/DM activities for the MCR including: accepting 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 14:

- 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 12.2 to 13, and version 13 to 14.
  - Completed deduplication by social security number, first and last name, and date of birth for years 2002-2011.
  - Continued to perform internal QA including: peer-to-peer oversight; director supervision; and the production of 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 2011.
  - Completed six facility audits of hospital reporting facilities with feedback reports to the facilities.

3.2. ROUTINE DATA PROCESSING

3.2.1. MCR Facility Audits

Westat conducted a total of six facility audits to determine the quality of data submitted by reporting facilities, and to direct the type of training the MCR provides to facilities. For each audit, the selected facility was required to submit a list of potential reportable cancer cases to Westat, who then performed a review of each case to determine: 1) if the cancer case should have been reported, and if so, 2) whether the case had actually been reported. In addition, Westat re-abstracted a number of cases to determine if the coding provided by the facility was correct. Findings were presented to the reporting facility as a component of the reconciliation records prepared for reporting hospitals.

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. Westat continued to apply a SAS-based algorithm for conducting the tumor comparison step of the death case finding process. Westat staff also reviewed death certificate data to confirm case reportability and estimate the date of diagnosis for tumors not reported by other sources. Additionally, the MCR identifies people with cancer reported to the MCR and matches them to the Vital Statistics Administration deaths in order to identify cause of death and date of death; Westat then writes the information in the MCR database.

3.2.3. Case Consolidation

Westat received 34,161 facility abstracts in FY 14 and processed them into consolidated, newly diagnosed tumor records (see Table 3.4.1.). There were fewer abstracts processed during FY 14 compared to previous years, partially due to a delay in the delivery of essential Registry Plus programs from CDC, and updates to facilitate NAACCR conversions to the MCR database from version 12 to version 13.

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 and abstracting/coding expertise to Maryland cancer case abstractors and reporters. Westat also provided training during Tumor Registrars Association of Maryland meetings.

3.3. ACTIVITIES TO IMPROVE MCR QA/DM

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

- Install the eMaRC application for processing physician reports resulting from Meaningful Use Stage 2.
- Develop new improved automated edits to verify the MCR database on a regular basis.
- Develop and automate the production of a report for Maryland cancer case reporters.
- Develop a system to identify and alert the data acquisition manager on gaps in the accession numbers as a tool to improve case completeness.
- Restructure the hospital audits:
  - To implement blind re-abstracting by a Westat auditor using a copy of the medical record provided by the facility via access to EHRs or hard copy.
  - To ensure cases are randomly selected for re-abstracting rather than focusing on more common sites.
  - To focus re-abstraction on limited data items rather than a full case review.
- Mandate that case-finding audits based on disease indexes become a routine procedure for facilities licensed by the DHMH Office of Health Care Quality.
- Undertake sustained efforts to obtain cancer reports from federal facilities, in particular from those that support the American College of Surgeons Commission on Cancer accredited registries such as the NCI Clinical Centre, the Baltimore Veterans Administration Medical Center, and the Department of Defense Central Cancer Registry Program.

DHMH plans to continue discussions with Westat regarding the implementation of the above recommendations for improvement. Implementation by Westat is expected to be completed during FY 15.

3.3.1. Data Quality and Completeness

Westat staff continued to provide presentations and one-on-one training to new users of Web Plus, the online software used to report cases of cancer to Westat. The trainings include instructions on identifying reportable cancer cases, "abstracting" case records, utilizing Web Plus, and handling 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:

- American College of Surgeons Commission on Cancer conference;
- The NAACCR annual conference;
- The National Cancer Registrars Association annual conference; and
- CDC Reverse Site Visit and Technical Advisory meeting.

3.4. TUMOR ABSTRACTS RECEIVED DURING FY 14 AND NUMBER OF BRAIN/CNS AND MYELODYSPLASIA CASES IN THE MCR

Table 3.4.1. displays the number of tumor abstracts received in FY 14 from all reporting facilities by year of tumor diagnosis and state of residence at diagnosis. Tumor abstracts are reported quarterly to the MCR within 6 months of the date of diagnosis.

During FY 14, 34,161 tumors were reported from in-state and out-of-state reporters. Tumors diagnosed predominantly in calendar year 2012 were reported (22,349); however, during FY 14 some abstracts were received on tumors diagnosed in calendar year 2011 and before (5,640), and in calendar years 2013 and 2014 (6,179).

Tables 3.4.2. and 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 were reported and entered into the MCR as of June 30, 2014. As noted in the table footnote, as of June 30, 2013, reporting and processing of cases diagnosed in 2012 and 2013 have not been finalized, so 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, 2014. As noted in the table footnote, as of June 30, 2013, reporting and processing of cases diagnosed in 2012 and 2013 has not been finalized, so the total numbers for those two years are lower than the finalized case numbers diagnosed in prior years.

Table 3.4.1. Number of Tumor Abstracts Received in FY 14 by the Year of Diagnosis and State of Residence at Diagnosis

Received July 1, 2013 to June 30, 2014

Year of Tumor Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2014	29	3	**32**
2013	5,466	681	**6,147**
2012	19,538	2,811	**22,349**
2011	3,720	509	**4,229**
2010	726	87	**813**
2009	131	12	**143**
2008	133	11	**144**
2007	66	8	**74**
2006	86	3	**89**
2005	35	2	**37**
2004	16	1	**17**
2003	13	1	**14**
2002	15	0	**15**
2001	13	0	**13**
2000	8	2	**10**
1999	5	0	**5**
1998	4	0	**4**
1997	2	0	**2**
1996	4	1	**5**
1995	2	0	**2**
1994	1	0	**1**
1993	1	0	**1**
1992	4	0	**4**
1991	0	0	**0**
1990	2	1	**3**
1989	4	0	**4**
1988	0	0	**0**
1987	0	0	**0**
1986	0	0	**0**
1985	3	1	**4**
Before 1985	7	0	**7**
TOTAL:	30,034	4,134	**34,161**

Data Source: Westat from the MCR abstract database as of June 30, 2014
Table does not include voided abstracts not included in the MCR database because they were duplicates or were 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 at Diagnosis as of June 30, 2014 by the Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)**

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2013^	129	8
2012^	743	68
2011	821	86
2010	994	85
2009	846	118
2008	837	92
2007	736	84
2006	663	62
2005	638	67
2004	610	68
2003	499	62
2002	398	41
2001	220	18
2000	51	5
Before 2000	741	88
Total	**8,926**	**952**

*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, 2014

^ As of June 30, 2014, the MCR is still completing its data for submission for the 2012 incidence year and has just begun gathering cases diagnosed in 2013, therefore the data are incomplete.

Table 3.4.3. Total Number of Malignant Myelodysplastic Syndrome* Tumors in the Maryland Cancer Registry Diagnosed in Maryland Residents as of June 30, 2014 by the Year of Diagnosis **

Year of Diagnosis	Number of Cases
2013^	32
2012^	139
2011	212
2010	209
2009	187
2008	186
2007	148
2006	114
2005	109
2004	97
2003	109
2002	117
2001	81
2000	18
1999	6
Before 1999	11
Total	**1775**

**Data Source: Westat from the MCR consolidated database of finalized cases as of June 30, 2014
*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-Mylodysplastic Syndrome with 5q deletion syndrome
- 9987-Therapy-related myelodysplastic syndrome, not otherwise specified
- 9989-Myleodysplastic syndrome, not otherwise specified

^ As of June 30, 2014, the MCR is still completing its data for submission for the 2012 incidence year and has just begun gathering cases diagnosed in 2013, therefore the data are incomplete; see text on page 9.

3.5. DATA REQUESTS

Table 3.5. shows the number of requests for data that the MCR received and processed in FY 14.

Table 3.5. Data Requests Requiring MCR Analysis
Received and Processed in FY 14

Type of Request	Number of Requests Pending as of July 1, 2013 (start of FY 14)	Number of Request Received in FY 14	Number of Requests Processed by June 30, 2014 (end of FY 14)
Research/Special Studies	8	8	12
Reporting Facilities Requesting their own Information	0	5	4
Health Services Planning	2	18	17
Public Request for Information	1	3	3
DHMH Use	0	7	6
Total	11	41	42

4. CONCLUSION

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