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

OCT 0 9 2012

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)
2012 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

cc: Marie L. Grant, J.D.
Frances B. Phillips, R.N., M.H.A.
Donna Gugel, M.H.S.
Kelly Sage, M.S.
Courtney Lewis, M.P.H.
Ms. Sarah Albert, MSAR #5544

Maryland Department of Health
and Mental Hygiene

ANNUAL REPORT
Maryland Cancer Registry

Fiscal Year 2012

Martin O'Malley
Governor

Anthony G. Brown
Lieutenant Governor

Joshua M. Sharfstein, MD
Secretary

OCTOBER 2012

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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, 2011 through June 30, 2012 (FY12). 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 amended again later 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 FY12, the MCR began preparations to release a Request for Proposals (RFP) for vendor selection for the database management and quality assurance of the Registry.

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 2012 ACTIVITIES

3.1. ADMINISTRATIVE ACTIVITIES

During FY12, 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 FY12, 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.

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 the Institutional Review Board (IRB) submission, and analyzes data for DHMH program planning and for request fulfillment. Administrative highlights from FY12 include:

1. *NAACCR Silver Certification*
   The MCR submitted 2009 incidence data for evaluation and confidential feedback from the North American Association of Central Cancer Registries (NAACCR) and received "Silver" 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 1996-2009 data to be included in the publication, "Cancer in North America". This data also passed all required EDITS.

2. *Social Security Death Index and National Death Index Linkage*
   The MCR matched its registry data with the Social Security Death Index. Following that, in FY12 the MCR sent two epidemiologists to the Kentucky Cancer Registry for training in the use of the National Death Index linkage. The MCR is working with the Kentucky Registry along with other Appalachian state registries on a study of cancer in Appalachia.

3. *Maryland Cancer Collaborative Disparities Committee Update*
   The Maryland Cancer Collaborative Disparities Committee set the goal of reducing cancer disparities in Maryland. The Committee listed an objective

to conduct an assessment and to create and implement a plan to improve data systems that better identify and track cancer disparities defined by race, ethnicity, language, disabilities, sexual orientation, and other factors. To assist in accomplishing this, the Committee requested a presentation demonstrating the type of data collected by the Maryland Cancer Registry, the Behavioral Risk Factor Surveillance System and the Vital Statistics Administration. During FY12, the MCR gave a presentation about how data are collected by the Registry.

4. *MCR Data Linkage with Indian Health Service*
   The Indian Health Service (IHS), an agency within the Department of Health and Human Services, is responsible for providing federal health services to American Indians and Alaska Natives. The IHS is the principal federal health care provider and health advocate for American Indians, and its goal is to raise the health status of American Indians to the highest possible level. To assist with the achievement of this goal, the IHS requires data from the MCR be linked every 5 years; the MCR completed this linkage with the IHS data during FY12.

5. *MCR Data Submission to International Agency For Research on Cancer*
   During FY12, the MCR submitted data to the International Agency for Research on Cancer to be included in the report "Cancer on Five Continents".

6. *United States Cancer Statistics Publications (Pending)*
   In FY12 the MCR data for incidence years 1996 through 2009 was submitted to the National Program of Cancer Registries (NPCR) and will be included in the United States Cancer Statistics Publication.

7. *NAACCR Conversion version 12.1 Update*
   The MCR completed its data conversion to the NAACCR version 12.1 format during FY12. The upgrades involved three programs used by the MCR:

   Web Plus – Used to bring data into the system
   Prep Plus – Used to edit and improve quality and consistency of data
   CRS Plus – Used to consolidate information received from different sources.

8. *MCR Hosts Training Webinars*
   During FY12, the MCR hosted a series of online seminars (webinars). Topics covered were 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 NAACCR. Certified Tumor Registrars (CTRs) who attended these sessions received Continuing Education Units (CEUs). The MCR also hosted a series of

webinars from the National Cancer Registrars Association (NCRA) on the change from International Classification of Disease (ICD)-09-Clinical Modification (CM) coding to ICD-10-CM coding.

9. *National Cancer Registrars Week (April 9-13, 2012)*
During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland Certified Tumor Registrars (CTRs) who submit quarterly data to the Registry. 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 with Unknown race, the MCR staff looked up names in the MVA database. Over 3,400 race unknowns were resolved through this process.

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

Westat performs QA/DM activities for the MCR. Activities conducted by Westat during FY12 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 FY12:

- Completed data submissions to NAACCR and NPCR;
- Assured data quality:
    - Completed conversion of the MCR database to NAACCR version 12.1
    - 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 develop 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 edits set and the abstracts edits set;
    - Completed the latest derived Hispanic and Asian/Pacific Islander ethnicity algorithm run and write-back to the master file for the entire database to the incidence year 2010.

3.2. ROUTINE DATA PROCESSING

3.2.1. MCR Facility Audits

Westat conducted seven facility audits between July 2011 and June 2012. 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. These 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 Matching and Clearance

Westat continued to improve death clearance procedures and the follow-back tracking tool. During FY12, Westat developed a SAS-based algorithm for conducting the tumor comparison step of the death clearance process. Westat staff reviewed all death certificates to confirm case reportability and to estimate the date of diagnosis.

3.2.3. Case Consolidation

Due to the conversion of the MCR database from NAACCR version 12.0 to NAACCR version 12.1, the MCR did not complete the 2011 and 2012 abstract processing in FY12. The MCR is processing those abstracts into consolidated cases in FY13.

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 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 FY12, 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-QUALITY ASSURANCE/DATA MANAGEMENT

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

- Convert the MCR database to NAACCR version 13.
- Install the eMaRC application for processing HL7 pathology abstracts.
- Systematically review cases by reporting source(s) to identify where cases are not being identified for submission and reported to the MCR.
- Update current edits to the version 13.
- Maintain global edits to update database on a regular basis.
- Develop and automate the production of "Report to Reporters".
- Increase the utilization of electronic means for communicating with Maryland reporters regarding the facility audit process and feedback.
- Develop a WebEx training session for non-hospital reporters to utilize when additional training is necessary.

The DHMH agrees with the recommendations and has had discussions with Westat regarding implementation. Implementation of these recommendations is expected to be completed during FY13.

3.3.1. Data Quality and Completeness

Several presentations about the need for submission of quality data were made to those who report data to the MCR. These presentations focused on coding and submitting correct text. These two important criteria enable the MCR to: 1) verify coded data and 2) ensure accurate address information so that geocoding can be completed correctly.

3.3.2. Other Activities

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

- The NAACCR annual conference; and
- The National Cancer Registrar Association annual conference.

3.4. ABSTRACTS REPORTED AND CASES ADDED DURING FY12

Data presented in table 3.4.1. show the number of tumor ***abstracts*** reported in FY12 (July 1, 2011—June 30, 2012) by year of diagnosis and state of residence at diagnosis. A total of 45,738 abstract reports were received in FY12 and processed into the MCR consolidated tumor case reports.

Table 3.4.1. Number of Tumor Abstract Reports Received in FY12 by Year of Diagnosis and State of Residence at Diagnosis

Year of Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2012	94	19	113
2011	3,640	648	4,288
2010	30,237	4,755	34,992
2009	3,470	762	4,232
2008	1,168	75	1,243
2007	364	48	412
2006	133	12	145
2005	87	11	98
2004	49	6	55
2003	22	2	24
2002	10	4	14
2001	18	1	19
2000	14	1	15
1999	13	0	13
1998	16	1	17
1997	9	0	9
1996	5	0	5
1995	4	0	4
1994	5	0	5
1993	7	0	7
1992	2	0	2
1991	4	0	4
1990	2	0	2
1989	2	0	2
1988	1	0	1
1987	1	0	1
1986	4	0	4
1985	0	0	0
Before 1985	12	0	12
Total	39,393	6,345	45,738

Data Source: Westat (MCR Registry PRDV12 database, abstract table as of 07/25/2012)
* 227 Abstracts missing (Diagnosis Date or Year of Diagnosis)
* Report does not include voided Abstracts.

Table 3.4.2. presents the number of benign brain and central nervous system tumor cases in the MCR by year of diagnosis as of June 30, 2012.

Table 3.4.2.

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

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2011***	53	10
2010	832	68
2009	797	106
2008	808	89
2007	721	84
2006	656	61
2005	629	67
2004	603	66
2003	499	64
2002	398	42
2001	220	18
2000	51	5
Before 2000	741	88
Total	**7,008**	**768**

Data Source: Westat (MCR Registry PRDV12 database, medical sum table as of 07/25/2012)
* 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)
** One case is omitted that was missing year of diagnosis.
*** 2011 data are incomplete

Table 3.4.3. presents the number of Myelodysplasic Syndrome tumor cases in the MCR by year of diagnosis as of July 1, 2012.

Table 3.4.3.

Total Number of Malignant Myelodysplastic Syndrome* Cases in Maryland as Reported to the Maryland Cancer Registry by Year of Diagnosis

Year of Diagnosis	Number of Reported Cases
2011 **	34
2010	135
2009	172
2008	172
2007	138
2006	105
2005	105
2004	95
2003	106
2002	117
2001	81
2000	16
1999	6
before 1999	11
Total	**1,293**

Data Source: Westat. (MCR Registry PRDV12 database as of 08/08/12)
Three cases with missing year of diagnosis

*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 – Myelodysplastic syndrome, not otherwise specified

** 2011 Data are incomplete

3.5 DATA REQUESTS

Table 3.5. shows the number of requests for data that the MCR received and processed in FY12.

Table 3.5.

Data Requests Requiring MCR Analysis Received and Processed in FY12

Type of Request	Number of Requests Pending as of July 1, 2011 (start of FY12)	Number of Requests Received FY12	Number of Requests Processed by June 30, 2012 (end of FY12)
Research/Special Studies	2	16	16
Reporting Facilities Requesting their own Information	1	0	1
Health Services Planning	1	19	20
Public Request for Information	0	7	7
DHMH Use	0	3	3
Total	**4**	**45**	**47**

4. CONCLUSION

The MCR is a valuable resource for tracking and evaluation of State cancer statistics. The collection of this data also makes it possible to compare cancer rates in Maryland to those in other states. By collecting and analyzing MCR data, Maryland can better focus its cancer prevention and control efforts, and evaluate its cancer programs. The MCR will continue to collect, analyze, and disseminate data in its efforts to further the goal of a healthier Maryland.

The services and facilities of the Maryland State Department of Health and Mental Hygiene (DHMH) are operated on a non-discriminatory basis. This policy prohibits discrimination on the basis of race, color, sex, or national origin and applies to the provisions of employment and granting of advantages, privileges, and accommodations.

DHMH, in compliance with the Americans with Disabilities Act, ensures that qualified individuals with disabilities are given an opportunity to participate in and benefit from DHMH services, programs, benefits, and employment opportunities.