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

NOV 14 2011

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)
2011 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.
Patrick Dooley, M.A.
Frances B. Phillips, R.N., M.H.A.
Donna Gugel, M.H.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 2011

Martin O'Malley
Governor

Anthony G. Brown
Lieutenant Governor

Joshua M. Sharfstein, MD
Secretary

October 2011

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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 contains the Maryland Cancer Registry's Annual Fiscal Year Report for the period July 1, 2010 through June 30, 2011 (FY11).

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 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, Inc.), 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. FISCAL YEAR 2011 ACTIVITIES

3.1 ADMINISTRATIVE ACTIVITIES

During Fiscal Year 2011 (FY11), the MCR-Quality Assurance/Data Management (QA/DM) team at Westat, Inc. met with the 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 FY11, 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. Dr. Kathy Helzlsouer continued to serve as CRAC's Interim Chairperson.

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 fulfillment of requests. Administrative highlights during FY11 included:

1. *NAACCR Gold Certification*
   The MCR submitted 2008 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.

2. *United States Cancer Statistics Publication*
   During FY11, the MCR data for incidence years 1996 through 2008 met the requirements for inclusion in the United States Cancer Publication Standard for the National Program of Cancer Registries.

3. *CDC Audit*
   As a requirement for receiving Federal funds from the Centers for Disease Control and Prevention (CDC) National Program of Central Registries (NPCR), the MCR is audited by the CDC every five years on the MCR data and the processing of incoming data from

selected hospitals. The MCR prepared for the audit in FY10, and auditors began their work in Maryland in FY11. NPCR auditors concluded that:

- The MCR had an overall case completeness rate of 97.75 percent for all cancer sites audited and is to be commended for this excellent result.
- The MCR's overall data accuracy rate was 94.18 percent. Implementation of the recommended procedures in the audit report will help the MCR improve these results. In addition to reviewing basic abstracting principles, the MCR was strongly encouraged by the CDC to continue conducting visual editing to improve data quality in the MCR.

4. *CDC Site Visit*

The CDC NPCR conducted a site visit at the MCR on June 1 – 2, 2011. The primary purpose of the site visit was to increase the understanding of the MCR and to assess the MCR's progress towards meeting the CDC goals.

The MCR was commended by the CDC for:

- Collecting missing race information by using the Maryland Motor Vehicle Administration (MVA) database;
- Adding nursing homes, assisted living facilities, and hospice facilities to the MCR regulations for follow-up on missing cases found on death certificates;
- Starting follow-back to Dermatologists and Urologists who were the ordering physician when the tumor was initially reported by a laboratory only;
- Working with DHMH's Office of Vital Statistics to amend their regulations so that the MCR could release death data back to the reporting hospitals; and
- Working with the Geographic Information Unit of the DHMH Office of Information Technology to geocode all tumors with dates of diagnosis in the year 2000 or later; geocoding of cases back to 1992 is currently in process.

5. *MCR Regulations Update*

The MCR revised the cancer registry chapter in the Code of Maryland Regulations to reflect Federal requirements and changes in reportable conditions from national organizations. The regulations were promulgated on January 3, 2011 and are available on the MCR website (http://fha.maryland.gov/cancer/mcr_regs.cfm).

6. *MCR Hosts NAACCR Webinars*

During FY11, the MCR hosted a series of online 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 NAACCR. Certified Tumor Registrars (CTRs) who attended these sessions received Continuing Education Units (CEUs).

7. *National Cancer Registrars Week (April 11-15, 2011)*
   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.

8. *MCR Reporters' Teleconference*
   The MCR hosted one reporters' teleconference during FY11 for reporters from facilities (hospitals, freestanding ambulatory care facilities, radiation facilities, physicians' offices, and laboratories) who report data to the MCR. The purpose of the teleconference was 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.

9. *Social Security Death Index*
   During FY11, the MCR worked on developing procedures for matching its data with the Social Security Death Index database. This will allow the data to be more complete and is the first step required before matching with the National Death Index.

10. *MCR Cancer in Maryland 2002-2007 Incidence Report (Selected Tables)*
    During FY11, the MCR prepared the Cancer in Maryland 2002-2007 Incidence Report (selected tables).

11. *NAACCR Version 12.0 Update*
    The MCR completed its database conversion to the NAACCR version 12.0 format during FY11. The upgraded version 12.0 includes a significant increase in the number and complexity of data fields collected by the MCR.

12. *Department of Motor Vehicle Unknown Race Lookup*
    To identify the race of people reported with Unknown race, the MCR staff looked up over 3,700 names in the MVA database for missing race information.

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

Under their contract with the MCR, Westat, Inc. performs QA/DM activities. Activities conducted during FY11 included: collection of cancer reports from reporting facilities, case finding and quality assurance/quality control of data submitted, completion of data submission through incidence year 2009 to NAACCR and NPCR, and updating the database to NAACCR version 12.0.

Westat, Inc. accomplished the following during FY11:

- Completed data submissions through 2009 to NAACCR and NPCR;
- Assured data quality:
  - Completed conversion of the MCR database to NAACCR version 12.0;
  - Maintained global edit fixes for correcting over 5,500 records per year;
  - 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; and
- Completed the Hispanic algorithm run and write-back to the master file for the entire database to the year 2009.

3.2 ROUTINE DATA PROCESSING

3.2.1 MCR Facility Audits

Westat, Inc. completed facility audits on six reporting hospitals during FY11. Each facility submitted a list of potential reportable cancer cases to Westat, Inc. Westat, Inc. 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, Inc. also 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 Matching and Clearance

Westat, Inc. continued to improve the death clearance procedures and the follow-back tracking tool. Westat, Inc. developed a SAS-based algorithm for conducting the tumor comparison step of the death clearance process. Westat, Inc. also checked for tumors reported on the 2009 death certificates that were not reported on people already in the MCR database.

3.2.3 Case Consolidation

Because of the conversion of the MCR database from NAACCR version 11.3 to NAACCR version 12.0, the MCR did not complete the 2009 and 2010 abstract processing in FY11. The MCR is processing those abstracts into consolidated cases in FY12.

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 12 states and the District of Columbia.

3.2.5 Technical Assistance and Training

Westat, Inc. maintained its dedicated Help Line to provide technical assistance to callers. During FY11, Westat, Inc. provided technical help and abstracting/coding expertise to Maryland cancer case reporters. Westat, Inc. also provided training during the reporters' teleconference and the Tumor Registrars Association of Maryland (TRAM) meetings.

3.3 ACTIVITIES TO IMPROVE MCR-QUALITY ASSURANCE/DATA MANAGEMENT

Westat, Inc. made recommendations for improving the MCR-QA/DM system. The recommendations for FY12 included:

- Convert the MCR database to NAACCR version 12.3;
- Install the eMaRC application for processing HL7 pathology abstracts;
- Systematic review of case reporting sources to identify where primary case submissions are not being identified and reported to the MCR;
- Update edits to current NAACCR Version 12.3;
- Maintain global edits to update database on a regular basis;
- Continue to develop the tracking system to accommodate the requirements of the 2010 Death Clearance Manual; and
- Increased utilization of electronic means for communicating with Maryland reporters regarding the facility audit process and feedback.

The DHMH agrees with the recommendations and has had discussions with Westat, Inc. regarding implementation. Implementation of the Westat, Inc. recommendations is expected to be completed during FY12.

3.3.1 Data Quality and Completeness

Several presentations were made to reporters addressing the need for submission of quality data. These presentations focused on elements of coding, including the importance of accurate data entry for the MCR to verify coded data, and to geocode address information.

3.4 REPORTS AND CASES ADDED DURING FY11

Data presented in table 3.4.1 shows the number of tumor abstracts reported from all facilities reporting in FY11 by year of diagnosis and state of residence at diagnosis. Due to the change of the MCR database from NAACCR version 11.3 to NAACCR version 12.0, many abstracts had not been processed as of June 30, 2011. These abstracts are listed in the Diagnosis State 'To Be Determined' column in Table 3.4.1.

Because cases diagnosed in calendar year 2011 are not required to be submitted until September 2011, there are very few 2011 cases currently reflected in Table 3.4.1 and none in Table 3.4.2 or 3.4.3 for diagnosis year 2011.

Table 3.4.1

Number of Tumor Abstracts Submitted in FY11 by Year of Diagnosis
Reporting Period: July 1, 2010 to June 30, 2011

Diagnosis Year	Diagnosis State			
	Maryland	Non-Maryland	To Be Determined*	Total
2011	542	139	490	1,171
2010	2,063	208	23,590	25,861
2009	6,037	476	4,153	10,666
2008	4,429	38	1,347	5,814
2007	412	12	1,103	1,527
2006	173	4	139	316
2005	95	4	80	179
2004	54	3	73	130
2003	40	0	51	91
2002	55	1	42	98
2001	21	1	41	63
2000	18	3	47	68
1999	16	0	25	41
1998	19	3	14	36
1997	7	1	10	18
1996	9	0	10	19
1995	6	0	7	13
1994	5	2	20	27
1993	8	0	8	16
1992	8	0	6	14
1991	4	0	7	11
1990	3	0	2	5
1989	4	0	2	6
1988	2	0	2	4
1987	1	0	1	2
1986	2	0	1	3
1985	3	0	3	6
Before 1985	12	0	4	16
Unknown	23	0	0	23
Total	14,071	895	31,278	46,244

Data Source: Westat, Inc.

*To Be Determined includes unprocessed abstracts as of June 30, 2011 due to the conversion of the MCR database from NAACCR version 11.3 to NAACCR version 12.0.

Table 3.4.2

Table 3.4.2 represents the provisional number of newly diagnosed benign brain and central nervous system tumors in the MCR by year of diagnosis as of June 30, 2011.

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

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2010	10	1
2009	711	85
2008	778	88
2007	708	83
2006	654	61
2005	625	67
2004	600	66
2003	499	64
2002	398	42
2001	220	18
2000	51	5
Before 2000	741	88
Total*	**5,995**	**668**

*Numbers are not complete because all data have not been processed due to the conversion from NAACCR version 11.3 to NAACCR version 12.0 (see table 3.4.1).
**Data Source: MCR RegistryPRD database, Medicalsum table, as of 08/03/2011.
***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).

Table 3.4.3

Table 3.4.3 represents the number of newly diagnosed Myelodysplasic Syndrome tumors in the MCR, by year of diagnosis as of July 1, 2011.

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

Diagnosis Year	Diagnosis State	
	Maryland	Non-Maryland
2010	5	0
2009	123	12
2008	159	16
2007	142	22
2006	111	25
2005	104	15
2004	99	17
2003	107	27
2002	119	21
2001	83	18
2000	16	4
1999	4	0
before 1999	10	3
Total***	**1082**	**180**

**MCR consolidated data as of 07/13/2011.
*** Numbers are not complete because all data have not been processed due to the conversion from NAACCR version 11.3 to NAACCR version 12.0 (see table 3.4.1).

*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

3.5 DATA REQUESTS

Table 3.5 shows the number of requests for data that the MCR received and processed in FY11 that required analysis.

Table 3.5

Data Requests Requiring MCR Analysis
Received and Processed in FY11

Type of Request	Number of Prior Requests Pending at the Start of July 1, 2009 (FY10)	Number of Requests Received in FY11	Number of Requests Processed in FY11
Research/Special Studies	5	17	12
Reporting Facilities Requesting their own Information	0	2	1
Health Services Planning	1	18	17
Public Request for Information	10	17	16
Total	16	54	46

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, to evaluate its cancer control programs, and to contribute to national cancer surveillance. Outside researchers use this data to examine trends in cancer and specific types of cancer in particular geographic regions and to enhance the overall understanding of cancer. The MCR will continue its efforts to advance 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.