



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

November 14, 2008

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 -
2008 Legislative Report of the Maryland Cancer Registry

Dear Governor O'Malley, President Miller and Speaker Busch:

Pursuant to Health-General Article, §18-203 and 18-204, 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, Office of Governmental Affairs, at 410-767-6481.

Sincerely,

John M. Colmers
Secretary

Enclosure

cc: Russell W. Moy, M.D., M.P.H.
Ms. Donna Gugel
Ms. Anne Hubbard
Ms. Sarah Albert, MSAR# 5544

Maryland Cancer Registry 2008 Annual Legislative Report

Martin O'Malley
Governor

Anthony G. Brown
Lt. Governor

John M. Colmers
Secretary
Department of Health and
Mental Hygiene

CONTENTS

1. INTRODUCTION	3
2. MCR MISSION STATEMENT	4
3. FY08 ACTIVITIES	4
ADMINISTRATIVE ACTIVITIES	4
CANCER REGISTRY ADVISORY COMMITTEE (CRAC).....	4
ADMINISTRATIVE ACTIVITIES-MCR HEADQUARTERS.....	5
DELIVERABLES.....	6
ROUTINE DATA PROCESSING	7
MCR FACILITY AUDITS.....	7
LABORATORY FOLLOW BACK	7
DEATH MATCHING AND CLEARANCE.....	7
CASE CONSOLIDATION	8
GEOCODING OF CANCER CASE DATA.....	8
INTERSTATE DATA EXCHANGE.....	8
TECHNICAL ASSISTANCE AND TRAINING	9
MCR SOFTWARE.....	9
ACTIVITIES TO IMPROVE MCR-QADM	10
DATA QUALITY AND COMPLETENESS	10
UPDATING THE MCR CENTRAL DATA	
MANAGEMENT SOFTWARE.....	10
OTHER ACTIVITIES	10
REPORTS AND CASES ADDED DURING FY 08	11
DATA REQUESTS	13
4. CONCLUSION	13

1. INTRODUCTION

This report contains the Maryland Cancer Registry's Annual Fiscal Year Report for the period July 1, 2007 through June 30, 2008 (FY08).

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, early detection, 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, management, and quality assurance activities of the MCR to an outside entity. In August 2005, the DHMH identified an unusual increase in the number of 2002 cervical cancer and melanoma cases in the MCR. As the anomaly was investigated, it became evident that although at least one laboratory was incorrectly coding cervical cancer in situ cases as invasive, other case errors originated with the Macro MCR-Quality Assurance and Data Management (MCR-QADM) vendor team. Once this was discovered and discussed, Macro agreed to a three-part corrective action remediation plan, as described in the FY 2006 annual report. The final remediation plan was accepted by DHMH in September 2006. As part of this plan, the MCR database was frozen in May 2006, became accessible again in October 2006, and Macro did not have sufficient time or staff to consolidate and finalize cancer cases for the diagnosis year 2004. Therefore, as described in the FY 2007 annual report, the MCR did not submit 2004 cases to either the North American Association of Central Cancer Registries (NAACCR) or the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR).

During FY08, Macro International (Macro) was the database management and quality assurance vendor for the MCR from July 1, 2002 until January 31, 2008. The MCR worked closely with Macro International to finalize and approve remediated data. The MCR submitted its data to NAACCR on December 1, 2007 for incidence year 2005 and to the NPCR on January 31, 2008 for incidence years 1995-2006. For the remainder of FY08, a new vendor, Westat, Inc., began providing database management and quality assurance to the MCR under a contract that began on February 1, 2008.

2. MCR MISSION STATEMENT

The Mission of the Maryland Cancer Registry is:

1. Oversight of activities that implement Health-General Article, §18-203 and §18-204, Annotated Code of Maryland and COMAR 10.14.01;
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. FY08 ACTIVITIES

ADMINISTRATIVE ACTIVITIES

During FY08, the QADM contract with Macro was extended for an additional seven months. During the seven-month contract extension, the MCR-QADM team at Macro met with DHMH staff weekly to discuss progress, plans, issues and data remediation solutions and ongoing processing of current reports. The team participated in monthly cancer registry software meetings (Registry Plus User Group) with CDC and other states regarding software-related issues. Data were exchanged twice with the 12 states and District of Columbia cancer registries that have agreements with MCR.

Cancer Registry Advisory Committee (CRAC)

During FY08, the CRAC met four times. Discussion topics included MCR-QADM activities, data use and dissemination, status of data remediation, data use policy and procedures, MCR regulations, and cancer research and surveillance activities.

Administrative Activities – MCR Headquarters

The MCR Headquarters, located in the DHMH office complex, is charged with administrative and custodial oversight of MCR 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 FY08 included:

1. *Staffing Changes-*
The position of the Director of Maryland Cancer Registry was filled in early Fiscal Year 2008 by Kimberly Stern who is a Certified Tumor Registrar (CTR). She has a Master's Degree in Health Services Administration and has several years experience in the cancer data management field. She is a member of the Tumor Registrar's Association of Maryland.

Jennifer Hayes was appointed Senior Epidemiologist in FY08. She has a Master's Degree in Education and a Master's Degree in Public Health.
2. *New Quality Assurance and Database Manager Selected-*
In Fiscal Year 2007, a Request for Proposals (RFP) was developed to provide quality assurance and database management support to the MCR. Westat, Inc. was selected through a competitive bidding process. The five year-five month contract began on February 1, 2008. During FY08, Westat, Inc. transitioned databases and software from the former vendor, hired staff and began operations. Facility reporting to the new vendor began on March 3, 2008.
3. *NAACCR Web Seminars for Central and Hospital CTR Training-*
During FY08, the MCR hosted a series of Web seminars (referred to as "Webinars") for Abstracting Cancer Incidence and Treatment Data for Hospital Tumor Reporting and Cancer Surveillance Data Collection by Central Cancer Registries. Each Web seminar session was presented by NAACCR and included a presentation by an instructor with an audio portion (via telephone) and a visual portion (via computer Internet). Continuing Education Units were received by CTRs who attended a full session.
4. *MCR Web site (www.fha.state.md.us/cancer/registry) -*
The MCR regularly updates its Web site to better serve the needs of the public, reporting facilities, and data requesters. During FY 08, several new links were added to assist reporters including the MCR Announcements, Training, and Dates to Remember page in addition to updates to a Reporters page that provides important information for facilities reporting to the MCR.

5. *MCR Data Release Policy and Procedure Document-*
The MCR Data Release Policy and Procedures (formally called MCR Data Use Policy) was updated to incorporate/update two types of studies: 1) linkage studies, and 2) patient contact studies. Linkage studies procedures define when and under what circumstances the MCR will take a researcher's database and match it with the registry data to either find cancer cases or update diagnosis information. Patient contact studies procedures define how the registry will work with researchers who wish to contact individual patients who have cancer and are in the MCR.
6. *MCR Regulations Update-*
No changes were finalized to the MCR Code of Maryland Regulations 10.14.01 in FY08; changes were drafted and pending at the end of FY08.
7. *MCR Quarterly Reporters Teleconference-*
The MCR hosted quarterly reporters' teleconferences during FY08 for all Maryland Reporters. The purpose of the teleconferences is to provide an opportunity for the MCR central office staff, the MCR Quality Assurance/Data Management contractor, and reporters to come together for information sharing, updates, and training.

In July 2008, a Legislative Audit Report cited the data problems in the MCR as one of their Findings. DHMH had been implementing its remediation plan previously discussed in order to address the data problems cited in the Audit Report. Further, DHMH made the MCR staffing changes and contracted with Westat, Inc. in order to provide heightened quality assurance and data management support to the MCR.

Deliverables

Macro

From July 1, 2007 through January 31, 2008, the period of the seven-month contract extension, Macro delivered the following:

- Provided DHMH with the remediated dataset;
- Submitted data to NAACCR on December 3, 2007, but data did not receive NAACCR certification;
- Submitted data to NPCR on January 31, 2008, but data did not receive NPCR certification;
- Conducted interstate data exchange with States and the District of Columbia with whom the DHMH has entered into exchange agreements;
- Applied newly geocoded data back to the master consolidated records;
- Updated information in the vital status, date of death, and cause of death in the consolidated database using files from DHMH's Office of Vital Statistics; and
- Transferred database to Westat, Inc.

Westat, Inc.

From February 1, 2008 through June 30, 2008, Westat, Inc. delivered the following:

- Delivered a final Work Plan for the five-year-five month contract;
- Developed internal quality assurance procedures, including supervision by the Director, and monthly, quarterly, and annual management reports to identify anomalies in data;
- Hired staff, transferred databases, and began operations;
- Installed the Facilities and Reporters' Logs;
- Developed data defaults to help detect errors early;
- Completed Hispanic algorithm match and applied back to the database; and
- Provided training to hospital and other reporters.

ROUTINE DATA PROCESSING

MCR Facility Audits

No facility audits were performed in FY08.

Laboratory Follow Back

Macro

Macro did not call laboratory reporters to obtain missing race data on cases reported only from laboratories.

Westat, Inc.

Westat, Inc. in FY08 did not call laboratory reporters to obtain missing race data on cases reported only from laboratories.

Death Matching and Clearance

Macro

In FY08, Macro began death matching and clearance for the 2004 and 2005 deaths from cancer but did not complete the process by NPCR submission in late January 2008.

Westat, Inc

In FY08, Westat, Inc. received data on 2006 deaths, and developed a software application through which to perform death matching and clearance.

Case Consolidation

Because the focus in the first one-half of FY08 was the 2004 and 2005 incidence years, Macro was behind in case consolidation for the 2006 incidence year cases. On February 1, 2008, there was a backlog of 2006 cases that Westat, Inc. needed to complete. During the handover of data and operations from Macro to Westat, Inc. the operations were shut down for about six weeks for the following:

- The physical transfer of the database and data;
- The set up of a secure Web site;
- The set up of the Registry Plus suite of programs;
- The hiring and training of staff;
- The review of MCR historical files from Macro; and
- The review, revision, development of manuals, forms & procedures.

Consolidation of cases has been on-track at Westat, Inc. since March, 2008.

Geocoding of Cancer Case Data

Macro

Macro extracted street addresses from the registry data and provided them to DHMH. DHMH Information Resources Management Administration (IRMA) geocoded 2000 - 2005 incidence year data in the MCR to correct problems and to update latitude, longitude, county, and census tract; DHMH provided the information to Macro who updated the database.

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).

Macro

Macro completed data exchange with those registries with MCR exchange agreements in the fall, 2007.

Westat, Inc.

Westat, Inc. completed data exchange with those registries with MCR exchange agreements in the spring, 2008.

Technical Assistance and Training

Macro

MCR-QADM maintained a dedicated Help Line for reporting facilities that needed assistance with data submission-related issues until the end of the seven-month contract extension.

Westat, Inc.

Westat, Inc. established a dedicated Help Line that became operational on March 3, 2008 to provide technical assistance to callers. All calls are documented in a Westat, Inc.-developed program called “Issue Tracker.” The program is also used to look for areas where there may be a need for additional training.

Westat, Inc. has participated with DHMH MCR staff in a Process Improvement program sponsored by NAACCR with the Tumor Registrars Association of Maryland (TRAM). This has included surveys, meeting for discussions of items of importance, development of a TRAM Program and presentations at that program.

MCR Software

Westat, Inc. has been working with the CDC on improving the Registry Plus suite of programs. They were able to fix a “reply feature” that provided reporters with automatic acknowledgement upon data submission. They have been beta testing and making recommendations on a new NPCR program called Mapper Plus, which maps HL7 pathology report data elements to NAACCR data elements and allows for an abstract to be completed.

In FY08, Westat, Inc. began developing a “Follow-back tracker” program to assist with tracking of activities including laboratory follow back and death follow back.

ACTIVITIES TO IMPROVE MCR-QADM

There are numerous long standing issues left after the completion of the Macro contract. Westat, Inc. has begun to develop strategies to deal with the identified issues.

Data Quality and Completeness

Data processing and case finding should be completed by six months after the data due date. For example by June 30, reporters should have reported the total previous year's cancer cases to the MCR. In January 2008, 90% of the cases diagnosed in 2006 should have been in the registry ("12-month data"); the MCR's 2006 data were only 75% complete.

In FY08, Westat, Inc. and DHMH began a review of case reporting sources, timing, methods, and quality of data reported.

In addition, Westat, Inc. is working to get all pathology labs who report through hard copy pathology reports to report electronically as required by Maryland law.

Updating the MCR Central Data Management Software

See MCR Software, 4.2.8, above.

Other Activities

Other MCR activities in FY08 included the following:

- Key MCR staff at DHMH and Westat, Inc. attended the National Cancer Registrars Association and NAACCR conferences.
- CCSC Medical Director and DHMH Registry Director attended the NPCR National Program Directors Meeting in Atlanta.
- DHMH Registry Director attended the Central Cancer Registries: Design, Management, and Use training at the NAACCR conference, and SAS training.
- MCR Senior Epidemiologist attended the NAACCR Cancer Surveillance Institute I: Principles and Public Health Applications.

REPORTS AND CASES ADDED DURING FY 08

MCR had 68,201 cancer case abstracts reported during FY08 (See Table 4-1).

Table 4-1. Number of Abstracts Submitted in FY08 by Year of Diagnosis

Reporting Period: July 1, 2007 to June 30, 2008

Diagnosis Year	Diagnosis State	
	Maryland	Non-Maryland
2008	1,020	64
2007	19,134	2,450
2006	13,912	1,313
2005	13,262	905
2004	9,972	368
2003	2,175	105
2002	1,446	71
2001	558	20
2000	115	19
1999	78	7
1998	62	4
1997	52	5
1996	42	5
1995	78	6
1994	213	5
1993	204	1
1992	38	1
1991	29	0
1990	209	17
1989	18	3
1988	21	2
1987	12	3
1986	20	1
1985	28	0
Before 1985	123	5
Total	62,821	5,380

Data Source: Westat, Inc. as of August 2008

Table 4-2 presents the provisional number of benign brain and central nervous system tumors (consolidated cases) reported to MCR, by year of diagnosis, as of June 30, 2008. A total of 3,611 consolidated cases had been reported with Diagnosis year 1999 to 2007.

Table 4-2. Total Number of Benign and Borderline Brain and Central Nervous System Tumors by Year of Diagnosis (ICD-10 Topography: C70.0-C72.9, C71-C75.3 with Behavior = 0 or 1)

Diagnosis Year	Behavior ICD-O-3	
	0 Benign	1 Borderline
2007	296	34
2006	576	53
2005	605	68
2004	576	65
2003	502	64
2002	399	42
2001	221	18
2000	51	5
1999	35	1
Total	3261	350

Data Source: Westat, Inc. as of June 30, 2008

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)

DATA REQUESTS

Table 4-3 shows the number of requests for data that the MCR received and processed in FY08.

Table 4-3. MCR FY08 Requests

Type of Request	Number of Requests
Research/Special Studies	23
Reporting Facilities Requesting their own Information	2
Health Services Planning	10
Public Request for Information	26
Media Requests	3
Total	64

4. CONCLUSION

The MCR is a valuable resource for the State in its efforts to reduce cancer prevalence. By collecting, analyzing, and distributing these data, the State can better focus its cancer prevention and control efforts. The MCR will continue collecting and analyzing data in its efforts to further the goal of a healthier Maryland.