

***Bidirectional Reporting of
Michigan Cancer Registry
Data: A Pilot Project***

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Outline

- **Overview of the Michigan Cancer Surveillance Program (MCSP)**
- **Genomics and MCSP**
- **The Facility Specific Report**
 - **What cancers are included**
 - **What materials are in the report**
 - **How they were disseminated**
 - **Who receives the report**
- **Evaluation**
- **Future Steps**

Twenty-fifth Anniversary in 2010!



- **2.0 million reports**
- **1.2 million patients**
- **Data on 670,000 deaths**
Complete for 1985-2008
- **Geocoded population-based data**

Methods and Quality

- **Passive Reporting**
 - **Quality Assurance Reviews**
 - **Benefits from large SEER registry**
 - **Detroit Region**
- **NPCR Registry since 1995**
- **NAACCR Certified since 1999**

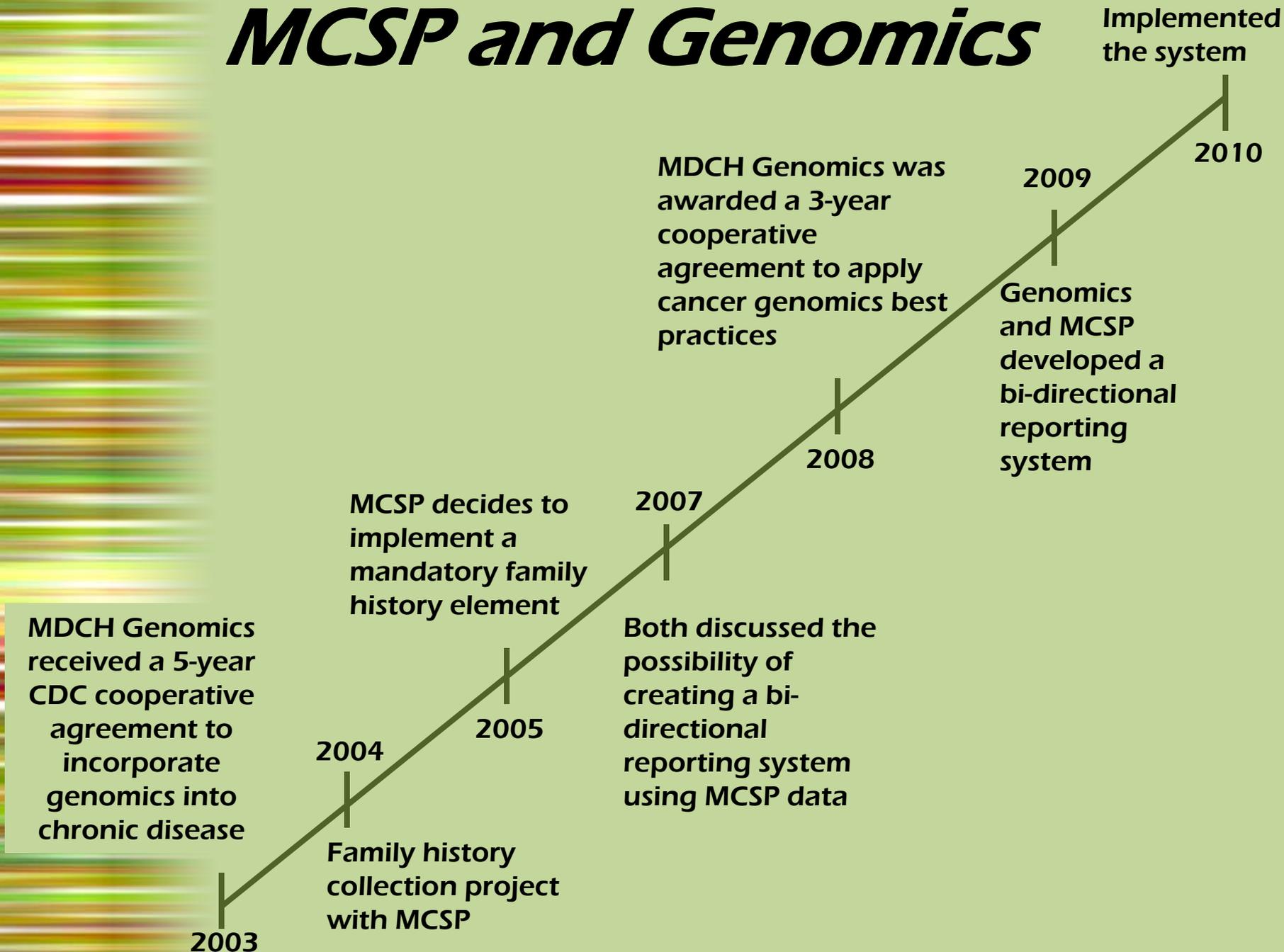
Registry Uses

- **Data**
 - Statistics on incidence and mortality
 - Cancer Control Outcome Measures
 - Facilitated 112 research protocols
- **Intervention Tool**
 - Bi-directional reporting
 - Improved screening of risk family (?)
 - Contact prostate cancer survivors (?)

Genomics, Public Health and Cancer Surveillance

- **Genomics Suggests Key Registry Role**
 - Elevated familial risk and public health
 - Promoting testing/counseling
 - Interventions to elevate awareness
 - Efforts to promote screening/follow up
- **Need to Develop Models**
 - Find role for the known
 - Be prepared to adapt to new discoveries

MCSP and Genomics



Cooperative Agreement

- Promote cancer-genomics best practices and evidence-based recommendations
 - U.S. Preventive Services Task Force
 - EGAPP
- Activities include surveillance, education, and health plan policy projects
- This project demonstrates the translation of surveillance data into education

Multiple Primaries Methods

- 1990- 2007 cancer registry data, with at least one diagnosis in 2006 or 2007
- Proxies for cancers with a higher genetic load
- Multiple primaries defined as two or more BRCA1/2 or HNPCC- potentially related cancers that were classified as separate primary tumors
- Examples of multiple primaries: breast-breast, breast-ovarian, colorectal-endometrial, and colorectal-colorectal

Single Primary Cancers

- **Number of cancer cases in 2006-2007 with a diagnosis at any age for the following :**
 - Colorectal (Lynch)
 - Male Breast (BRCA)
 - Ovarian (BRCA & Lynch)
- **Number of cancer cases in 2006-2007 with a diagnosis between 18-49 years for the following:**
 - Female Breast (BRCA)
 - Endometrial (Lynch)

Sample Hospital and Medical Center Cancer Genetics Data Report (2006-2007) on Hereditary Breast and Ovarian Cancer Syndrome (HBOC) and Lynch Syndrome

Michigan healthcare facilities are required to report all cancer diagnoses to the Michigan Cancer Surveillance Program (MCSP) within the Michigan Department of Community Health (MDCH). MDCH has compiled state-wide registry data as well as facility-specific data, in order to provide you with the number of patients at your facility who may be at risk for HBOC syndrome or Lynch syndrome, also called Hereditary Non-Polyposis Colorectal Cancer (HNPCC). These patients should have a formal risk assessment by a suitably trained health care provider to discuss the appropriate indications for genetic testing. HBOC accounts for approximately 5-10% of all breast cancer diagnoses and is associated with increased risk for ovarian cancer. Approximately 3-5% of all individuals with colorectal cancer will have Lynch syndrome, which is associated with an increased risk for endometrial and ovarian cancers. Proper documentation and discussion of the above and related cancers, along with demographic features suggestive of a hereditary cancer syndrome, is critical. Individuals diagnosed with early onset cancers, multiple primary diagnoses, or rare cancers are at risk for hereditary cancer syndromes and may benefit from increased cancer surveillance, genetic testing, or special medical management.

Table 1. Age 18-49 at diagnosis	Sample 2006 - 2007	Michigan 2006 - 2007
Breast (female)		3,025
Endometrial		459

Table 1. Number of early onset female breast and endometrial diagnoses within your health system and within Michigan.

Table 2. All ages	Sample 2006 - 2007	Michigan 2006 - 2007
Colorectal		10,340
Ovarian*		1,544
Breast (male)		147

Table 2. Number of colorectal, ovarian* cancer and male breast diagnoses within your health system and within Michigan.

Table 3. All ages	Sample 2006 - 2007	Michigan 2006 - 2007
Multiple primary cancer diagnoses		1,985

Table 3. Number of people with multiple cancer diagnoses between 1990 to 2007 with a cancer diagnosis in 2006-2007 including: breast-breast, breast-ovarian*, ovarian*-ovarian*, colorectal-colorectal, colorectal-endometrial, colorectal-ovarian*, endometrial-endometrial, ovarian*-endometrial.

* All ovarian cancer data also include those cases diagnosed with cancer of the fallopian tube.

Patient names associated with the reported diagnoses can be sent to a designated person in your facility upon request. If requested, the names will be disclosed to your facility using current confidentiality rules.

Facility-specific Profiles



Jennifer M. Granholm, Governor
Janet Olszewski, Director

A Cancer Genetics Profile: Prepared for Sample Hospital



Focusing on Your Patients' Hereditary Cancer Risk

March 1, 2010



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STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH

LANSING

JENNIFER M. GRANHOLM
GOVERNOR

JANET OLSZEWSKI
DIRECTOR

May 2010

Dear Healthcare Partner:

The Michigan Department of Community Health (MDCH) is pleased to provide this Cancer Genetics Profile. The profile highlights the number of cancer patients at your facility who may be at risk for **Hereditary Breast and Ovarian Cancer (HBOC) syndrome** or **Lynch Syndrome** (also called Hereditary Non-Polyposis Colorectal Cancer Syndrome or HNPCC). Patients who have early onset cancer, multiple primary diagnoses of cancer, rare cancer, or a significant family history are at increased risk for the above conditions. These patients should be offered genetic counseling to discuss the risks, benefits, and limitations of genetic testing and to evaluate the need for increased cancer surveillance. Identifying those at risk for hereditary cancer benefits patients and family members who may be unaware of the familial risk.

As you may know, healthcare facilities in Michigan must report cancer diagnoses to the Michigan Cancer Surveillance Program (MCSP). We analyzed case reports received in 2008-07 to create a summary specifically for your facility. In addition, your facility's cancer registrar will be sent the names of patients who might be at increased risk for hereditary cancer so you may determine whether appropriate genetic services were offered. Included in this profile are:

- Facility Report with the number of cancer patients at your facility who may be at risk for hereditary disease
- Clinical recommendations for patients with a family history of breast and/or ovarian cancer
- Clinical guidelines for the evaluation of Lynch syndrome in colorectal cancer patients
- Genetic and Family History resources and resource CD with additional printable patient and provider education resources.
- The Michigan Informed Consent Law Booklet
- Contact information for the Cancer Genomics Educator at the Michigan Department of Community Health.

The resources and services provided in this profile may also be used to meet the American College of Surgeons (ACS) Cancer Program Patient Care Improvement Standards. Standards 6.2 and 8.2 focus specifically on early prevention or detection programs and improving direct patient care respectively. MDCH is sharing your facility's data with you in order to promote evidence-based practices for the appropriate use of genetic services and tests. Your individual report will not be shared with any parties outside your health system and is for internal use only.

The MDCH cancer genomics educator, Ms. Jenna McLosky, MS, CGC, is available to discuss this report in greater detail. If you would like to order copies of the enclosed resources or schedule an on-site training about hereditary cancer, please contact Ms. McLosky at 517-335-8826 or jmclsky@michigan.gov.

Thank you for helping to promote cancer genomics best practices within the state of Michigan.

Sincerely,

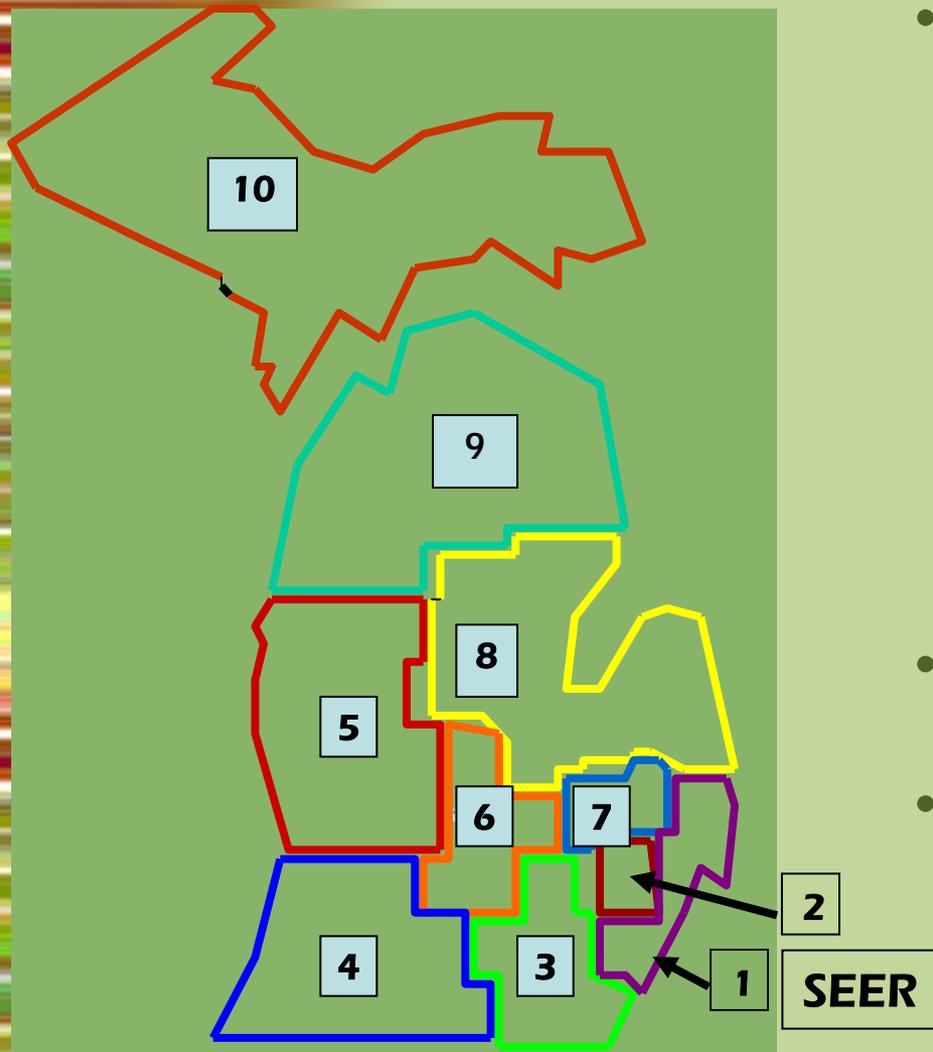
Gregory S. Holzman, MD, MPH
Chief Medical Executive

- Introductory letter
- Guidelines
- Data Report
- MCGA Directory of Cancer Genetics Services
- Resources: informed consent brochure, newsletters, fact sheets
- Front cover: Resource CD, MDCH fact cards, and our new pocket guide

Who did we target to receive the report?

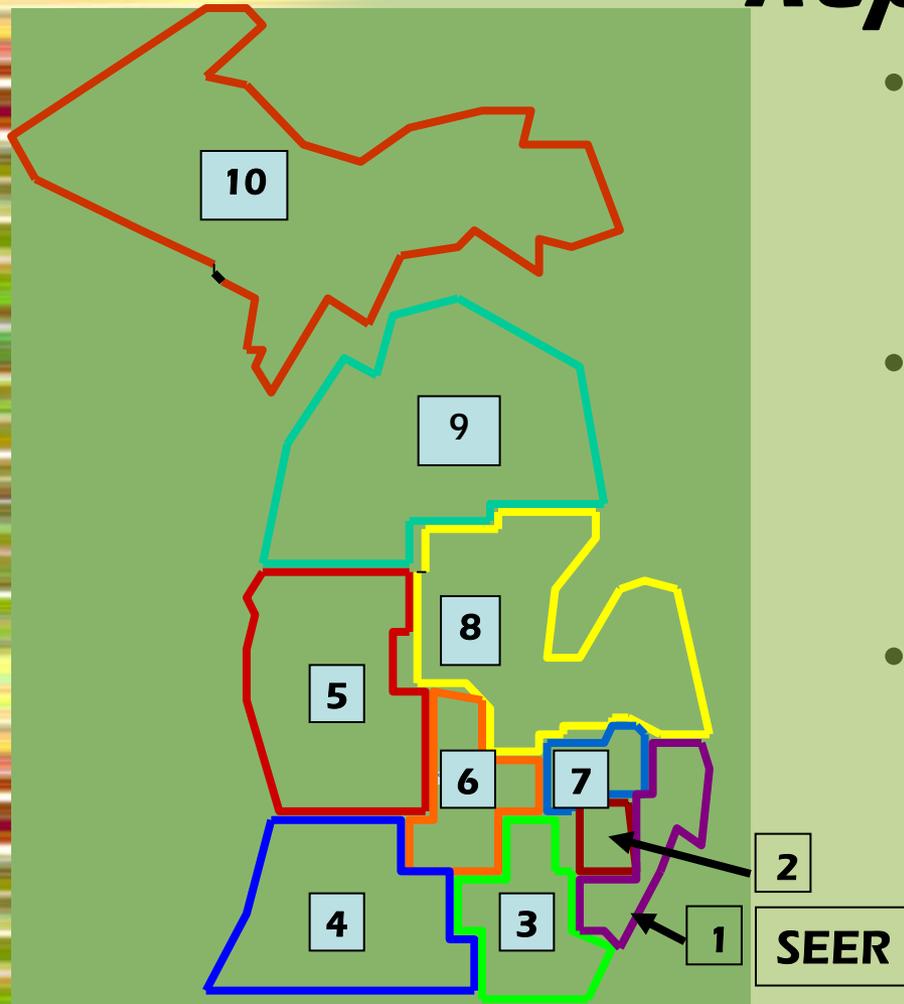
- Cancer Registrar
- President and CEO
- Medical/Clinical Affairs
- Medical Director
- Quality Assurance/Risk Management
- Patient Care
- Legal Affairs
- Nursing
- Sometimes Oncology or OB/GYN

Dissemination of Facility Reports - 2010



- Dissemination occurred by region to 98 of 129 facilities in 2010 (excluding labs, dermatology, dental, etc) = 298 Profiles total
 - Region 3/6/7 in July 2010
 - Region 5 in Sept 2010
 - Region 4 in Oct 2010
 - Region 8 in Nov 2010
 - Region 9/10 in Dec 2010
- 1 facility report was held to be mailed with SEER sites
- 30 facilities had no cases reported in 2006-2007 data
 - Went back to 2003-2007 data and generated reports for 10 of these

Dissemination of Facility Reports - 2011



- Dissemination occurred by region to 9/10 additional facilities in January 2011 (one could not be contacted)
- Dissemination will occur to up to 50 SEER sites in 2011 to regions 1 and 2
- To Date →
 - Dissemination to 107 Facilities
 - 1 Facility could not be contacted
 - 1 Facility was held for SEER sites
 - 331 profiles total

Evaluation Plan

- **Created a feedback form – included in the profile and available online**
- **Offered Grand Rounds or Lunchtime Learning Sessions**
- **Follow-up email or phone contact**
- **Offered to provide the names of their specified patients**

Evaluation

- **Received 8 Feedback Forms**
 - 7/8 very positive
 - 8/8 have shared the report with others in and out of their facility
- **One facility is using data as a baseline for their genetics program**
- **3 facilities have scheduled grand rounds presentations**
- **Follow-up contact has been made with 77/107 facilities**
- **4 facilities have requested the names of the individuals in their report so they can follow-up with the patients and provide educational materials or support**

Future Steps

- **Continue reporting to the SEER sites as their data becomes available. Most have consented to release their data at this time.**
- **Present Grand Rounds to the facilities that have requested educational trainings.**
- **Continue evaluation via email / phone contact**
- **Write up the results of our findings to be shared nationally so other states can use this surveillance/educational project**
- **Cost analysis**

Other Collaborative Surveillance Activities

- **Mail Survey to 500 breast cancer survivors**
- **Chart Abstractions**
- **Mortality statistics related to those with young age at diagnosis**

Thank you!

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517-335-8826