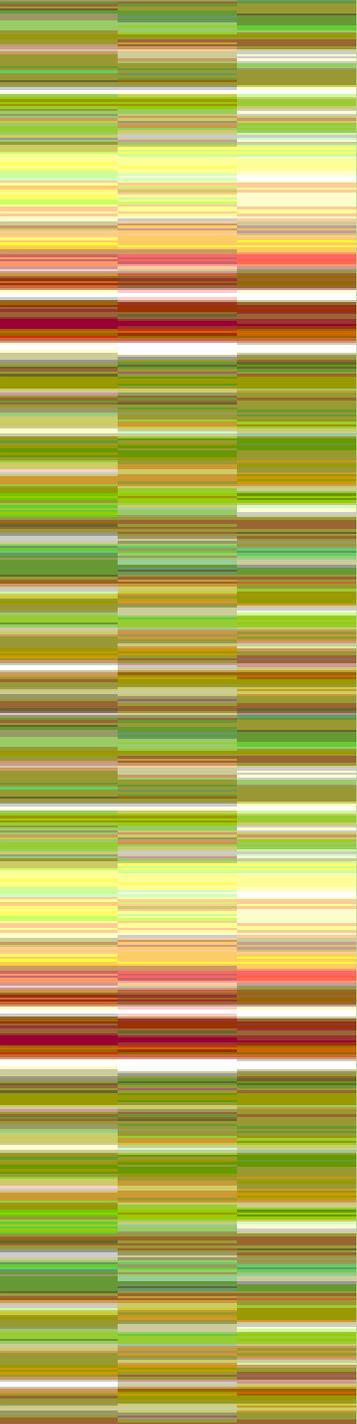


***Bidirectional Reporting of
Michigan Cancer Registry
Data: A Pilot Project***

**4th National Conference on Genomics
and Public Health
December 9, 2010**

**Beth Anderson, MPH
Cancer Genomics Epidemiologist
Michigan Department of Community Health**

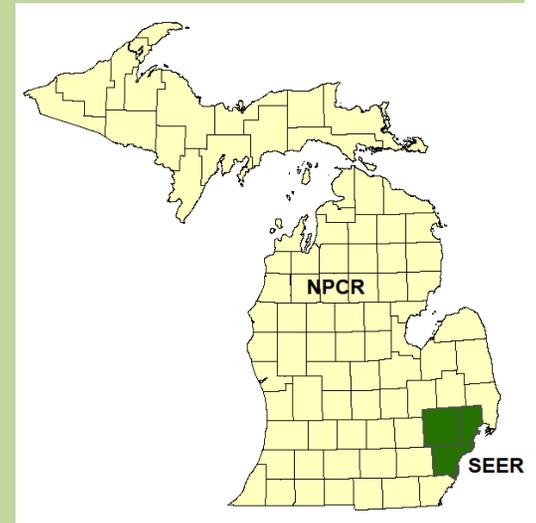


Outline

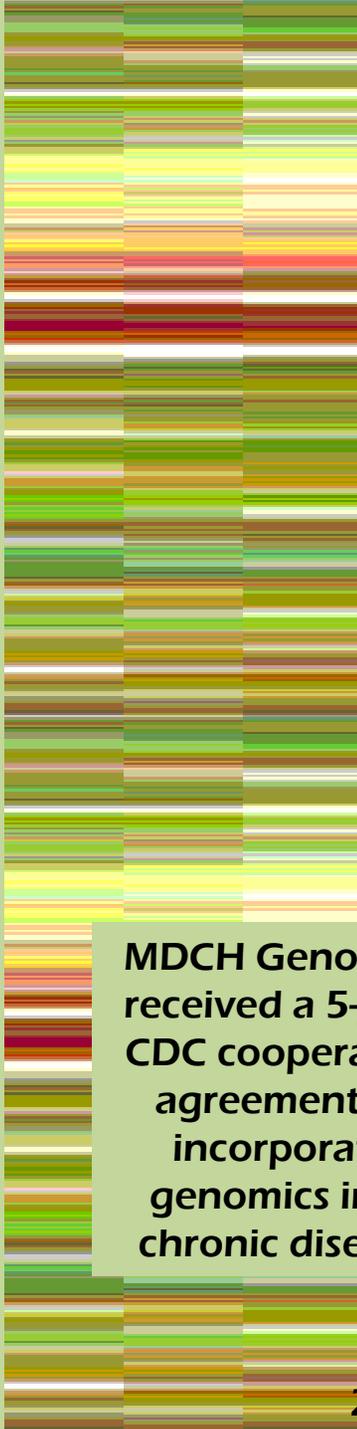
- Overview of the Michigan Cancer Surveillance Program (MCSP)
- Genomics and MCSP
- The Facility Specific Report
 - What cancers are included
 - What materials are in the report
 - How they were disseminated
 - Who receives the report
- Evaluation
- Future Steps

Michigan Cancer Surveillance Program (MCSP)

- MCSP has been collecting cancer data since 1985
- Reported through 2 sources:
 - National Program of Cancer Registries (NPCR)
 - National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program
- Collects data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment.



MCSP and Genomics



MDCH Genomics received a 5-year CDC cooperative agreement to incorporate genomics into chronic disease

2003

2004

Family history collection project with MCSP

2005

MCSP decides to implement a mandatory family history element

2007

Both discussed the possibility of creating a bi-directional reporting system using MCSP data

2008

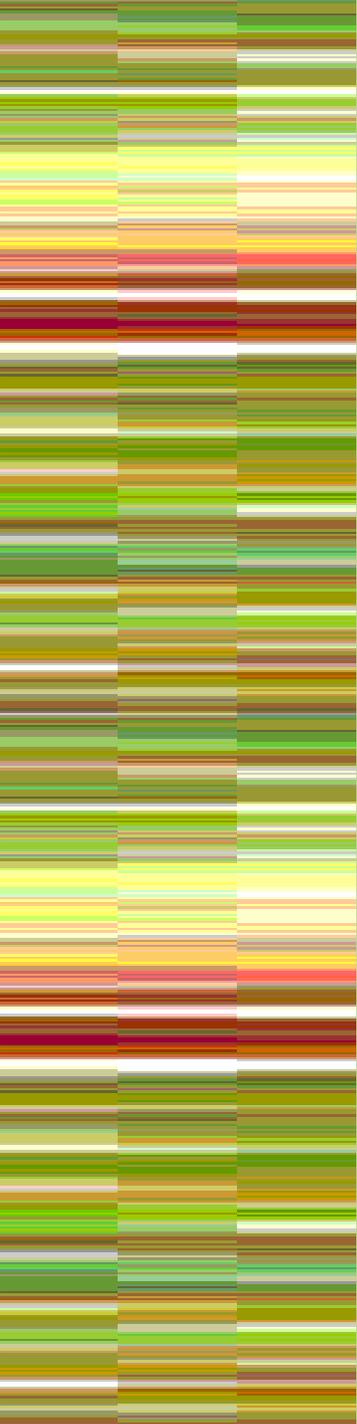
MDCH Genomics was awarded a 3-year cooperative agreement to apply cancer genomics best practices

2009

Genomics and MCSP developed a bi-directional reporting system

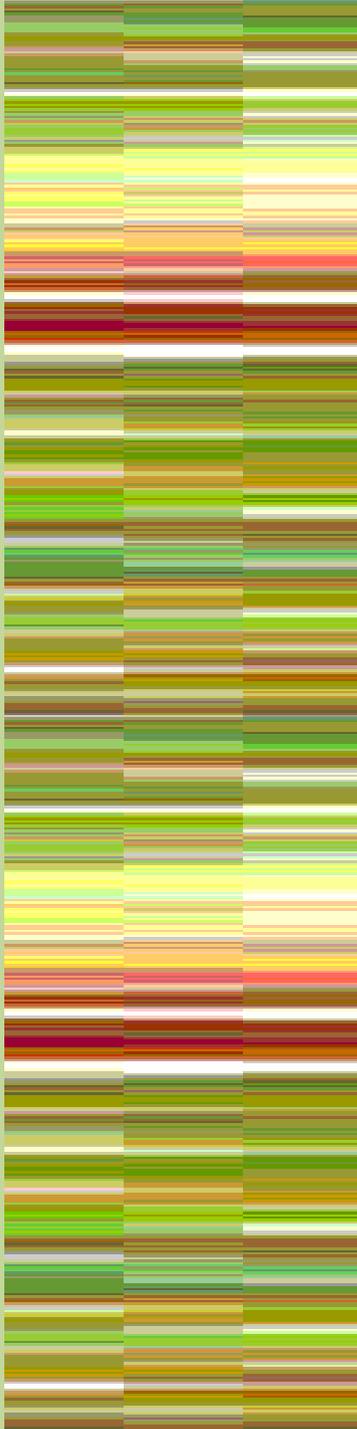
2010

Implemented the system



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



Michigan Department
of Community Health
MDCH
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



Contents



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,

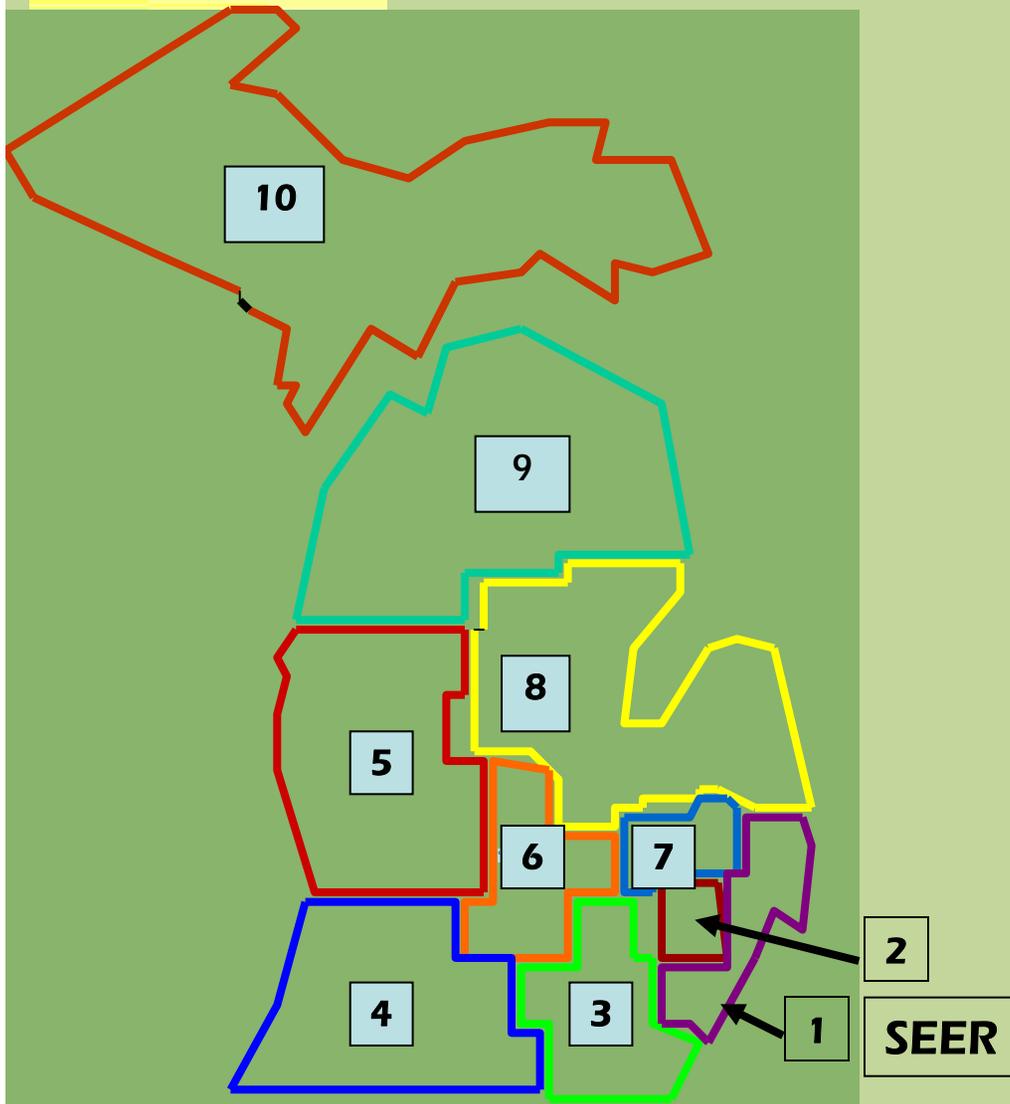
Gregory S. Holzman, MD, MPH
Chief Medical Executive

DOH-1272 (0705/09)

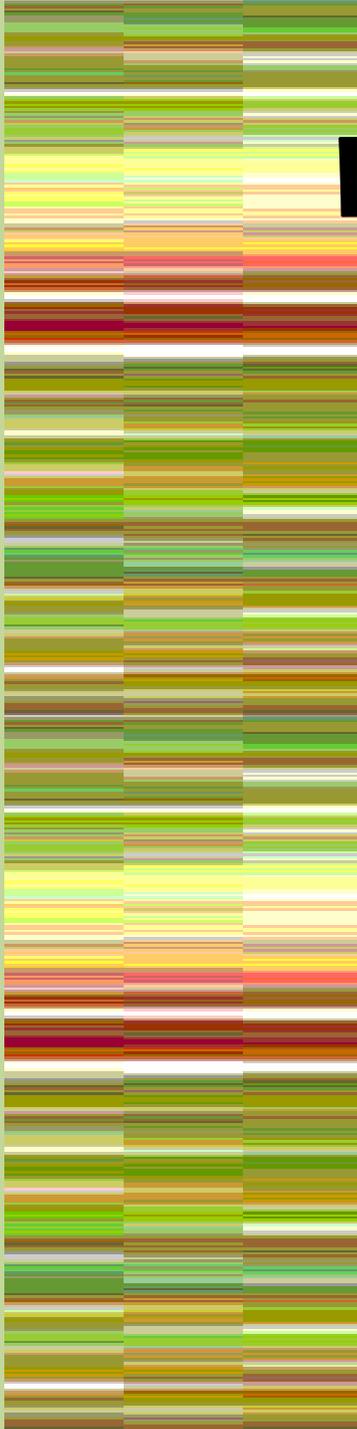
CAPITOL VIEW BUILDING • 2017 OAKBEND STREET • LANSING, MICHIGAN 48913
www.michigan.gov • (517) 375-3740

- **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**

Dissemination of Facility Reports

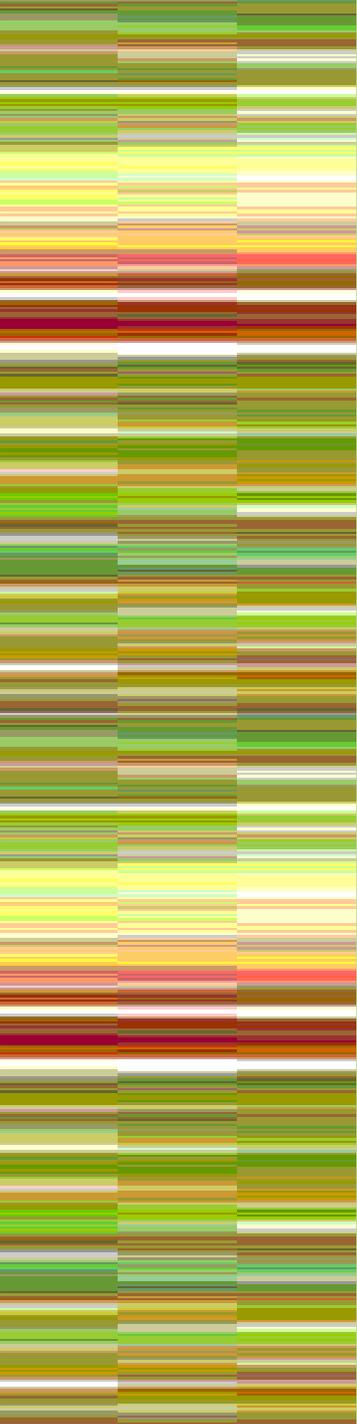


- Dissemination will occur by region to 129 facilities in 2010 (excludes labs, dermatology, dental, ect)
 - Region 3/6/7 in July 2010
 - Region 5 in Sept 2010
 - Region 4 in Oct 2010
 - Region 8 in Nov 2010
 - Region 9/10 in Dec 2010
- To date 77 facilities have received reports
- 30 facilities had no cases
- 21 facilities will receive reports this month
- Up to 50 reports will be mailed out in 2011 to the SEER sites (Regions 1 and 2)



Who receives the report?

- Cancer Registrar
- CEO of Medical or Clinical Affairs
- Head of Legal Affairs
- Head of Risk Management
- Medical Director
- Head of Nursing
- Head of the Oncology Department

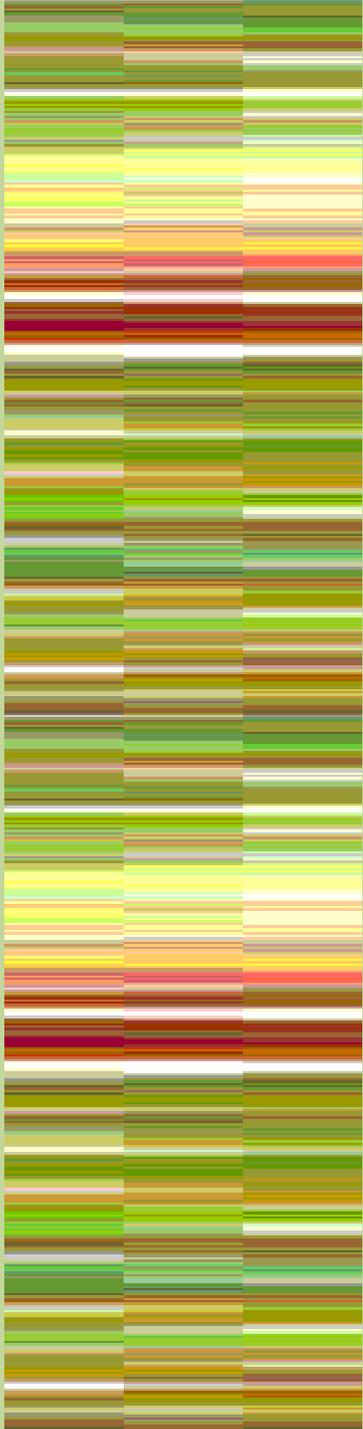


Evaluation

- All that we have heard back from have shared the report with others in and out of their facility
- One is using data as a baseline for their genetics program
- Several have expressed interest in grand round presentations
- A facility has 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

- 30 facilities had no cases of cancer in 2006-2007. For these, we will evaluate data back to 2003 and mail reports by the end of 2010.
- Present Grand Rounds to the facilities that have requested educational trainings.
- Develop an evaluation tool to be completed via phone when our educator calls to confirm receipt of the facility report
- Write up the results of our findings to be shared nationally so other states can use this surveillance/educational project
- Cost analysis



Thank you!

Co-authors:

Jennifer McLosky MS, CGC

Debra Duquette MS, CGC

Janice Bach MS, CGC

Questions:

Beth Anderson

AndersonB@michigan.gov

517-335-9785