

Promoting Cancer Genomics Best Practices through Surveillance, Education and Policy Change in the State of Michigan

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“The challenge is over one million people in the US carry mutations predisposing to cancers that are preventable or treatable at an early age...but only 3% know it.”

- William Rusconi, Vice President of Marketing for Myriad Genetic Laboratories, Inc. in 2005



Desired Ultimate Impact

- A reduction in early cancer deaths (before age 50) through statewide surveillance and implementation of systems of care for inherited breast, ovarian, colorectal and other HNPCC related cancers that use best practice recommendations for family history assessment, cancer genetic counseling and testing



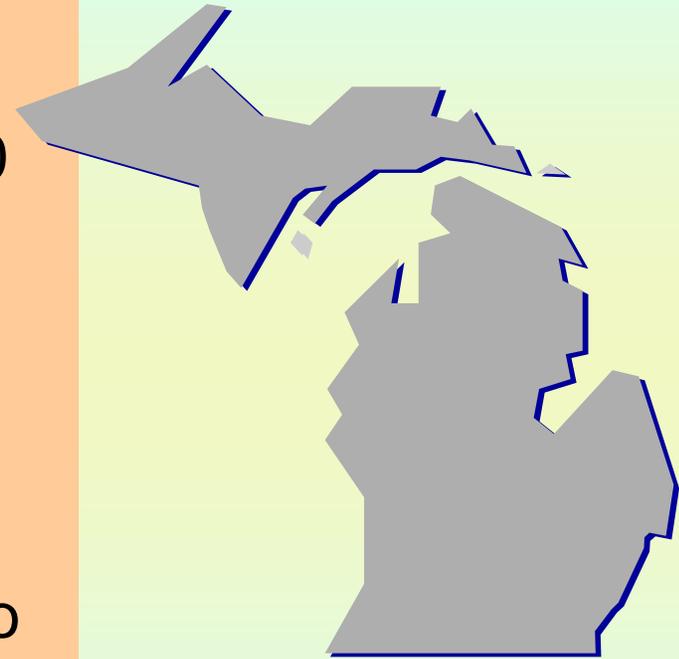
Our Program's Goals

- Develop and implement a model for surveillance of inherited cancers and use of relevant genetic tests; and share with other cancer registries and national programs
- Identify model provider education programs to increase use of appropriate screening, counseling and evidence-based genetic tests; and share with public health and/or clinical practice organizations
- Identify a model health insurance policy for BRCA1 & 2 cancer genetic testing; and share with health plans in Michigan and other states

Target Population

State of Michigan

- Public
 - ~ 7 million residents below 50 years of age
 - Individuals at increased risk for hereditary cancer
- Health systems and Providers
 - 144 hospital systems report to the state cancer registry
- Health insurance plans
 - 19+ in Michigan



Steering Committee

- MDCH Genomics and Genetic Disorders Section
- MDCH Cancer Surveillance Program and Vital Records
- MDCH Cancer Prevention and Control Section
- National Office of Public Health Genomics (NOPHG)
- Michigan Cancer Consortium (MCC)
- Michigan Cancer Genetics Alliance (MCGA)
- Sentinel Clinical Sites
- Health Plan “Champion”

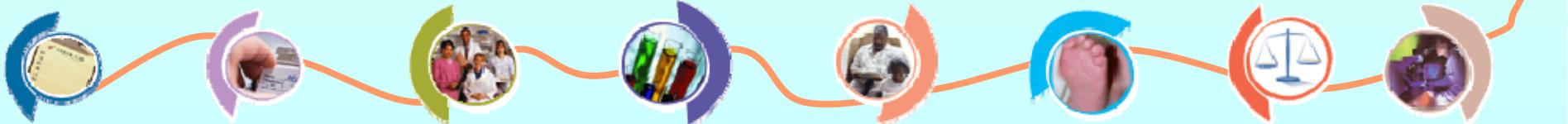
Michigan Cancer Surveillance Program (MCSP)- Essential Key to Project

- Established in 1985 as statewide registry
- Certified by NAACR (Gold Standard)
- Funded by vital records fee and CDC/NPCR
- Passive reports
 - Includes SEER region (Wayne, Oakland, Macomb)



More on MCSP

- Registry established by law (Act 82 of 1984)
 - Cancer and precancerous disease
 - Confidentiality established
 - Endorses uses in research
 - Requires statistical reports
- Includes in situ or invasive malignancies other than basal or squamous nongenital skin; benign brain and CNS tumors since 2004
- ~64,000 new reportable cases per year



Examples of Past Surveillance Activities (2003-2008)

- Review of early onset cancer diagnoses and deaths associated with BRCA1/2 and Lynch syndrome
- Review of males with breast cancer
- Chart reviews regarding provider collection of family history
- Revision of Cancer Registry form in 2007 to include mandatory collection of family history

Early Onset Cancers

*Number of Invasive Cancer Cases by Primary Site and Age of Diagnosis,
Michigan Residents, 1995-2004*

Primary Site	<50 years	50+ years	% < 50 years	Increased risk when diagnosed < 50 for:
Breast	15,476	55,053	21.9%	BRCA1/2
Colorectal	4397	49,992	8.1%	HNPCC
Ovarian	2024	6472	23.8%	BRCA1/2,HNPCC
Endometrial	1896	11,932	13.7%	HNPCC
Prostate	2141	79,406	2.6%	BRCA2
Stomach	649	6508	9.1%	BRCA2, HNPCC
Pancreas	843	10,491	7.4%	BRCA2

Males with Breast Cancer

Numbers of Invasive Cancers of the Breast
by Age and Year of Diagnosis
Male Michigan Residents, 1995 - 2004

Year	< 50	50 - 74	75 +	All Ages
1995	6	21	14	41
1996	6	32	26	64
1997	2	27	20	49
1998	5	35	15	55
1999	5	36	21	62
2000	9	36	17	62
2001	8	30	21	59
2002	5	42	18	65
2003	5	38	17	60
2004	14	49	17	80

Source : Michigan Resident Cancer Incidence File. Includes cases diagnosed in 1995 - 2004 and processed by the Michigan Department of Community Health, Vital Records and Health Data Development Section by December 15, 2006.

Current Surveillance Activities

- Retrospective review of early onset cancers, early deaths, multiple primaries and males with breast cancer (1990-current)
 - Demographics (including geocoded residence at diagnosis)
 - Family history
 - Treatment and survival information
- Increase understanding of statewide incidence rates and trends for mortality associated with breast/ovarian, colorectal and other HNPCC related cancers

“What Is Your Status?”



- Cancer genetic status reports/profiles
 - Bidirectional reporting system to all 144 reporting hospitals
 - Individual hospital reports will not be available to public
 - Profiles of numbers of patients with cancer genomic risk factors:
 - Cancer family history
 - Males with breast cancer
 - Early onset and early deaths
 - Multiple primaries

“The astute clinician must have knowledge of the evidence that exists and the wisdom to understand how to apply this necessarily limited body of data to the care of the individual patient”

- Evans and Khoury, 2007



Provider Education Goals

- Change provider knowledge, attitudes and intentions to ultimately reduce the number of early cancer deaths
- Use statewide surveillance data in conjunction with EGAPP and USPSTF guidelines
- Increase provider awareness about EGAPP recommendations for Lynch syndrome/HNPCC and gene expression profiling tests for early stage breast cancer
- Increase use of USPSTF clinical practice guidelines for USPSTF

“Cancer genetic test results inclusion in state cancer registry?”

- For data quality assurance, MCSP audits 10% of total number of cases submitted per hospital
- 1600 hospital chart reviews planned
 - Attempt to select male breast cancer, early onset cancer, multiple primaries
- Assess provider practice:
 - Documentation of cancer family history
 - Referral to genetic counseling
 - Genetic tests considered, consented, and ordered



Cancer Survivor Survey



- Contact 500 cancer survivors to participate in mail survey
 - Over-sample endometrial cancer
 - \$10 incentive
- Assess barriers/facilitators to knowledge/attitudes about:
 - Family health history
 - Genetic counseling
 - Genetic testing



Forming a Network

- Develop new methods for collecting data on clinical genetic counseling visits and use of BRCA1/2 testing
 - Consider adding Lynch syndrome/HNPCC in year 3
- Share data on cancer genetic referrals and use of testing for BRCA1/2
- Partner with four clinical sites
 - Beaumont Hospitals
 - Henry Ford Health System
 - Oakwood
 - Karmanos Cancer Institute



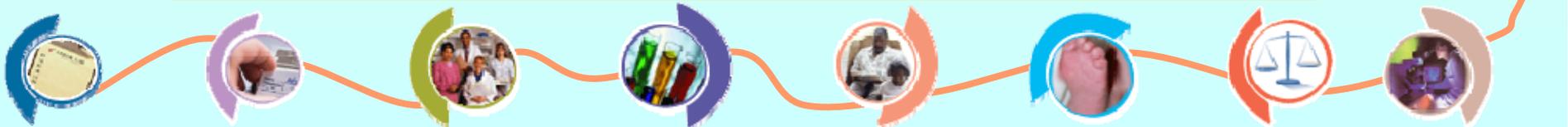
Purpose of Network

- Who is accessing genetic counseling and testing?
- What providers are ordering the tests?
- Is testing appropriate under USPSTF guidelines?
- What are test results?
- Do health plan policies that are consistent with USPSTF guidelines influence visits?



Michigan Health Plan Policies

- Increase understanding of current status of health insurance policies for BRCA1/2 testing with respect to USPSTF guidelines
- Increase number of plans with policies consistent with USPSTF guidelines
 - Recognize health plans that comply with USPSTF
 - Disseminate USPSTF BRCA1/2 guidelines
 - Workshop with Michigan health plans and cancer genetic experts
 - Provide technical assistance to health plans

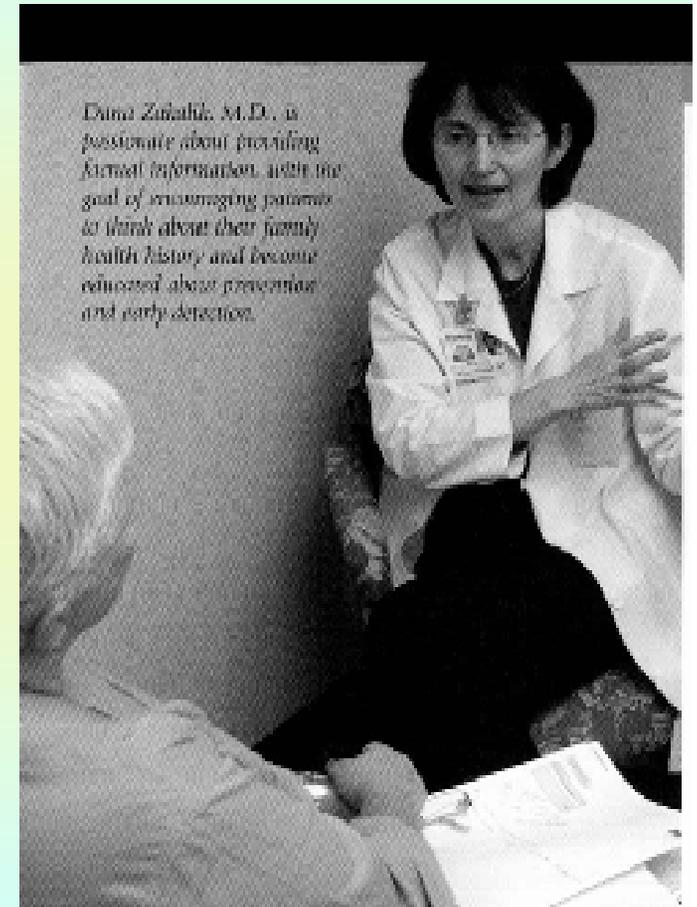


National Examples of Health Plan Policies for BRCA1/2 testing

- Require prior authorization based on specific criteria
 - Aetna
 - Medicare
- Require pre-test counseling by a qualified and appropriately trained provider
 - Medicare
 - Aetna
- Require signed informed consent
 - Medicare
- Coverage for those with personal and/or family history consistent with USPSTF guidelines
 - Aetna
- Coverage for personal history of breast or ovarian cancer
 - Medicare

State Example

- Harrington Insurance for Beaumont employees
 - Established in 2007
 - Requires prior authorization
 - Requires written informed consent
 - Requires pre- and post-test counseling
 - Personal history of breast cancer criteria
 - Personal history of ovarian cancer criteria
 - Family history of breast/ovarian cancer criteria
 - Consistent with USPSTF



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