Lynch Syndrome Universal Screening Network Planning Meeting

September 23, 2011
Chicago O'Hare Hilton

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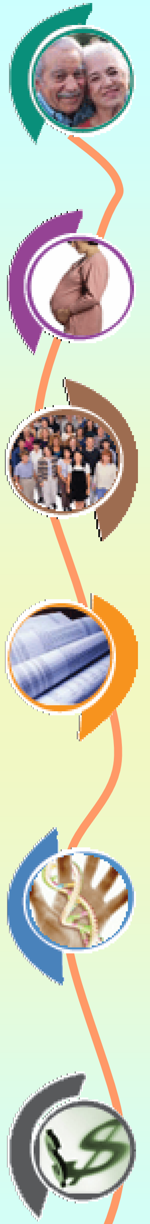
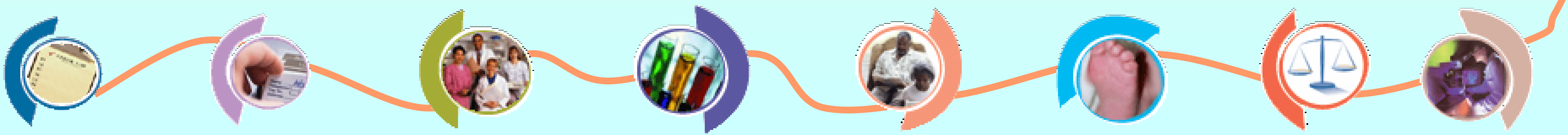




Extra Special Thank Yous

Planning Committee

- Cecelia Bellcross
- Heather Hampel
- Kory Jasperson

Centers for Disease Control and Prevention/Office of Public Health Genomics

- Muin Khoury
- Scott Bowen
- Katie Kolor

McKing Consulting Corporation

- Maggie Ritsick
- Trisha Charles-Rennie

Michigan Department of Community Health Genomics

- Janice Bach
- Sarah Mange
- Sommer Hayden

And all of you in attendance either in-person or by phone!

Today's Participants Selection Criteria

1. Interest and willingness to attend September 23rd event
2. Significant likelihood to begin universal screening by 2012
3. Likely willingness to share data and educational resources
4. Board certified genetics professional involvement in screening program
5. Existing relationship with planning committee members

- All attendees MUST have are #1 and #3 above.
- All invitees should meet at least 1 out of 3 of the other criteria (i.e. #2, 4, 5) with preference given to those that meet all 5 criteria.
- One person per institution will be able to attend

Today's Meeting Objectives

1. To bring together a group of individuals from multiple institutions who are currently performing or considering universal Lynch syndrome screening on newly diagnosed colorectal cancers and other Lynch syndrome related malignancies
2. To discuss developing a network/consortia that would enable continued ongoing cooperative efforts to pool educational resources, screening protocols and key patient data
3. To share existing materials (i.e. educational materials, screening protocols) and to create new resources (i.e. database, website) to organize information from multiple institutions

Today's Agenda

- Background Presentations
- Existing and New Educational Materials
- New Database
- Creating a Network/Consortia
- Small Group Discussion
- Next Steps

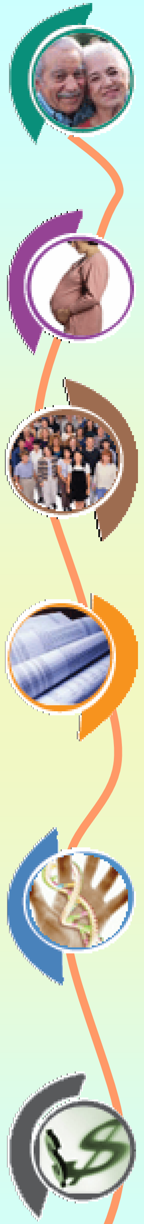
Genomics Applications in Practice and Prevention (GAPP): Translation Programs in Education, Surveillance, and Policy

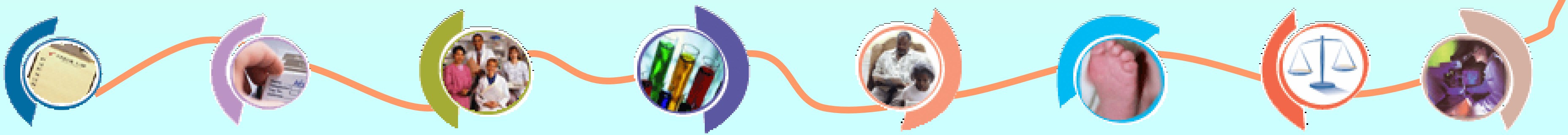
- **3 year cooperative agreement, 2008-2011**
  - Large, well-defined populations in US (greater than 100,000)
- **Goal:** move human genome applications into health practice to maximize health benefits and minimize harm through non-research activities

- **Expected measurable outcomes:**
  - **Surveillance**: measure use of counseling and testing for BRCA1/2; knowledge of providers or public on use of BRCA1/2 or EGAPP-identified genetic test(s); use of EGAPP genetic test(s); use of family history tools
  - **Education**: increase knowledge of validity, utility, harms and benefits of EGAPP-identified genetic test(s); increase use of family history, counseling and BRCA1/2 tests as recommended by USPSTF
  - **Policy**: increase use of family history, counseling, and BRCA1/2 tests as recommended by USPSTF

The 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 Lynch syndrome (HNPCC) related cancers that use best practice recommendations for family history assessment, cancer genetic counseling and testing



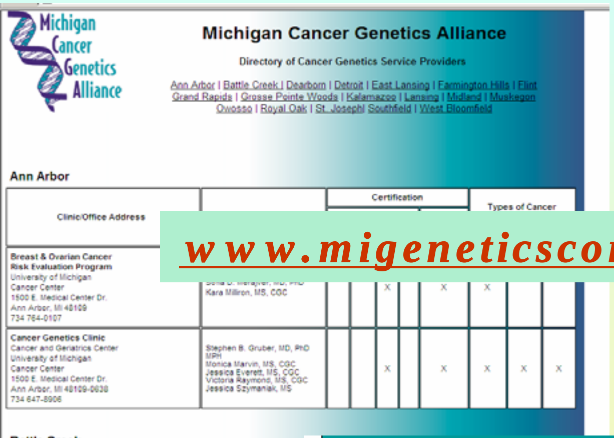


Our Program's Goals

2008-2011

- 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

Websites



Michigan Cancer Genetics Alliance

Michigan Cancer Genetics Alliance

Directory of Cancer Genetics Service Providers

Ann Arbor | Battle Creek | Dearborn | Detroit | East Lansing | Farmington Hills | Flint
Grand Rapids | Grosse Pointe Woods | Kalamazoo | Lansing | Midland | Muskegon
Owosso | Royal Oak | St. Joseph| Southfield | West Bloomfield

Ann Arbor

Clinic/Office Address		Certification					Types of Cancer		
Breast & Ovarian Cancer Risk Evaluation Program University of Michigan Cancer Center 1500 E. Medical Center Dr. Ann Arbor, MI 48109 734 764-0107	Kara Milliron, MS, CGC			X		X	X		
Cancer Genetics Clinic Cancer and Geriatrics Center University of Michigan Cancer Center 1500 E. Medical Center Dr. Ann Arbor, MI 48109-0638 734 647-8906	Stephen B. Gruber, MD, PhD MPH Monica Marvin, MS, CGC Jessica Everett, MS, CGC Victoria Raymond, MS, CGC Jessica Szymaniak, MS			X		X	X	X	X

Battle Creek

Clinic/Office Address	Contact Person(s)
The Cancer Care Center 300 North Ave. Battle Creek, MI 49017 269-966-8647	Gretchen Neff, MS, CGC Susan DeRuiter, RN

www.migeneticsconnection.org

Promoting Cancer Genomics Best Practices through Surveillance, Education and Policy Change in the State of Michigan, 2008-2011

The MDCH Genomics Program, in collaboration with the CDC Office of Public Health Genomics, is identifying and promoting cancer genomics best practices for appropriate translation of cancer genetic tests and gene profiling tests into clinical and public health practice. Project goals include:

counseling and evidence-based genetic tests

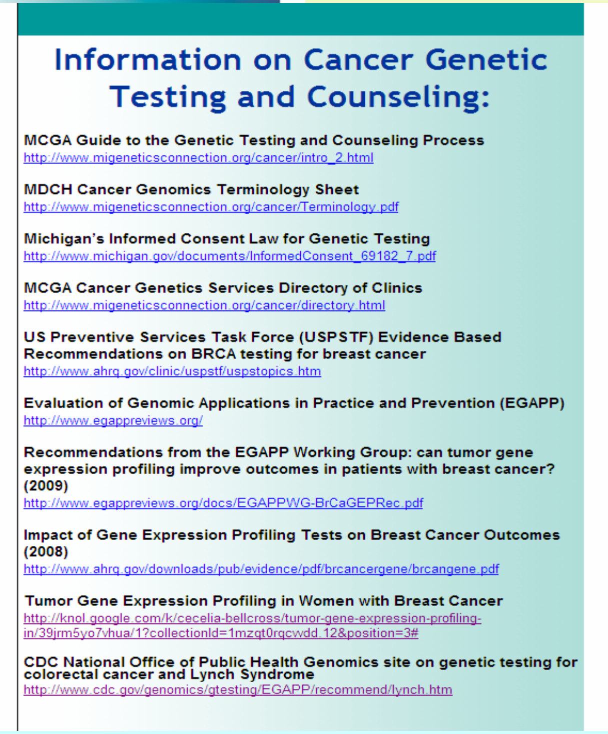
3) Identifying a model health insurance policy for BRCA1 & 2 cancer genetic testing

Methods:

The core MDCH team includes a project director, coordinator, cancer genomics educator and epidemiologist. In addition, we have identified the partners needed to 1) develop a surveillance system to monitor the use of genetic counseling and testing for BRCA1/2, and the use of genetic tests for colorectal cancer (Lynch Syndrome); 2) implement educational activities; and 3) identify the need for health plan policy changes in relation to the US Preventive Services Task Force Guidelines for the use of BRCA testing. Multiple different activities will address each of these objectives. For further details, please see our logic model.

Related Content
- Newborn Screening Program
- Michigan Newborn Screening Questions and Answers
- Public Health Genomics Program: Publications and Presentations
- Birth Defects and Genetic Conditions:
- Genomics and Genetic Disorders Staff Directory
- Fact sheets for the eleven NBS disorders

www.michigan.gov/genomics



Information on Cancer Genetic Testing and Counseling:

MCGA Guide to the Genetic Testing and Counseling Process
http://www.migeneticsconnection.org/cancer/intro_2.html

MDCH Cancer Genomics Terminology Sheet
http://www.migeneticsconnection.org/cancer/Terminology.pdf

Michigan's Informed Consent Law for Genetic Testing
http://www.michigan.gov/documents/InformedConsent_69182_7.pdf

MCGA Cancer Genetics Services Directory of Clinics
http://www.migeneticsconnection.org/cancer/directory.html

US Preventive Services Task Force (USPSTF) Evidence Based Recommendations on BRCA testing for breast cancer
http://www.ahrq.gov/clinic/uspstf/uspstopics.htm

Evaluation of Genomic Applications in Practice and Prevention (EGAPP)
http://www.egappreviews.org/

Recommendations from the EGAPP Working Group: can tumor gene expression profiling improve outcomes in patients with breast cancer? (2009)
http://www.egappreviews.org/docs/EGAPPWG-BrCaGEPRec.pdf

Impact of Gene Expression Profiling Tests on Breast Cancer Outcomes (2008)
http://www.ahrq.gov/downloads/pub/evidence/pdf/brcancergene/brcangene.pdf

Tumor Gene Expression Profiling in Women with Breast Cancer
http://knol.google.com/k/cecelia-bellcross/tumor-gene-expression-profiling-in/39jrm5yo7vhua/1?collectionId=1mzqt0rqcwdd.12&position=3#

CDC National Office of Public Health Genomics site on genetic testing for colorectal cancer and Lynch Syndrome
http://www.cdc.gov/genomics/gtesting/EGAPP/recommend/lynch.htm

Spotlight

The Community Network Collaborative Breast Cancer Screening Project is a Detroit Community Network Program project that brings together five organizations to provide breast health awareness, mammography screening, and system navigation to underserved African-American women in the city of Detroit and the surrounding area. Read more about this award-winning project.

- Visit our Spotlight Archive.

- April 18-24 is National Minority Cancer Awareness Week
- 2009 MCC Annual Meeting concurrent session available online as Webinar worth 1.5 CEUs
- MCC Screening Guidelines for Early Detection of Breast Cancer
- MCGA / MCC Position Paper for Healthcare Providers: *Testing for Hereditary Cancer Predisposition Syndromes and Genetic Counseling*
- *Michigan Cancer Survivorship Resource Guide*
- *A Survey of Genetic Counselors in Michigan*

www.michigancancer.org

Today's Funding

- One time, end of fiscal year remaining funds
  - Centers for Disease Control and Prevention, Contract No. 200-2009-F-32675
- Creation of educational resources or events permitted with funding
  - Today's event ☺
  - New fact sheets (Heather Hampel)
  - New Database (Greg Sundberg, Cecelia Bellcross, Sarah Mange)
- No funds (yet) identified to continue work in 2011/2012 fiscal period