



Michigan Cancer Genetics Alliance

Guide to the Genetic Counseling Process

This guide was developed with a focus on primary care providers and was a collaborative effort between the Michigan Cancer Genetics Alliance, the Michigan Cancer Consortium and the Michigan Department of Community Health. It was recently updated in 2012 to reflect new evidence-based practice recommendations and new standards published by the American College of Surgeons (ACOS) Commission on Cancer.

The Michigan Cancer Genetics Alliance (MCGA) is a collaborative network of genetics experts and others with an interest in cancer genomics, the Michigan Cancer Genetics Alliance (MCGA) serves as the leading resource on cancer genetics in the state of Michigan. MCGA promotes quality utilization of genetics technology and clinical genetics services to improve care and health outcomes through education, leadership, and advocacy. For more information on MCGA or becoming a member of MCGA, contact genetics@michigan.gov.

The Michigan Cancer Consortium (MCC) is a statewide, broad-based partnership that strives to include all interested public and private organizations and provides a forum for collaboration (communication, coordination, and the sharing of resources) to reduce the burden of cancer among the citizens of Michigan by achieving the Consortium's research-based and results-oriented cancer prevention and control priorities. For more information on the MCC or how your organization can get involved in cancer prevention and control, visit www.michigancancer.org.

To visit the MiGRC resource database, visit www.migrc.org.

View the MI Directory of Cancer Genetic Services Providers at www.migrc.org/cancer/directory.html.

What is Genetic Counseling?

Genetic counseling is a specialized health education process designed to help affected or at-risk persons understand genetic disorders and their impact, transmission, prevention, management, and treatment options. The counseling process, however, should help patients and their family members to understand that genetic testing is not always an option¹.

Components of the Risk Assessment, Genetic Counseling and Testing Process:

Persons who are determined to be at an increased risk for developing cancer by their primary healthcare provider should be referred for genetic counseling. Cancer genetic counseling is a consultative process whereby the patient's risk is evaluated by means of a review of personal and family history information. Once a patient's level of risk is identified they receive education regarding their level of risk, genetic testing, if available, screening options/frequencies and other diet and lifestyle issues relating to the type of cancer or a specific cancer syndrome. Persons who choose to have genetic testing will then have a second genetic counseling session to review test results and their meaning. Patients are referred back to their primary healthcare provider once the counseling process is completed. Referring care providers should receive a letter detailing information specific to their patient. The following are components of the risk assessment, and the genetic counseling and testing process.²

1. Cancer Risk Assessment
 - Medical History Information
 - Family History Information
 - Physical Exam (when appropriate)
 - Determination of Level of Risk (Risk Assessment)

2. Genetic Education
 - Education regarding the individuals level of risk
 - Discussion about whether genetic testing is available and/or likely to be informative
 - Discussion of benefits, limitations, and risks of genetic testing, when appropriate
 - Discussion of screening/surveillance recommendations and follow-up if no genetic testing
3. Genetic Susceptibility Testing
 - Completion of above steps
 - Signed consent in compliance with [Michigan PA 29 of 2000](#)
 - Specimen obtained for testing process (may be blood or tissue)
 - Education session regarding results of genetic testing
 - Known or unknown mutation in family
 - Negative, Positive, Uninformative
 - Diet & Lifestyle Considerations
 - Informing family members of test results
4. Follow-up Plan of Care
 - Screening recommendations based on results of genetic testing
 - Type of screening and frequency
5. Discussion of treatment and prevention options if appropriate
 - Prophylactic surgery options
 - Chemoprevention, if appropriate
 - Discussion of available research protocols and clinical trials if appropriate
 - Inclusion of primary care/referring provider in discussions and follow up plan

Defining Clinical Genetics Professionals^{2,3}

According to the ACOS Commission on Cancer, Cancer Program Standards for 2012, “Cancer risk assessment and genetic counseling are performed by a cancer genetics professional who has extensive experience and educational background in genetics, cancer genetics, counseling, and hereditary cancer syndromes to provide accurate risk assessment and empathetic genetic counseling to patients with cancer and their families.” In addition, the CoC depicts which genetics professionals have adequate or appropriate training to provide cancer genetics services.

Genetics professionals include people with the following:

- An American Board of Genetic Counseling (ABGC) or American Board of Medical Genetics (ABMG) board-certified/board-eligible or (in some states) a licensed genetic counselor
- An American College of Medical Genetics physician board certified in medical genetics
- A Genetics Clinical Nurse (GCN) or an Advanced Practice Nurse in Genetics (APNG), credentialed through the Genetics Nursing Credentialing Commission (GNCC). Credentialing is obtained through successful completion of a professional portfolio review process.
- An advanced practice oncology nurse who is prepared at the graduate level (master or doctorate) with specialized education in cancer genetics and hereditary cancer predisposition syndromes*; certification by the Oncology Nursing Certification Corporation is preferred.
- A board-certified physician with experience in cancer genetics (defined as providing cancer risk assessment on a regular basis).

*Please note, specialized training in cancer genetics should be ongoing; educational seminars offered by commercial laboratories about how to perform genetic testing are not considered adequate training for cancer risk assessment and genetic counseling.

Medical Geneticist - A medical geneticist is usually an MD or a DO (occasionally a PhD) who has completed fellowship (or comparable) training in medical genetics. The American Board of Medical Genetics (ABMG) certifies medical geneticists. Medical genetics is a recognized subspecialty of the American Board of Medical Specialties (ABMS). The American Society of Human Genetics (ASHG) is the professional organization and the American College of Medical Genetics (ACMG) is the representative body for geneticists.

Board Certified/Board Eligible Genetic Counselor - A genetic counselor has completed a masters' level training program specializing in genetic counseling. The American Board of Genetic Counseling (ABGC) certifies genetic counselors. Before 1993, The American Board of Medical Genetics (ABMG) certified genetic counselors. The National Society of Genetic Counselors (NSGC) is the professional organization for genetic counselors.

Genetic Nurse - Genetic nurses are typically registered nurses or master' level nurses with special training in human genetics. The Genetic Nursing Credentialing Commission (GNCC) certifies genetic nurses. Their professional organization is The International Society of Nurses in Genetics (ISONG).

Genetics certification and credentials of various health professionals can be verified at the following Web sites:

- [American Board of Medical Genetics](#)
- [American Board of Genetic Counseling](#)
- [Advance Practice Nurse in Genetics credential from the Genetic Nursing Credentialing Commission](#)

References:

¹ STAT!Ref Online Electronic Medical Library, ACP's PIER: The Physicians' Information and Education Resource, Philadelphia, PA, 2004 Available at: <http://online.statref.com/document.aspx?fxid=50&docid=2424>

² Riley, BD, Culver, JO, Skrzynia, C, Senter, LA, Peters, JA, Costalas, JW, Callif-Daley, F, Grumet, SC, Hunt, KS, Nagy, RS, McKinnon, WC, Petrucelli, NM, Bennet, RL, & Trepanier, AM. Essential Elements of Genetic Cancer Risk Assessment, Counseling, and Testing: Updated Recommendations of the National Society of Genetic Counselors. J Genet Counsel 2012; 21:151-161.

³ American College of Surgeons Commission on Cancer "Cancer Program Standards 2012: Ensuring Patient-Centered Care." Retrieved May 2012 from <http://www.facs.org/cancer/coc/cocprogramstandards2012.pdf>.

⁴ Information from Gene Tests website at: <http://www.genetest.org>

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