

## GENETIC CENTERS IN MICHIGAN

**Detroit Medical Center, Detroit**  
Children's Hospital: Div. of Genetics &  
Metabolism (313) 745-4513

**Henry Ford Hospital, Detroit**  
Outreach clinics: Saginaw & Midland  
Dept. of Medical Genetics (313) 916-3188

**Michigan State University, E. Lansing**  
Outreach clinics: Flint & Kalamazoo  
Genetic Counseling Clinic (517) 353-2030

**Spectrum Health, Grand Rapids**  
Genetic Services (616) 391-2700

**University of Michigan, Ann Arbor**  
Outreach clinics: Marquette, Traverse City &  
Gaylord  
Pediatrics Genetics Clinic (734) 764-0579

**William Beaumont Hospital, Royal Oak**  
Pediatric Genetics Clinic (248) 551-0487

# DRAFT

## STATE OF MICHIGAN RESOURCES

**Genetics Program**  
E-mail: [genetics@michigan.gov](mailto:genetics@michigan.gov)  
Phone: (866) 852-1247 (toll-free)  
(517) 335-8887  
Web Site: [www.MIGeneticsConnection.org](http://www.MIGeneticsConnection.org)

**Early Hearing Detection and Intervention  
Program**  
Phone: (517) 335-8884  
TTY: (517) 335-8246  
FAX: (517) 335-8036  
Web Site: [www.michigan.gov/ehdi](http://www.michigan.gov/ehdi)

**Children's Special Health Care Services**  
E-mail: [cshsfc@michigan.gov](mailto:cshsfc@michigan.gov)  
Phone: (800) 359-3722 (toll-free)  
Web Site: [www.michigan.gov/cshcs](http://www.michigan.gov/cshcs)

**Early On<sup>®</sup> Michigan**  
Phone: (800) Early-On or (800) 327-5966  
TTY: 517-668-2505  
Web Site: [www.1800earlyon.org](http://www.1800earlyon.org)

## Genetics

&

## Young Children with Hearing Loss



### Resources on the Web

**MI Genetics Connection**, Support Directory - [www.migeneticsconnection.org/supportdirectory.shtml](http://www.migeneticsconnection.org/supportdirectory.shtml)

Boys Town National Research Hospital - [www.boystownhospital.org/home.asp](http://www.boystownhospital.org/home.asp)

**National Institute on Deafness and Other Disorders** - [www.nidcd.nih.gov/index.asp](http://www.nidcd.nih.gov/index.asp)

Gene Reviews - [www.geneclinics.org/profiles/deafness-overview/details.html](http://www.geneclinics.org/profiles/deafness-overview/details.html)

**Raising Deaf Kids** (Children's Hospital of Philadelphia) - [www.raisingdeafkids.org](http://www.raisingdeafkids.org)

Centers for Disease Control and Prevention - [www.cdc.gov/NCBDDD/EHDI/genetics.htm](http://www.cdc.gov/NCBDDD/EHDI/genetics.htm)

**Newborn Screening ACT Sheets and Algorithms** -

<http://www.acmg.net/resources/policies/ACT/condition-analyte-links.htm>



*The Michigan EHDI Program recommends a genetic evaluation for babies and young children with hearing loss. Families may wonder why this is important. This pamphlet provides some information about genes and hearing loss. It also explains what to expect at a genetics clinic.*

## What are genes?

Genes are like a recipe for the human body. They tell all the parts of the body how to grow and function. A *genetic condition* occurs when a person has a change in a gene that prevents it from working correctly.

## How are genes related to hearing loss?

More than *one-half* of all cases of hearing loss are caused by genetic factors. This is true even when no other family members are known to have hearing loss. Genetic hearing loss may be linked to health or learning problems.

## Why is it important to find out if my child's hearing loss is genetic?

It is important to find out if your child is at risk for other health conditions. You might also want to know the chance for your other children to

have hearing loss or other problems. By knowing more about your child's hearing loss, you can best decide what to do for your child and family.

## How is hearing loss inherited?

Genetic hearing loss can be passed through a family in different ways. Sometimes hearing loss occurs in every generation. More often, only one child, or brothers and sisters, may be affected. Even if your child has no family history of hearing loss, the cause could still be genetic.

## How do I find out if my child has a genetic hearing loss?

Make an appointment to have your child seen at a genetics clinic. Your child's primary health provider, audiologist, and/or an *Early On*<sup>®</sup> provider can help you make the appointment and collect the medical information needed. You can also call one of the clinics listed on the back of this brochure.

## What happens at the genetics appointment?

Your child's health history and records will be reviewed. Your child's development will be discussed. You will also be asked questions about your family's medical history. A health exam will be done to look for signs of genetic hearing loss.

Based on the history and exam, the doctor will discuss with you whether any tests (such as blood or urine) are needed and what might be learned from them.

The doctor will then look at all the information and try to figure out if the hearing loss is caused by genetic or other factors. You will have time to discuss what has been learned with the genetics clinic staff. This may include suggestions for your child's future medical care. A report will also be sent to your child's doctor.

## What happens if the cause is not found?

More is being learned about genetics every day. If the cause of your child's hearing loss is not found the first time, your family may be asked to return in a year or two to see if there is any new information. If your child develops new medical or developmental problems, it may be time to revisit the genetic specialist.

## Will insurance cover the cost of the appointment?

The clinic visit and testing are covered by many insurance plans, including Medicaid and Children's Special Health Care Services. Check with your plan to be sure. If you are in a managed care plan, you will need a referral from your child's primary doctor. If you need help finding coverage, please e-mail [genetics@michigan.gov](mailto:genetics@michigan.gov) or call (866) 852-1247 (toll-free).