Four basic components of genetic services

Identifying a diagnosis: Involves taking a medical and family history, a physical exam and tests to identify if your child has a genetic condition.

Information counseling: Provides information about a genetic condition to help the family understand what it is.

Support counseling: Helps the family members cope with their feelings, understand why they feel that way, and help them find other people who can give them support.

Follow up care: Refer your child to appropriate specialists and work with all of your child's doctors to help them provide the best care for your child.

Parent Tips:

- ⇒ Your appointment may last 45-90 minutes. Be prepared by bringing small toys or snacks for your child.
- ⇒ You may wish to bring someone with you to help you remember what is discussed and to provide support.
- ⇒ Taking notes can give you a way to review what was talked about after the appointment. Your support person may be a good person to take notes.
- ⇒ Bringing your child's baby book may help you to remember important firsts in your child's life.

Region 4
Midwest Genetics Collaborative

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www.Region4Genetics.org

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Clinic info here

What to expect when your child is referred for a Genetics Appointment

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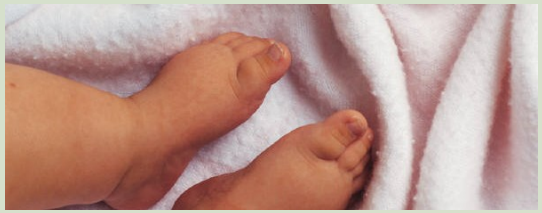
What are genetic services?

Genetic services are specialized medical services that focus on the diagnosis, care and treatment of health issues arising from variations in a person's genetic make-up.

Reasons your child might have a genetics appointment:

- Your child's newborn screening test indicated a need for follow up.
- There are concerns about your child's growth or development.
- Your child has certain medical symptoms or physical traits.
- There is a family history of a genetic condition.



Who provides genetic services?

- Medical geneticists are doctors who specialize in identifying and treating medical conditions with a genetic cause.
- Genetic counselors provide information, counseling and support to children and families with genetic conditions.
- Medical geneticists and genetic counselors often work together as a team. Both give information and support to families to help them make the best choices for their child and family.
- Specialty clinics trained to diagnose and treat specific genetic conditions, such as cystic fibrosis. They may provide additional services as well.

How should you prepare for the appointment?

Write down your concerns and questions you want to discuss with the doctor. Information you could gather to help the doctor identify your child's diagnosis include:

- The mother's pregnancy history, including any tests, problems or illnesses during pregnancy.
- Your child's medical records and health history along with any copies of tests related to the reason for your visit.
- Your child's growth and development including the age your child first rolled over, sat up, walked or talked.
- Your family's health history. It is helpful to know about any relatives with medical conditions, or if any family member has a genetic condition or birth defect or delays in growth , development or learning.
- Your family's ethnic background or where your ancestors came from. Some genetic conditions are more common in certain ethnic groups.
- List of specialists who have seen or are caring for your child.
- If anyone has concerns about your child and what the concerns are (for example, grandparent, babysitter, friend).
- Why you think your child is seeing a geneticist.

What happens during your appointment?

Here are some things you can expect during your child's appointment. These may take place over more than one visit. The medical geneticist and/or genetic counselor will:

- Review the reason for your child's visit.
- Collect information on your family's health history, including any genetic conditions or medical problems of each family member.
- Complete a physical exam if necessary.
- Decide on what tests are required to rule out or identify a genetic condition.
- Review any test results with you and provide you with information about what the results mean and what happens next.
- Work to assist your child's regular doctor to get the information needed to take care of your child.
- Make referrals to other doctors for additional medical care if needed.
- Help you find additional resources for information and support.

It is important to remember not every condition can be identified or diagnosed right away. However, new conditions and tests are identified over time, so staying in touch with your child's genetic provider may be helpful for the future.