



What are Genetic Services?

Genetics is a medical specialty which provides diagnostic services and genetic counseling for individuals and families who have or are at-risk for developing genetic conditions. It is concerned with the diagnosis, treatment and management of hereditary and genetic conditions. There are thousands of documented genetic conditions but the most common conditions include the following:

- Chromosomal changes (e.g. Down syndrome), which cause birth defects, intellectual/developmental disabilities and/or reproductive problems
- Single gene disorders such as cystic fibrosis, muscular dystrophy, Huntington's disease and sickle cell disease
- Birth defects that can have a genetic component such as spina bifida, cleft lip and cleft palate

When Would I or my Child Be Referred to a Genetic Clinic?

- There is an abnormal finding on an ultrasound or other test during your pregnancy
- Your baby's newborn screening results were concerning
- You or your doctor is concerned that your child may have a genetic or inherited condition and would like more information

Who Will My Child See at the Genetic Clinic?

Most children are born healthy with no medical problems or birth defects. However, some children are born with differences in body structure, brain development, or body chemistry that can lead to problems with health, development, school performance, and/or social interaction. The two professionals commonly seen are pediatric geneticists (doctors) and genetic counselors.

Geneticists:

- Are doctors who are trained to recognize specific genetic conditions
- Suggest tests to help determine a diagnosis and if the conditions can be inherited (through the genes)
- Will provide information about prognosis, management, and treatment to aid in understanding the condition and caring for your child.
- Offer testing to other family members who may be at risk for having children with similar health concerns



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Genetic Counselors:

- Review family and medical histories
- Explain how genetic conditions are passed down through families
- Determine if you or your family members (including other siblings) are at risk for disease
- Provide information about testing options and help you make informed choices or life plans
- Help you find referrals to medical specialists, advocacy and support networks, and other resources

What should I Expect at My Child's Appointment?

Most genetic appointments are 45 to 60 minutes long. Typically a lot of information is shared. Bring someone with you that can help you ask questions and take notes. Appointments vary depending on why your child is being seen and if this is their first visit with a genetics clinic. The following often occur:

- Discussion of health concerns of your child that have brought you to the clinic
- A collection of family health history of at least three generations, documenting all genetic conditions, health concerns, and cause and age of death of your child's family members. (Gather and bring as much of this information as possible)
- A medical examination of your child (and possibly other family members)
- Photographs may be taken to document certain features for the medical record
- The doctor (geneticist) will explain their findings to you, and discuss options for further evaluation if needed.
- You will be encouraged to ask questions, and you, the geneticist and the genetic counselor will make a decision together about any further testing and evaluations.
- Some children require tests (usually a blood sample) which may be offered immediately. Others may require an authorization with insurance and may be drawn at another time

Where Can I Find Support? Oklahoma Family Network (OFN)

Who we are? Our families and staff have children with special healthcare needs, disabilities, or we have lost a child with special needs

How we can help?

- By encouraging and supporting you
- By attending your child's appointment with you
- By connecting you with another family with a child similar to yours for emotional support and information
- By helping you find information about your child's condition
- By helping you find resources in your community



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