



## Why See a Geneticist?

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The Community Health Clinic (CHC) is a medical clinic that helps diagnose and treat genetic disorders. Genetic disorders are medical conditions caused by changes in a person's genetic information (genes and DNA)—the blueprint inside our cells that gives instructions for how our bodies develop, look, grow, and work. People with genetic disorders are born with them, but the actual signs of a genetic disorder can appear while a baby is still in the womb, at birth, or later in life. Genetic disorders can have a wide variety of symptoms, which often requires care by many types of doctors. The CHC's medical care is led by Dr. Ammous ("Dr. Z" for short), who is a geneticist—a doctor with specialized training to diagnose and manage rare genetic disorders. Sometimes a genetic disorder can be easily diagnosed, but many times, it is not that simple. In some cases, a diagnosis may not be found if the cause of the genetic disorder is still unknown or if the necessary medical technology is not available yet.

*How do I know if I have a genetic disorder?* Some people already know that they have a genetic disorder, but many more community members have various special needs that lack an explanation. In many of these families, those special needs may be a result of an underlying genetic disorder. Common signs of genetic disorders include birth defects, developmental delay, intellectual disability, physical disability, behavior issues, abnormal movements, seizures, speech problems, unusual facial features, etc. For example, people with slow learning ability, cerebral palsy, speech impairment, and seizures may actually have a genetic disorder that has caused these special needs. If you are concerned that you, your child, or a relative may have a genetic disorder, then you can always contact the CHC to see if that is indeed a possibility.

*I already have medical care for my special needs or my child's special needs. Why would we want to find a diagnosis for a genetic disorder?* The goal of finding a genetic diagnosis is to keep the person as healthy as possible. While many genetic disorders do not have a complete cure, they can still be treated to help lessen the symptoms that appear or to prevent future complications. Even if someone has special needs that have been managed over the years, a genetic diagnosis may help doctors find a better tailored treatment or care plan to further help the patient. If a genetic disorder is suspected but not yet found, the CHC would help treat the person even if a diagnosis cannot be made.

*We already have a genetic diagnosis, but we do not see a geneticist anymore. Why would we come to the CHC?* Since genetic disorders are rare, lifelong diseases, it is important for someone with a genetic disorder to see a geneticist throughout their life. A person with a genetic disorder may often see many types of doctors (family doctor, neurologist, cardiologist, etc.). However, these doctors may not be as familiar with genetic disorders as a geneticist, so it is important that a geneticist is involved. Research is done every day, so the testing and treatment plan for genetic disorders may change frequently. The CHC is trained to manage genetic diseases and is sure to keep up with current changes to treatment. How often someone with a genetic disorder would be seen at the CHC depends on the type of genetic disease, the current health of the person, and their age. Some patients may be seen very frequently and some may only be seen yearly.

The mission of the CHC is to "provide excellent and affordable medical care consistent with the needs of the Amish, Mennonite and other rural Indiana communities, with a focus on individuals and families with special health care needs." Even though the CHC is not able to currently provide families with primary health care or medical services beyond genetics care, the CHC can help coordinate your or your child's healthcare with other doctors that may be needed to alleviate the symptoms associated with genetic disease. Please do not hesitate to contact that CHC to find out if you or your child could benefit from being a patient at the CHC.