

A Fact Sheet for Parents: My Child Has Autism- How Can Genetics Help?

Sometimes, a Cause of Autism May Be Found Which Can Help both Child and Family

When a child receives a diagnosis of autism, parents often ask “why” or “how” did this happen to their child. There are no easy answers to these questions. Many of the genetic causes of autism remain unknown, but about one in 10 children with autism have a genetic syndrome. In these children, autism may be their first sign of a genetic syndrome.

A Genetic Syndrome as a Cause of Autism

A genetic syndrome is a set of signs that may affect health, looks, behaviors, and sometimes learning. There are several different genetic syndromes that may cause autism. A diagnosis of a genetic syndrome may help to find underlying or possible health and developmental concerns. If found early, these concerns may be lessened or avoided.

Seeking Help from Genetics Professionals

A genetics clinic is where a family meets a medical doctor with special training in genetics called a geneticist. A genetic counselor, also present in the clinic, assists the geneticist and the family.

What families can expect at the genetics clinic:

- Being asked about their child’s and their relatives’ medical and health histories including parents, grandparents, siblings, aunts, uncles and cousins.
- Having a genetic counselor draw out their family tree and pointing out any patterns that may suggest the presence of a genetic syndrome in the family.
- Learning about our genetic make-up and how we inherit our traits in the form of chromosomes and genes.
- Having the geneticist provide a full physical exam of the child and if needed, recommend testing. A blood sample is often obtained on the same day.
- Understanding the types of genetic tests available and how helpful they may be for the child and family.

If a genetic syndrome is found, the geneticist works with the child’s primary care provider to manage the medical needs of the child. The genetic counselor shares with the family resources and information such as support groups and reading materials. Many parents are reassured when they understand the cause of their child’s autism. Knowing what to expect helps parents actively respond to their child’s needs.

Affording Genetic Testing

Testing is often needed to check for the presence of a genetic syndrome in children with autism. Parents may choose not to have their child tested at the time of the clinic visit, choosing instead to seek information from the geneticist and genetic counselor. Sometimes a test may be expensive, especially if it is not covered by insurance or Medicaid. Genetic services, including testing, is a medical specialty whose expenses are not covered by the Children’s Developmental Services Agency (CDSA). Parents with medical insurance should call their insurance provider to ask about the basic coverage of genetic tests. For families without Medicaid or private insurance, assistance may be available through the genetic service provider. Also, hospitals and medical centers providing genetic services have payment plan options.

To find genetic services resources, please contact the Children with Special Needs Help Line:
1-800-737-3028 (English and Spanish).

To find information on genetic syndromes, genetic testing or to obtain a genetics appointment, please contact a regional public health genetic counselor through the Genetics and Newborn Screening Unit, NC Division of Public Health:
1-866-431-7434 (English) or 1-800-367-2229 (Spanish and English)

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