

# **Autism Spectrum Disorder Genetics Clinic:**

Discuss with a genetic counselor the impact of genetics on your child with ASD.

### What do we know about genetics and autism spectrum disorder?

**Autism Spectrum Disorders** (ASD) are a complex group of neurodevelopmental disorders. The cause of ASD is not always known, however, we know that genetics plays a major role. Many different genetic changes have been associated with ASD and scientists are regularly discovering new genetic causes. Genetic changes can run in the family or they can occur for the first time in your child with ASD. A genetic evaluation can help you understand the impact of genetics in your child diagnosed with ASD.

### What is Genetic Counseling?

Genetic counselors help translate complicated genetic and scientific information while providing you with help and support. Genetic counselors can explain genetic testing, help parents with decision making, as well as support emotional responses to recent diagnoses or information. They can also discuss the chances of having another child with ASD, provide resources and information on management or support groups.

### What is Genetic Testing?

The purpose of genetic testing is to search for changes in the DNA or chromosomes that may be related to your child's ASD diagnosis. There are many types of genetic tests. Some tests are targeted at a specific gene or genetic condition, while others take a broader look across many genes, or look at the chromosomes. The presence of a genetic change as detected by genetic testing does not diagnose a child with ASD. Rather, genetic testing helps identify an underlying genetic cause for ASD symptoms that have been diagnosed by your medical provider, typically a pediatrician or a developmental pediatrician. Genetic testing is optional and a genetic counselor will quide you through the decision to pursue testing.







## What Are Possible Benefits and Limitations of Genetic Testing?

### **Benefits** Limitations or Risks

- · Discussion of prognosis and information on additional health concerns
- · Possibility of specific treatment options
- Discussion of whether ASD was inherited or new in your child
- Discussion of more accurate and personalized risk numbers for family members, siblings or future pregnancies
- Connect your family with support groups

- The possibility of unclear results leading to anxiety or uncertainty
- The possibility of no change in management or
- · The possibility of finding unexpected information, such as risk for health conditions not related to the main concerns for ordering the test, or unexpected familial relationships
- · Concerns about genetic discrimination are discussed (www.GINAhelp.org)

### What to Expect At Your Genetics Appointment

#### 1. Setting Goals

Sessions begin with a discussion about what you hope to learn or accomplish during your time with the counselor. Think about questions and concerns ahead of time and these can be used to guide the session.

#### 2. Family History

A family history will be taken to gather information about any diagnoses or medical concerns in family members. Before the session, check in with family members and try to gather some information on diagnoses, pregnancy losses, and health concerns. We use information to see if there are any clues for particular genetic conditions that may run in your family.

#### 3. Education and Information-Giving

The counselor can review and answer any questions or concerns you have related to your child's diagnosis or genetic testing. The genetic counselor will walk you through the different

types of genetic testing, as well as the logistics, such as health insurance, timing of results, and sample collection and follow up. If they cannot answer your questions, they will provide you with resources or connect you with a professional who can provide you with the information you need.

#### 4. Decision-Making

The counselor will explain the genetic tests and the possible results. The purpose of the discussion is to answer questions, help you explore your concerns, thoughts, and feelings about these tests and give you information so you can make a fullyinformed decision about whether or not to pursue genetic testing.

### 5. Support and Counseling

The counselor can help you cope with your feelings and emotional responses to the diagnosis, the genetic testing or any information given in the session, or any other related set of circumstances you may face in your life.

To schedule an appointment call: 703.876.2788. A referral from your provider is required. For additional questions, email: genetics@psvcare.org.





