

Preparation for Genetic Testing

Understanding and managing your child's medical testing can be challenging. This fact sheet covers information on how to prepare for your child's genetic testing appointment. For more information on genetic testing, see our Fact Sheets: ***Genetic Testing Basics*** and ***What to Expect After Genetic Testing***.

Preparing for Your Child's Genetic Testing Appointment:

Before undergoing genetic testing, your family will likely have an appointment with both a Geneticist and Genetics Counselor. This is often called "genetics counseling". During the pre-test counseling, the providers may discuss: your family history, the types of testing available, insurance and financial concerns, the benefits of testing, the risks and limitations of testing, and the possible results. The genetic counselor is educated in both genetics and counseling, and they will likely include your child in the conversation to the extent that they are able and within your family's comfort level. The genetics counselor is trained to help explain complex medical terms and procedures to your family in a way that you can understand, even if you have no previous medical knowledge or experience. They are also trained to provide your family with emotional support during this often complex and complicated process.

In order to prepare for your pre-test genetics counseling appointment, it may be helpful to come prepared with information on your family's medical history. This could include any medical conditions, disabilities, learning difficulties, surgeries, or significant symptoms in biological family members, such as your child's: parents, grandparents, siblings, cousins, and/or aunts and uncles. It is okay if any part of your child's family medical history is unknown, but this is important information to share with your genetic providers.

It may also be helpful to come prepared with questions for your genetic providers, such as:

- What type of testing do you recommend for my child?
- How is this testing done?
- What are the risks involved with this type of testing?
- What will my out-of-pocket costs be for this testing?
- What genetics conditions are you testing my child for?
- Does this condition run in families? Are other family members at risk?
- What should I expect from a positive result?
- What should I expect from a negative result?
- What will the next steps be if my child gets a diagnosis from this testing?
- What will the next steps be if my child does not get a diagnosis from this testing?
- What will happen if I decide NOT to have this testing for my child?
- Are there any supportive resources available to my family during this process?

What to Expect During Genetic Testing

Talk with your doctor about how your child's genetic testing will be completed. A few types of genetic tests are done through a medical procedure, such as: amniocentesis, fluid collection, bone marrow collection, or a blood draw; however, most genetic tests are a simple cheek swab that will likely not be traumatic or painful for children.

It's also important to talk with your doctor to find out if the parents and/or other family members need to be tested along with the child, as this may be required.

For more information about genetics testing, contact Indiana Family to Family at 1-844-323-4636 or visit inf2f.org.

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Paying for Genetic Testing

Not all insurance policies will pay for genetic testing, so it's important to talk with your insurance company about your policy and coverage options. If your insurance is through an employer, you can also talk with your Human Resources department for more information.

As a part of your pre-test genetics counseling, you can talk about financial concerns with your geneticist and genetics counselor. They should be able to answer questions, such as:

- Does my insurance cover this testing?
- What will my out-of-pocket costs be for this testing?
- Are there financial resources available for my family if this test is denied by our insurance?
- Does the medical center or hospital have financial assistance available to help with my out-of-pocket expenses?

Communicating With Your Providers

Remember, it is so important to communicate with your provider and advocate for your child before, during, and after the genetic testing process. Your child's geneticist and genetics counselor are a team that should help you through your child's genetics testing process. Families should not be afraid to ask questions, ask for clarification, or ask for additional resources and information from their genetics providers. Many families have a wide range of emotions during the genetics testing process, including feelings of frustration and grief. Genetics counselors are trained to not only help families through the genetic testing process, but also through the feelings that come along with the process.

Where to find more information

For more information about genetics testing, see our other genetic testing fact sheets or the following resources:

- [Genetic Testing](#) (Mayo Clinic, 2023)
- [Genetic Testing 101: What Parents Need to Know](#) (CHOP, 2019)
- [Pediatric Genetic Counseling](#) (IU Health Riley, 2023)
- [Prenatal Genetic Counseling](#) (AAP, 2013)
- [Your Family Health History and Genetics](#) (AAP, 2015)
- [The Journey Through Diagnosis](#) (Midwest Genetics Network, 2022)

If you have additional questions about the genetic testing process or would like help finding more information, contact Indiana Family to Family at 1-844-323-4636 or inf2f.org

Programs and systems change often. It is important to ensure that you are using the most current information. This fact sheet was updated July 2024. Please check <https://www.inf2f.org/fact-sheets.html> for the most recent edition.

La versión en español de esta información está disponible [aquí](#).

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