

AN INVITATION FOR GENETIC COUNSELING

Hello,

We are writing to invite you to speak with a genetic counselor about your child's newborn screening results. A genetic counselor can answer questions you might have about newborn screening and your child's results. The visit is free.

All families with a child diagnosed with a medical condition following newborn screening are invited.

Visits with the genetic counselor can be in person or can be virtual through telehealth (using a smart phone or computer). For in person visits, the office is located at 11 South Road in Farmington, Connecticut. Visits (in person or virtual) can be arranged whenever you feel ready.

What Do Genetic Counselors Do?

Genetic counseling is a conversation.

Think of genetic counseling as a conversation. Your goals, your feelings, and your concerns are all important. Genetic counselors can work with you – and your physician – to understand complex genetic information and help you make informed decisions.

Genetic counselors receive specialized training in genetics and counseling. They can help you understand the genetics of a disorder, learn if genetic testing might be right for you or other family members, and help to explain results when they are available.

Genetic counselors are there to:

- ✓ Listen to you.
- ✓ Answer questions.
- ✓ Help find support services, if needed.

What Does a Genetic Counseling Session Involve?

Genetic counselors ask about your health history and the health history of your family, discuss how disorders are inherited, and review testing options.

You should plan for a conversation that lasts 30 minutes to one hour.
You are welcome to have someone with you: a family member or a friend.

Your genetic counselor will:

- Explore your family health history.
- Explain medical and genetic information such as:
 - How genetic conditions are passed on from parents to kids (inherited)
 - If you or your family members are at risk to develop a disease

- Tell you about genetic testing options, what testing can and cannot tell you, about the testing process, and about costs.
 - Arrange testing and work with you and your insurance company to understand your coverage, IF you decide to have testing done.
- Receive test results and explain the results to you.
- Talk about what your results or diagnosis mean for your family and how you can talk to your family about your results.
- Give you information about support groups, resources, and referrals for medical specialists for the management of your health.
- Listen and offer support as you decide what is best for you.
 - Genetic counselors are not licensed therapists and will not tell you what to do.

How can I prepare for a genetic counseling visit?

- Review your medical and family history.
 - Genetic counselors may ask about the health of your spouse or partner, children, parents, siblings, grandparents, and other blood relatives.
- You may want to make a list of questions.

What should I do during a counseling appointment?

- Ask questions and talk about any concerns you have. Remember, the genetic counselor is there to help you.

What about privacy issues?

The visit will be treated like a visit with any other healthcare provider, as outlined in The Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Cost:

A genetic counseling visit is free for families identified through newborn screening. We are able to provide this service thanks to funding from the State of Connecticut Department of Public Health Newborn Screening Program.

How do I make an appointment?

When you are ready to schedule an appointment, you can call or email the Division of Genetics at Connecticut Children's:

Phone: 860-837-5759

Email : genetics11south@connecticutchildrens.org

Your child's pediatrician can also make the referral for genetic counseling at Connecticut Children's, if you prefer.