

+ What Is Genetics?

Genetics is a medical field that deals with health and growth problems that may be due to changes in our genes. Geneticists and genetic counselors are health care providers for people with genetic issues.

What is a gene?

A gene is a chemical message that tells your body how to look and work. You inherit (get your genes) from each of your parents, and you pass down your genes to your children. Differences that you can see, like the color of your hair and eyes, are controlled by genes. Genes also control differences that you can't easily see, like how you learn and grow. They keep you alive and healthy.

Genes can also cause health problems. There are thousands of genetic conditions. Some common ones include changes in chromosomes (collection of genes), which can cause problems with learning, growing, staying healthy, or having children.

Some examples of genetic health problems are:

- Down syndrome
- Cystic fibrosis
- Muscular dystrophy
- Spina bifida
- Cleft lip or cleft palate



+ Resources

New England Regional Genetics Network

www.negenetics.org

Resource map, educational videos, links to events, and a resource library

Genes in Life

www.genesinlife.org

Resources, genetic testing 101, after the diagnosis

Parent to Parent USA

www.p2pusa.org

Information and support for families of children with special needs

Genetic Alliance

www.geneticalliance.org

Resources and research

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A Few Things to Know About Your Child's Visit to the Genetics Clinic

+ Why Was My Child Referred to a Genetics Clinic?

Learning about genetics may not be easy, but it is important to your family. This guide should help answer some of your questions. Sometimes the best answers can be given by another family whose child has a genetic condition. Family Voices has a network of families in every state and territory. These families can help you connect to other families and resources. They can also give you advice on how to access and pay for genetic services. Learn more in the "Family Support Organizations" section.

Why was my child referred to the genetics clinic?

- Your child has been referred to a genetics clinic because of questions about their health or development – how your child learns.
- Your child may not be growing or developing the same way as other children their age. They may not digest food normally, or may be sick a lot. There may be something different about how your child looks, talks, or behaves.

These differences may be explained by genetics.



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NEW ENGLAND REGIONAL
GENETICS NETWORK

+ Why Visit a Genetics Clinic?

Why is it important to go to a genetics clinic if my child is already under a doctor's care?

Geneticists focus on genetic conditions, many of which are very rare. So a geneticist may be able to discuss things that your regular doctor may not know about, like other special treatment choices and what to expect in the future.

Who can refer my child to a genetics clinic?

- Depending on your health plan, your child may need a referral from your doctor's office.
- You may be able to make an appointment without a referral.

How long will I have to wait for an appointment?

- It depends on the number of geneticists in your area, and how serious the situation is.
- You may have to wait 3–6 months.
- If a condition is identified as urgent, most offices will see your child within 1–2 days.

Tip: ask if there is a cancellation list so the office can call you on short notice if an appointment opens up.

What can I do while I wait to see the geneticist?

You may want to talk to another parent whose child has similar health issues. Parent to Parent USA (P2P USA) can match you with a parent who can provide emotional support and information. Learn more and find the contact in your state at www.p2pusa.org

+ Before the Visit

- Ask a relative or friend to come with you to help ask questions and take notes.
- Write down information about your child's health history, the health of your other children, your siblings, cousins, parents, and grandparents.
- Write down questions you have for the doctor.
- Be prepared for the appointment to take up to one hour.
- Ask if there are tests your child should have before the visit.
- Check your health plan to see if you need prior approval for any tests.
- Check your health plan to see if it covers genetic tests.

+ At the Clinic

Your child will see a medical genetics team. The team may have:

- A doctor, physician's assistant, or nurse practitioner who specializes in medical genetics.
- A genetic counselor.
- Other health care providers such as nurses, medical students, or resident doctors.

A genetic provider will examine your child.

- They may take pictures to record your child's physical features.
- They will ask about challenges with your child's health and growth.
- They will ask about your family health history.
- The genetic provider will speak with you about what may be going on.
- The provider may want your child to have some tests.
- You will be able to ask questions.

+ Possible Testing

- The genetics team may test your child's blood or urine.
- Your child may have X-rays or other special testing.
- Genetic testing can be expensive. Some health plans do not cover genetic tests. Ask what you will have to pay. Most genetic clinics can write a letter of medical necessity or an appeal so your plan will pay for the tests.

+ After the Appointment

Will my child get a diagnosis at the first visit to the genetics clinic?

Probably not. It can take months to learn if your child has a genetic condition. Waiting is hard. It can help to connect with other parents. *See "What can I do while I wait to see the geneticist?"*

The genetics team will send a letter to you and the person that referred your child. The letter will tell about your child's condition and the findings of any tests.

- Your child may or may not need to return to the genetics clinic.
- Your child may or may not need to see other medical specialists.

+ If My Child Does Not Have a Genetic Condition

What happens next?

- Your child can still get care from the person who referred them.
- Your child may still return to the genetics clinic every 1 or 2 years. Sometimes, new tests or information can help improve your child's health care.

+ If My Child Does Have a Genetic Condition

What happens next?

You may meet with a genetic counselor to talk more about:

- Your child's condition.
- Whether other members of your family may develop or have the same condition.
- How other babies you or your children have can inherit the genes that cause the condition.
- Whether other family members may benefit from testing.
- In many cases, your child can still get care from the person who referred them.

+ New England Family Support Organizations

Connecticut

Path CT

www.pathct.org

Maine

Maine Parent Federation

www.mpf.org

Massachusetts

Federation for Children with Special Needs

www.fcsn.org

New Hampshire

NH Family Voices

www.nhfv.org

Rhode Island

Rhode Island Parent Information Network

www.ripin.org

Vermont

Vermont Family Network

www.vermontfamilynetwork.org