



GENETICS VISIT FAQS

WHY SEE A CLINICAL GENETICIST?

Knowing the exact cause of your (or your child's) condition may help clinicians find the best treatment for you. Naming your condition also can help identify other health problems that might occur due to your condition. This information can help your healthcare team recommend other specialists you may need to see. In addition, some patients may need to see the genetics team on a routine basis to help manage their condition. Lastly, some genetic conditions run in families. Genetic testing may be recommended to determine who else in the family is at risk of having the same condition.

HOW TO PREPARE FOR A GENETICS VISIT

Make a list of questions that you have for the genetics team so that you don't forget to ask any of them during your appointment.

Before your appointment, ask your family about their health history. The genetics team will ask about the health history of your children, brothers, sisters, parents, aunts, uncles, nieces, nephews, cousins, and grandparents. It can be helpful to write this information down before your appointment and bring a copy with you. You should write down:

- Anyone in your family who has similar symptoms to you (or your child).
- How old each person was when those symptoms started.
- Who in your family has been diagnosed with any genetic condition, the name of the condition, and about how old the person was when they were diagnosed.
- Approximate ages of your living relatives.
- Ages at which relatives died and their cause of death.
- Your ethnicity/ancestry on both sides of the family (for example: English, African-American, Jewish).

It also is important to ask your relatives if they have had any genetic testing. With their permission, please bring a copy of their results with you to your appointment.

Depending on your genetic condition, you may be asked to bring your most recent diet record to your appointment.



GENETICS VISIT FAQS CONTINUED

WHAT TO EXPECT AT A GENETICS VISIT

Your genetics team will typically include a Clinical Geneticist and a Genetic Counselor, as well as additional members such as nurses and registered dietitians depending on your (or your child's) diagnosis and healthcare needs. This team will provide information, offer support, and address your questions and concerns.

To determine if your condition is due to a genetic disorder, the genetics team will ask about your (or your child's) symptoms and take a detailed family history. A physical exam may be performed and your team may recommend further tests.

If you are diagnosed with a genetic disorder, the genetics team will provide information about the diagnosis, how the condition is inherited, the chance of passing the condition to future generations, and options for testing and treatment.

The details about what happens at a genetic clinic appointment will depend on your unique circumstances, but typically include:

- A discussion of the problem that has brought you to the clinic.
- A discussion of your family health history. A family tree will be drawn and medical details of relatives may be discussed (such as the cause and age of their death).
- A medical exam of the patient and other family members who may have the same condition.
- A discussion of what the doctor finds and treatment and testing options.
- An open discussion to answer any of your questions and to help you understand your options and make your own informed decisions.
- Tests (such as blood, urine, saliva, or cheek swab tests) may be offered. Some tests can be done on the day of your visit, but often you will be asked to take some time to make a decision and to come back another day. Genetic testing is optional.
- Making a plan for further information gathering (by you or your doctor), special tests, or another appointment.
- A letter will be sent to you after your appointment, describing what was discussed and who to contact if you have questions or if anything is unclear.
- Depending on your condition, the genetics team may provide recommendations for continued treatment and diet management. This information may also be in the letter that is sent after your visit.
- A member of the genetics team will contact you with the results of any testing that was done.

