

Your visit to the NIH genetics clinic

You or your child has been asked to come to the National Institutes of Health (NIH) Genetics Clinic to talk about or be examined for a genetic condition. This evaluation will be done as part of an NIH research study. Some visits may take only 2 to 3 hours, while others will take more appointments over several days. This will be discussed with you before your visit.

About the NIH Genetics Clinic

The NIH Genetics Clinic is located in the NIH Clinical Center on the campus of the National Institutes of Health in Bethesda, Maryland.

It provides diagnostic evaluations and genetic counseling to individuals and families affected with, or concerned about, genetic conditions.

The clinic is staffed by doctors, nurses, genetic counselors, and medical staff in training. Diagnostic tests, consultations, and clinic visits at NIH are provided at no cost to you.

Before your appointment

If this is your first appointment at NIH, be sure to carefully read over the consent form that describes the study you will take part in. It explains the risks, benefits, and limitations of the study.

The clinic staff will need to review your medical records before your appointment. Your doctor may have already sent this information to us, but you might wish to check that this was done. Also, a genetic counselor from the clinic may call you for more information.

If travel plans to the clinic were arranged for you, confirm your travel plans.

When you arrive at NIH

You may park without charge on the P1 level of the Clinical Center garage.

If this is your first appointment, you or your child should check in at the admissions desk, located on the first floor of the building. The admissions process takes about 45 minutes, so please allow enough time before your appointment.

During your appointment

- ▶ During your first appointment, a staff member will explain the research study and talk with you about the consent forms.
- ▶ You will meet other members of the clinic's team, who will ask you about medical issues and family history. In most cases, a physical examination will also be done.
- ▶ Feel free to share information in your family history that you think is important. Also, do not hesitate to talk about your needs, values, and goals for the appointment.
- ▶ Ask all your questions. Many people find it helpful to write down questions in advance.
- ▶ At the end of your visit, the doctors will review their findings. They may also suggest ways to manage your or your child's condition, and get further care.
- ▶ A genetic counselor will be on hand to address any emotional concerns.

- ▶ Depending on your needs, the staff may inform you about other research studies at NIH that apply to you or your child's condition.
- ▶ To help you, the staff may send you a letter reviewing your clinic visit.

After your appointment

If you have questions about your visit, please call your genetic counselor or the NIH Genetics Clinic Coordinator at 301-402-9653.

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team.

Products/resources named serve as examples and do not imply endorsement by NIH. The fact that a certain product/resource is not named does not imply that such product/resource is unsatisfactory.

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Questions about the Clinical Center?
<http://www.cc.nih.gov/comments.shtml>
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