What will happen during a genetic counseling appointment? (continued)

• Help you plan what to do with the results
• Give medical screening recommendations if you have an increased chance of a genetic condition, even if you choose not to have testing
• Talk about what your results or diagnosis means 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
• Provide counseling and emotional support

What should I do during a genetic counseling appointment?

• Ask questions and talk about any concerns you have. Remember, the genetic counselor is there to help you.
• You can take notes

Helpful Websites

Iowa Institute of Human Genetics (IIHG)  
>> www.medicine.uiowa.edu/humangenetics

National Society of Genetic Counselors (NSGC)  
>> www.nsgc.org

American Board of Genetic Counselors (ABGC)  
>> www.abgc.net

Genes in Life  
>> genesinlife.org

Contact

Iowa Institute of Human Genetics, University of Iowa  
285 Newton Road, 5296 CBRB, Iowa City, IA 52242  
Phone: (319) 335-3688 | Fax: (319) 335-3484  
Email: iihg@uiowa.edu | www.medicine.uiowa.edu/humangenetics  
Follow us on Twitter @IIHG_Genetics

Ask for our other booklets about personalized genomic medicine, genetic testing, exome sequencing, and pharmacogenomics.

The Iowa Institute of Human Genetics (IIHG) can provide genetic counseling for genetic testing performed through the IIHG

Updated September 2013
What is genetic counseling?
A genetic counselor will talk with you about medical and genetic information in a way you can understand. Genetic counselors teach you and your family about genetics and how it affects your health. This helps you make choices about genetic testing and life plans. Genetic counselors are here to answer your questions and support you. They:
- Are part of your health care team and work closely with your doctors to choose the best health plan for you
- Can teach employers, teachers, or others about a genetic condition in your family
- Have a Master’s degree in human genetics or genetic counseling and must pass a national test to be a Certified Genetic Counselor (CGC)

Will a genetic counselor tell me what to do?
Genetic counselors are nondirective counselors. This means they do not tell you what to do. Instead, they will guide and help you make your own informed decisions.

Why would I need to see a genetic counselor?
You may want to see a genetic counselor if you:
- Are pregnant or thinking of becoming pregnant
- Have a genetic condition or a family history of a genetic condition
- Are considering having a genetic test or have had a genetic test or screen
- Have had an abnormal genetic test result

How do I choose the right genetic counselor for me?
Your doctor can refer you to a genetic counselor, or you can select one on your own. Genetic counselors work in different settings and may specialize in certain conditions, such as:
- Prenatal (pregnancy)
- Pediatric (kids)
- Cancer
- Adult onset disease
- Neurology (brain and nervous system)
- Personalized genomic medicine (using your genes and family history to improve your health)
- Psychiatric (mental health)
- Research

How can I prepare for a genetic counseling visit?
- You may want to make a list of questions
- Bring medical records about your condition or ask your doctor to send them
- Review your medical and family history. Genetic counselors may ask about the health of your spouse, children, parents, siblings, grandparents, and other blood relatives.
- Check with your insurance company to see if they cover genetic counseling. You may need to pay for some or all of the appointment.

You are welcome to bring someone or go to the appointment by yourself.

What will happen during a genetic counseling appointment?
It will depend on the reason for your appointment and the genetic counselor. Most appointments take an hour but can vary. You may need one appointment or several. Often, a genetic counselor will:
- Talk about why you are there
- Review your medical and family history
- Explain medical and genetic information, such as:
  - Describing a condition, its cause, if it will progress, and how to manage and treat it
  - How genetic conditions are passed on from parents to kids (inherited)
  - If you or your family members are at risk to develop a disease
  - How knowing the cause of your condition can help you
- Find the right genetic test for your condition
- Tell you about genetic testing options, what testing can and cannot tell you, testing process and costs, and any risks of discrimination based on your results
- Help you decide if genetic testing will be useful to you
- Arrange testing if you decide to have it and work with you and your insurance company to understand your coverage
- Receive test results and explain the results to you in person in a way you can understand