Genetic Counseling Key Messages and Interview Tips

For Internal Use Only

The following are NSGC key messages on topics that often come up when working with the media or in everyday discussions about your profession. It’s not realistic to memorize these or try to use them all in every conversation, but the messages can serve as a guide for your talking points. Whether you’re referring to them for a media interview, work presentation or something else, determine ahead of time what topics you’re going to discuss and select the top few key messages that relate to your points. Practice using those key messages in your own words so they organically fit into the discussion.

Key Messages

What is a genetic counselor?
Main message
- Genetic counselors empower patients and their families with information, guidance and emotional support to help them understand their family history, evaluate genetic testing options, and make informed choices based on test results.

Supporting messages
- Genetic counselors have specialized graduate degrees and experience in medical genetics and counseling, making them experts at interpreting and explaining complex genetic information, while providing emotional support.
- Genetic counselors are important members of the healthcare team, collaborating with a patient’s primary care physician and other physician specialists.
- Before undergoing any genetic test, patients should speak with their physician or a genetic counselor to determine if they should have a test, which test is appropriate and the benefits and limitations of the test. This is a critical step in the process to help avoid unnecessary costs or emotional turmoil for the patient and their family.
- Genetic counselors serve a variety of roles in the delivery of genetic services. Many genetic counselors see patients in-person, provide consults over the telephone or work in laboratories. Each of these roles is important to ensure that the patient and their doctor have access to the most appropriate information to help guide care.
- There are more than 5,000 certified genetic counselors working in the U.S. today.

Who can benefit from genetic counseling?
Main message
- Individuals and their family members who have a condition with a genetic link, have a family history of an inherited disease, or are considering genetic testing for any reason can benefit from meeting with a genetic counselor.

Supporting messages
- Genetic counselors work in a variety of specialty areas including prenatal, pediatrics, oncology, neurology, cardiovascular diseases, metabolic diseases and genomic medicine.
• Genetic counselors partner with primary care physicians and specialists who refer their patients. In addition, more than 60% of genetic counselors see patients who contact them on their own, many by using NSGC’s “Find a Genetic Counselor” tool.

• For example, according to the 2018 Professional Status Survey, top referral sources include OB/GYN (67%), primary care physicians (67%) and patient self-referral (60%)

What are the benefits of genetic counseling?
Main message
• Genetic counseling has many benefits, including being sure the right genetic test is ordered to avoid unnecessary costs or inappropriate tests, helping patients understand complex test results and how to use the information, and providing peace of mind for patients fearful about inheriting a disease.

Supporting messages
• Genetic counseling provides patients with information on the benefits and limitations of genetic testing, and can prepare patients mentally and emotionally for results that might be surprising or alarming. As part of a consultation, the genetic counselor will discuss genetic testing options, review the results and provide a summary of this information to patients and their doctors. As a result of the initial consultation, some patients may make an informed choice to not undergo genetic testing.

• When you become a patient, your entire family becomes a patient. Genetic counselors serve as advocates not only to the patient sitting in their office or on the phone, but also for their patient’s entire family – to ensure their brothers, mother, father, aunts, children and more can all benefit from genetic testing. Genetic counselors can provide emotional support, discuss how or if to deliver difficult findings to family members, and also provide recommendations for community support services.

How can genetic counseling guide patients and physicians through the process of genetic testing?
Main Message
• There currently are thousands of genetic tests available, and increasingly patients are considering these tests as part of their medical care. Genetic counseling can provide information, guidance and emotional support throughout the decision-making process.

Supporting Message
• As genetic and genomic technology continues to advance at a rapid pace, genetic counselors can partner with physicians to help navigate the ever-changing landscape of genetic testing and can help patients understand what tests (if any) may be right for them.

How do I get an appointment with a genetic counselor?
Main Message
• If you are considering genetic testing, want to learn more about your family history or have concerns about having or passing on a disease that runs in your family, visit AboutGeneticCounselors.com or ask your doctor to refer you to a genetic counselor. You also can contact a genetic counselor directly, using NSGC’s “Find a Genetic Counselor” tool at FindAGeneticCounselor.com to locate one in your area.

Supporting Messages
• Access to genetic counselors is increasing and most genetic counselors can see new patients in person within one to three days.
• Genetic counseling appointments vary by specialty, anywhere between 30 to 60 or 90-minute face-to-face meetings. Telephone counseling is becoming more common, making counseling available in rural or other areas where there are few genetic counselors.

Is genetic testing and genetic counseling covered by insurance?
Main Message
• Many insurance plans cover the cost of both genetic testing and genetic counseling if they’re medically indicated. Each policy is different and laboratories’ billing practices differ, so it’s important to ask. A genetic counselor can work with patients and insurance providers to determine what will be covered and help guide the patient’s financial decision.

Supporting Messages
• As part of the Affordable Care Act, genetic counseling and testing for breast and ovarian cancer may be available as part of all non-grandfathered health plans at no additional out of pocket costs.
• NSGC is working to introduce federal legislation that would authorize Medicare coverage for counseling provided by genetic counselors. The legislation will improve access to genetic counselor services for patients by making it easier for physicians who do not work alongside a genetic counselor to refer to one.

I can order genetic tests online. Why should I see a genetic counselor?
Main Message
• Genetic test results can be confusing or misleading and sometimes unexpected and even life-altering. A genetic counselor can explain results and provide counseling and guidance to you and to family members who may be impacted by the results.

Supporting Messages
• Genetic tests sold directly to consumers to screen for diseases or determine ancestry are accessible and are becoming less expensive. Consumers are encouraged to seek guidance from a physician or genetic counselor before considering these tests because of the important information they can provide.
• The results of these tests can sometimes provide confusing or unhelpful results. Without a healthcare provider to explain them or put them into context, genetic test results are not always useful and could be misinterpreted.
• Genetic counselors can discuss with patients the emotional and medical implications of tests and their results, and refer patients to appropriate support services.

What should I expect during an appointment?
• Most genetic counseling appointments consist of a 30 to 60 or 90-minute face-to-face consultation or phone call. During the meeting, the genetic counselor will draw your family tree, discuss your family history of disease and, if appropriate, discuss genetic testing options or walk you through your genetic test results. The genetic counselor will then use this information to help you understand your risk for certain conditions and work with your physician to personalize your medical care.

Are genetic counselors licensed or certified?
• Currently, 22 states require genetic counselors to be licensed, and approximately 25 additional states are moving forward with licensure proposals.
• Most genetic counselors are certified through the American Board of Genetic Counseling and certification is required for licensure in most states. It also is a frequent requirement for credentialing. Some genetic counselors are Board Eligible and are working to sit for the exam.

How can I become a genetic counselor?
• Students who are interested in genetics and healthcare, and are passionate about helping people, may find genetic counseling professionally challenging and personally rewarding. Anyone interested in exploring genetic counseling as a career can find additional information on the NSGC website under Student Resources.

Interview Tips
1. **Have a goal and a message.** What are your main points and what is the one thing you want people to remember about your story? This is the most important thing to prepare for when going into an interview.

2. **State your message early, often and with emphasis.** State your message at the beginning of the interview and keep coming back to it. Say things like: “This is very, very important. Here’s what I hope people will remember.” This will focus the audience on the message.

3. **Be passionate.** Your enthusiasm will help ensure your message is heard and remembered.

4. **You have more control than you think.** How you answer each question can direct the interview. If you say something interesting or surprising, the interviewer will want to know more.
5. **Tell a story.** Illustrating your key message with a story about real people will make the interview more interesting and the message more memorable. This is how we communicate in real life. If you do tell a story, be sure that you’re not providing any confidential patient information.

6. **Stay positive!** Focus on the bright side of the story – that is what reporters and their readers/viewers want to hear/read about.

7. **Be brief, but complete.** Try to think in soundbites. Often reporters have limited time or space; so, prior to the interview, practice summarizing key points with fewer words. This is especially important with broadcast interviews since your answers may be edited and aired without the question. To help make sure your message comes across in your “soundbite,” speak in complete sentences that restate the question. For example, if asked why exercise is important, say, “Exercise is important because…” Don’t say, “It’s important because…”

8. **If you don’t know the answer or aren’t comfortable answering, that’s ok.** If you are asked a question you don’t know the answer to, just be honest and say you don’t know. If you aren’t comfortable answering the question, you can say so. Know that nothing is “off the record.”

9. **Be prepared for difficult or controversial questions.** Think about what “difficult” or “negative” questions might be asked and practice answering them thoughtfully. It is okay to say you prefer not to answer questions that aren’t related to your mission.

10. **Don’t go “off the record.”** Don’t say anything you don’t want to see in print, online or hear on the air.

11. **In broadcast interviews, don’t let your wardrobe overshadow your words.** Dress conservatively in solid colors. Avoid busy prints, fussy styles, sparkly or jangly jewelry. If you’re offered make-up, say yes.

12. **Follow up.** Call or email the reporter after the interview to see if you can provide more information or clarification, and ask when the piece will run.