

## **Genetic Counselors & You S2E5 (Completed 10/20/20)**

**Transcript by Rev.com**

### **NSGC:**

Brought to you by the National Society of Genetic Counselors, this is Genetic Counselors and You. Answers to your genetic questions, by genetic counselors. For more information about genetic counselors, including what they do and why you might see one, visit [aboutgeneticcounselors.com](http://aboutgeneticcounselors.com).

### **NSGC:**

Who will win the Heart of Genetic Counseling Award? Register for the virtual award ceremony to find out live and hear the emotional stories of what excellent care feels like to patients. Presented by the National Society of Genetic Counselors and Invitae, the Heart of Genetic Counseling Award celebrates the heart that genetic counselors bring to patient care, giving patients compassion and insight as they understand and respond to genetic conditions. The distinguished nominees and finalists will be unveiled and one will be honored with the Heart of Genetic Counseling Award. Lindsay Avner, the Founder of Bright Pink, a leading national breast and ovarian health non-profit, is a featured guest speaker. Mark your calendars for November 19th, 4:30 Central time and register through NSGC. You don't want to miss it!

### **Heather Shappell (teaser):**

...understanding your health insurance coverage can be complicated when it comes to almost anything. And even though I work for a health insurer, that doesn't make me immune from feeling the same thing that all the listeners feel about how difficult it can be to really understand what's covered and how your health insurance company makes coverage decisions.

### **Deepti Babu:**

Hi, everyone. Welcome to our next episode of the Genetic Counselors and You Podcast. Health insurance can be complex to figure out. How do you know if something is or isn't covered in your plan? And what if you don't have insurance? This can make decisions about your health, which could include genetic testing and genetic counseling, even harder to figure out. It might make some of us avoid genetic testing or genetic counseling altogether, if we have a choice. But is that the right thing to do? What if it leads us to miss out on information that we'd want?

### **Deepti Babu:**

We'll speak to a genetic counselor with expertise in this area to help demystify insurance, as it pertains to genetic testing and genetic counseling. As always, we'll also suggest ways that you can navigate things as they apply in your life. We're talking with Heather Shappell, Precision Medicine Project Manager at Aetna. She's also a director at large on the board of directors for the National Society of Genetic Counselors. Heather is a genetic counselor with experience in the clinic, industry, and the corporate world. Her current role brings her knowledge in genetics and business direction to a large health insurer to support precision medicine initiatives. Welcome, Heather, and thank you for joining us today.

### **Heather Shappell:**

Thank you so much for having me, Deepti. I'm really happy to be here to try to answer some questions about health insurance specific to genetic counseling and genetic testing.

**Deepti Babu:**

Well, we are grateful that you're joining us because this is a big topic. Honestly, just hearing about insurance makes some of us want to run for the hills. I'm only being slightly facetious when I say that. So, we need you to help us resist that. Why do you think insurance can be complicated when it comes to genetic testing and genetic counseling?

**Heather Shappell:**

Well, I'm going to do my best to help everyone resist that, but the truth of the matter is that insurance can be complicated when it comes to anything, not just genetic testing and genetic counseling. So, while there are some things that are unique or a little bit more complicated about genetic testing and counseling insurance and understanding your health insurance coverage can be complicated when it comes to almost anything. And even though I work for a health insurer, that doesn't make me immune from feeling the same thing that all the listeners feel about how difficult it can be to really understand what's covered and how your health insurance company makes coverage decisions.

**Deepti Babu:**

I'm glad that someone with your expertise is on the inside and able to tell us a little bit more about how this all works. How do we break it down for people? It really can feel like a barrier, but I feel like if people are able to break through that, there would possibly be some opportunities on the other side that they can take advantage of with that new knowledge. We can start with some basics, like for example, what are things that an insurer typically wants to know about when they decide to cover something or to not cover something? I mean, these decisions don't come out of thin air.

**Heather Shappell:**

Right. There are many ways that we can help people break it down and we can give them concrete steps about how to really investigate what's covered and what decisions your health insurer has made around genetic testing and genetic counseling. But first and foremost, it's really important to understand how health insurers make decisions about what services and procedures and tests they'll actually pay for. And really, the general rule is that the service or lab test or genetic tests that a health insurer is considering has to be a test that's likely to provide the individual and their healthcare provider with information that will guide their medical care. And not just guide their medical care or medical decision-making, but guide it in a way that we know would lead or is likely to lead to improved health outcomes.

**Deepti Babu:**

What would be an example of something that would make a difference, that's going to change the outcome for that individual in terms of their health, that we can guess?

**Heather Shappell:**

Yeah. So, I'll go to, I think, a commonly known genetic test or hereditary condition, or one of the most commonly known and that's hereditary breast and ovarian cancer. We have clear evidence in the peer-reviewed medical literature, which is one of the most important sources that health insurers go to, to

determine whether a genetic test has that ability to provide information that would guide medical decisions. So that test, we clearly know from the literature and from nationally recognized organizations that put out guidelines around when genetic testing should be done, we know that that test can give people information about their future risks for both breast and ovarian cancer. And their risks for those cancers are much higher than the average person and their risk to get those cancers at much earlier ages are higher as well. They're also at increased risk to get more than one type of cancer or more than one cancer in their lifetime.

**Heather Shappell:**

So, because the research shows us all of that information very clearly and because there is also additional research that shows that screening individuals who have this hereditary condition earlier and more frequently, with types of technology that you might not use to screen people in the general population, because the literature shows us that using all of those efforts in people who have this hereditary condition can either find their cancer earlier, when it's much more likely to be treated effectively, or because they can take steps like having a surgery before cancer ever develops, to reduce the risks of cancer. Because the literature shows us that these things are all effective ways to improve the health outcomes for people with this hereditary condition. That's a test that's a no-brainer, it's covered by a health plan.

**Deepti Babu:**

You're looking at the evidence, you're basing your coverage decisions largely based on the facts. And of course, everybody's health plan is different, they're very nuanced, right?

**Heather Shappell:**

Right. Just like you alluded to, Deepti, we can't say that that test is covered universally for all people, for all health insurers. And that's an important thing to consider here as well, just because we know that that test can give the kind of information that changes medical decision-making and health outcomes, it doesn't mean that a health insurer would pay for that test for every individual. That's because most people out there don't have a gene mutation that causes hereditary breast and ovarian cancer, but the people who are more likely to have that are people who have some personal or family history of breast and/or ovarian cancer.

**Heather Shappell:**

And so, there are criteria out there from national organizations that put out guidelines that tell us, these are the types of individuals who are more likely to benefit from this genetic test. So, when there's peer-reviewed medical literature and/or nationally recognized guidelines out there that recommend genetic testing, health plans use that type of information to create their own clinical policies or coverage policies. Some health plans call them their medical policies, but most health plans around most genetic tests have these clinical policies that you can access on their websites. They're publicly available and you can find them as a consumer, as a healthcare provider, you can go out and search a health insurance website to find these policies and get a better understanding of what tests they cover and under what circumstances.

**Deepti Babu:**

Great. I mean, that's super helpful to know it even exists. We can get into picking your brain on how to better understand them, because I think they can be complicated to navigate, but I think with some tips from you, that will be super helpful. But you're kind of getting into my second question, which is, and this is kind of a perception I think sometimes, that genetic testing or genetic counseling would not even be covered. And so, you kind of answered my question, which is yes, it may be, because a lot of people think it may not be. Can you think of examples of, I guess, trends or ways that you can help people understand whether genetic counseling might be covered in a particular situation? Or is that something that they just need to be sure they're asking about?

**Heather Shappell:**

Yes. So, I can't speak for all health insurers or all health insurance plans, but in general, genetic counseling is covered for most individuals who have some personal or family history that makes them concerned or makes their healthcare provider concerned that a genetic test might be warranted or that there might be some increased risk for them based on that personal and family history, that could be informed by talking with a genetic expert. And so, genetic counseling is mostly covered by most insurers, but it also is important that just like any other healthcare provider that a person might want to visit, especially a specialist like a genetic counselor, it's important for people to contact their health insurers, by phone is one way, you could just call.

**Heather Shappell:**

Most people are directed to call the phone number on the back of their insurance card to get information, but there are also online provider search tools that most health plans have on their websites where you can go online and search for a genetic counselor, or a primary care doctor, or any other type of specialist that you might want to see, to see whether or not that healthcare provider is actually in network or is a participating provider with your health insurance plan.

**Deepti Babu:**

That's great.

**Heather Shappell:**

And that can help you understand whether their services would be covered.

**Deepti Babu:**

Yeah. Because it really does seem sometimes like it's a black box, it's hard to sort that out. Now, so you were talking, just to clarify, specifically about the type of genetic testing that a medical healthcare provider would be involved with in terms of ordering and determining if that's a good fit for you, after discussion with you. Let's talk a little bit about at-home genetic testing. So, many people who are listening to this podcast may be thinking about that avenue of genetic testing for them, which may not even involve their healthcare provider. Do you know whether, and again, I know you don't speak for all insurers, but just is that even something that would be a possibility, that the genetic test or genetic counseling that they get as a part of their at-home testing would be covered by their insurer?

**Heather Shappell:**

It's possible. There are so many different types of at-home genetic testing available now and especially since everything that has happened recently with the pandemic, it has forced a lot of clinical care that we might have received by going to the doctor or going to see a genetic counselor, it's forced a lot of that healthcare into the home. They're used to, I think, be a clear line to distinguish between something that was at-home versus something that was more directed by your healthcare provider or your healthcare team and that line is becoming a bit blurred. So, the answer is sometimes, not always.

**Deepti Babu:**

That's fair.

**Heather Shappell:**

It's unfortunately, one of those things where you just have to do your own due diligence as a healthcare consumer. I'd say that's probably one of the greatest lessons that I've learned since joining a health insurer and working inside a health insurer, I've in general just become much more likely to explore what might be covered, what providers that I want to see might be in network with my health insurer or contracted with my health insurer. I do a lot more research on my own before I make any decision about seeing a healthcare provider, about a test I might take, a procedure I might get.

**Heather Shappell:**

I just am more informed and I'm looking online and I'm calling the health insurer trying to get as much information as I can because the worst thing that can happen is that you end up getting this surprise bill in the mail when you thought something was covered, even because your healthcare provider told you, you needed to get it. And you come to find out later that it's not something that was covered or covered fully by your health insurer.

**Deepti Babu:**

That's really helpful to hear. Also what I'm hearing from you is, for sure if you know that genetic testing and/or genetic counseling is something you might be thinking about with your healthcare provider, certainly contact your insurer or perhaps, with your healthcare provider's help to figure out what is or isn't covered. But also, it might even open up possibilities for people to think, "Let me go to the insurer and ask, because I never thought this was even on the table as something that they might cover." So, I don't want people to rule out possibilities already without doing the investigational work and it is work. So, we know that it takes time and it takes effort. But I think what you're telling us is, is it's possible to get the information, so don't be afraid to even try to call or check the website or things like that because it is possible to navigate it. There's hope.

**Heather Shappell:**

Absolutely. Yeah. There's hope. I'm not going to make any false promises that it's simple.

**Deepti Babu:**

Right.

**Heather Shappell:**

But there are really these concrete steps that you can take and you really do have to take them to have a better understanding before you get that test or you have that visit, so that you have a better chance of having that visit or service reimbursed by your health insurer.

**Deepti Babu:**

One of the things that I wanted to mention is, we are seeing certainly more and more at-home genetic testing options available, as you mentioned, for so many, like a dizzying array of different either traits or ancestry information or medical and health information. And we're also seeing that groups like employers might be offering genetic testing as a part of a wellness program. And I just ... That's another opportunity, I guess, for people to potentially pursue genetic testing and/or genetic counseling, and maybe that's not something their insurer was going to cover, but they can access it this way. I'm just putting that out there as an avenue for people who may be thinking, "I'd still like to pursue this, but I don't know how to."

**Heather Shappell:**

Right. Yeah. There are definitely, like you said, a dizzying array of options out there and it shows no signs of slowing down. Ancestry testing, those things would not be considered coverable by a health insurer or reimbursed. They're not things that would help improve medical decision-making or health outcomes. And then, when it comes to these at-home test offerings that are "medical," I would just say that there is a wide variability out there in terms of the quality of those tests or what those labs offer in those tests. And whether those test offerings actually are providing the types of test results that can guide someone's medical care.

**Heather Shappell:**

So, it's important to, in my opinion, to work potentially with a genetic expert. Oftentimes those at-home testing labs, some of them employ genetic counselors themselves or genetic experts themselves, to really ask a lot of questions because all of those tests are definitely not created equal.

**Deepti Babu:**

Right. Right.

**Heather Shappell:**

Those are of better quality and provide better information than others and it's really difficult for the average person to look at that beautiful website and the really simple spit in a tube, brush your cheek swab, and mail it in it. It's as simple as one, two, three. It's really hard to distinguish which of those are providing really good medical actionable information that can help guide your medical care and improve health outcomes versus the ones that are not.

**Deepti Babu:**

Yeah. [crosstalk 00:17:23]. They're definitely not all created equal. And actually for the listeners, we had a really informative episode touching on some of what Heather's talking about, with a genetic counselor who is steeped in this, Brianne Kirkpatrick, talking about the ins and outs of this. So if you want to give that a listen, it is available as well. So, let's say that somebody has coverage for genetic testing and/or

genetic counseling and they want to go forward. Could their results impact their health insurance coverage or other things like employment?

**Heather Shappell:**

So, I can definitely speak to the health insurance aspect of whether genetic test results could impact their health insurance coverage. And there is a federal law that was passed in 2008 called GINA, for short, but that stands for the Genetic Information Nondiscrimination Act. And that federal law actually makes it illegal for health insurance companies to use genetic information in decision-making about an individual's eligibility or their coverage. And by eligibility, what I mean is will the health insurer cover you under their plan at all, yes or no? That's what eligibility refers to.

**Deepti Babu:**

And I mean, I think there's some obviously nuances to the act, the legislation that you just referred to, GINA, we're not going to get into that, but I will say that there's also some protections for employment. It's very state-specific and also other countries in the world have legislation as well. I'm based in Canada, in 2017, it was pretty recent actually, there's the Genetic Non-discrimination Act that was signed into law here. So, there are some nuances from area to area, but just for people listening, there are some protections that are either in place or being developed and that's worth investigating with the genetic expert as well, as you think about the possibility of genetic testing. But again, don't assume that it's all going to be problematic, I guess, is the take home there too.

**Heather Shappell:**

Right. And just one other caveat to put out there around GINA, that is specific to health insurance. And so, it does not apply to life insurance or disability insurance or long-term care insurance. So, those other types of insurance can have the legal ability to ask for genetic information and to make coverage or eligibility decisions based on that genetic information. But that is illegal according to GINA, for health insurers.

**Deepti Babu:**

Yeah. So, great questions to be talking about with your healthcare provider as you talk about the possibility of genetic testing. So, as we keep the conversation now looking forward a little bit, what do you see ... And you've touched on this a little bit in talking about how people are responding to healthcare and adjusting in the setting of this pandemic that we're all in globally. So, what do you see in the future with insurance and genetic testing, I guess, maybe because of influences like the pandemic, like you were talking about, interacting and engaging with healthcare more from home than we ever have been before.

**Heather Shappell:**

Yeah. I think genetic counseling is one of the healthcare professions where at-home conversations, or conversations or consultations by telephone or through telemedicine, through the web, our profession was out there with that option for many years. So, that has always existed since the mid-2000s as an option, that people could access genetic counselors through the telephone or through their computer. But certainly, the pandemic has made it much more important for genetic counseling providers who did not provide services by telephone or through telemedicine. They've had to adapt their practice from

seeing patients in-person to offering their services in these other ways, so that they can remain accessible during the pandemic. And I think that's a great thing because there are people throughout this country who don't have easy access to in-person genetic counseling, and it's really important for them to be able to access these experts in any way they possibly can when they need them.

**Deepti Babu:**

Right. The whole conversation has made me so grateful that an insurer has you on the inside, helping to navigate and understand genetics and genomics because we know it's so rapidly evolving and I'm glad they had the foresight to hire somebody to bring that expertise internally. Because I know you're working to help shape policies, help comb the evidence, help understand it, and then hopefully make that all so much better for the plan participants and the patients out there who need to navigate their coverage.

**Heather Shappell:**

It's becoming more and more common for health insurers to hire genetic counselors. And so, I think it's a great thing obviously, it's really important. This area is getting more and more complex by the day and it takes people with a certain level of genetic expertise to really help guide decision-making within the health plan, to make sure that they are keeping abreast of all the developments and making sure that they're keeping up.

**Deepti Babu:**

No, it definitely is. We all need the help. So, speaking of that, what are some steps that someone can take to understand their coverage, in concrete, digestible bits. What are the questions they could consider asking? Who should they ask? Where are places that they can look for help?

**Heather Shappell:**

Yeah. So, I think first, an important thing to do is to understand through your health insurer, whether there's an opportunity for you to create an account or log in, or to get into very specific information about your coverage, about your specific health plan, about what's covered, what's not covered. What are the bells and whistles of your health plan that you could be taking advantage of. And so, go to your health plan's website and look for an opportunity to sign up and log in using your name and the information on your insurance card so that you know that you're getting highly targeted and specific information about you and what's covered for you under your specific health plan. So, that's tip one, and is the way to really get the most targeted information. You certainly may not get answers to every question you have. Some of those portals that you can sign up for are much better than others, as with anything.

**Heather Shappell:**

So, if you don't have that opportunity to sign up and log into specific information about your own plan, or if you can't find what you're looking for there, you can always just call the number on the back of your insurance card and try to speak with someone to find out, is the healthcare provider or the specialist, like a genetic counselor, in network? And by in network, I know I used that word before, I just want to be clear about what that is, because it really is so important to making sure that when you're getting whatever healthcare service you're accessing, you're getting it at the lowest cost to you. And in

network means that that healthcare provider or that laboratory provider or the hospital that you're going to, that they have specifically contracted directly with your health insurer. And they've agreed that they'll accept the rates that your health insurer is willing to pay for different services and things like a genetic test or genetic counseling.

**Heather Shappell:**

And that means that the healthcare provider or the hospital or the lab has also agreed in that contract to follow the health plan's clinical policies for coverage. And because those agreements are in place, in general, anything that you do will be at a lower cost to you and to the health plan. So, it's better for everybody to whenever possible, make sure you're focused on using an in network provider. You can find that, again, by calling. You can, in terms of providers, again, think of your health plan's website as an important resource. And so, most health insurers have online healthcare provider search tools. Where you can go in and search for a genetic counselor or any other type of specialist or healthcare provider.

**Heather Shappell:**

And you'll find a list using your zip code and other ways to narrow down the search. You'll be able to find those providers who are in network or contracted with your health insurance company. If you can't find the provider you want to see, through any of the mechanisms I've mentioned so far, another option is to just contact that healthcare provider directly and ask them, "Do you participate with my health insurer? Would a visit with you be covered by my health insurer?" And that healthcare provider, they might know right off the bat, or they might have to do a little bit of research and get back to you about whether their services would be covered under your specific plan.

**Deepti Babu:**

Yeah. And I guess, willingness to do that tells you a lot too, right?

**Heather Shappell:**

Absolutely. So, those are the steps in terms of healthcare provider. In terms of finding out if the specific genetic test that you're interested in is covered ... And there are steps you can take on your own. Certainly, it's probably better to take those steps in collaboration with your healthcare provider and/or a genetic expert, because understanding all of this can be a bit complicated, even if the health plan does have a policy. But in terms of finding out if the test you're interested in would be covered, there is that online access that most health plans have, if not every health plan. I don't know of a health plan that doesn't have the availability for you to search their clinical coverage policies. Again, these can go by different names, by different health plans, they can be called medical policy, clinical policy, coverage policy. At the end of the day, these are written policies that are posted to the health plan's website that tell you whether a genetic test is covered and what are the circumstances or clinical criteria.

**Heather Shappell:**

What are the personal and family history things they're looking for to determine whether or not they would pay for this test for someone like you? So, that's an important resource. You can check it out yourself. It's not always crystal clear or very easy to understand. So, working with a healthcare provider or a genetic expert could probably help you understand that policy better, but it's important to know

those policies are available online. So, when looking at the test, it's first important to determine if that test would be covered at all for you. And that's where you'll get that information in a clinical policy.

**Heather Shappell:**

The next most important thing is to think about whether the lab that your healthcare provider is planning to order from is considered in network. Again, that means a lab is contracted, they've agreed to the health insurers contracted rates, and therefore in general, both you and the health insurer will pay the lowest costs to that lab for the test. So, it's an important thing to think about, is the lab we're planning to order from in network?

**Deepti Babu:**

Yeah. And that would be something that some people may know and maybe their genetic counselor or their nurse or their doctor that they're talking to would know, but all really, really important steps.

**Heather Shappell:**

Yeah. There should be as well, a place on the health insurer's website or by calling the health insurer. But certainly you could go to the health insurer's website, think most health insurers will have a way for you to search who their in network laboratories are. That should be easily available to you because it's a benefit to everyone for you to have easy access to that information.

**Deepti Babu:**

Absolutely. Well, I mean, this has been incredibly helpful just to help us understand the lingo and break that down. So, I think it's like kind of learning a new language and getting more comfortable with it and hopefully opening up some possibilities that people may have just brushed past because they were terrified of even digging into it. Thank you for making that less scary, more accessible, and hopefully more meaningful for people who admittedly are dealing ... We are dealing with a pandemic right now and maybe genetic testing is the last thing on your mind, but you may still be trying to figure out how to get something else covered that's really important right now, that has nothing to do with genetic testing or genetic counseling. But a lot of what Heather has ... You've shared, can be applied to other situations, as you've also mentioned. So, thank you for sharing your expertise today.

**Heather Shappell:**

Sure. Without a doubt, anything that I've said about how to get information about coverage for genetic counseling and testing can be applied universally to anything, any healthcare service you're trying to access through your health insurance.

**Deepti Babu:**

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