Genetic Counselors and You Podcast Series

“How to Make the Most of Your DNA Test Holiday Gift” | Season 2, Episode 1

Host:
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

Deepti Babu:
I'm Deepti Babu, certified genetic counselor, writer, and NSGC member. Welcome to our first episode for 2020. Just before we get started, a quick note that I am very excited to share with you. For 2020, I'll be hosting the Genetic Counselors and You podcast. Every two months, we'll continue to bring experts in to help break down complex topics in genetics that are making people curious with the goal of turning curiosity into knowledge that you can apply in your own lives. If you have an idea for a topic you'd like explored, please email the show at info@nsgc.org.

At home DNA tests are a popular gift, especially at the holidays. Did you receive one? Maybe by surprise or because it was on your wish list and now you're wondering how to take advantage of it? Today, we're talking with an expert who can give you sound advice based on conversations she's had with many people just like you.

Brianne Kirkpatrick:
So, let's say you got a kit for Christmas or Hanukkah or your birthday. It's still in its cellophane wrapper and you're just not sure that you want to do it. So, my advice is kind of think a little bit about what's holding you back.

Deepti Babu:
So, today we're talking with Brianne Kirkpatrick, who is a licensed and certified genetic counselor, writer and founder of Watershed DNA, a private practice specializing in ancestry testing. In addition, Brianne speaks to members of the media as NSGC's ancestry expert as part of NSGC expert media panel.

So Brianne, let's kick off the conversation here. Today we want to talk about at home DNA tests, which, as you know, are a popular holiday gift. I feel like there's always sales that come around the holiday season on these test kits. Some people ask for one as a gift, some get them as a surprise. But genetic tests are really not all the same. Right?

Brianne Kirkpatrick:
Right.
Deepti Babu:
So I'm wondering if you can start this off for us by helping us break down these tests into categories to help people understand their options.

Brianne Kirkpatrick:
Yeah, sure. So the most common type of home DNA tests that most people are going to be comfortable or familiar with is an ancestry test. So that's a test that looks at certain markers in your DNA and then identifies what part of the world your ancestors have come from.

There are also some companies that offer testing that tell you about traits. So these are things about your body, that are not necessarily related to your health, but are things like the type of earwax you're more prone to have or whether your skin flushes when you drink alcohol. Then there are some companies that also provide health reports, and these tend to be risk reports. So are you at a higher risk or a lower risk for certain conditions? They're not predictive of whether you're going to develop a genetic disease in the future.

And then there's also the aspect of a raw data file that comes from a lot of the companies that offer these other types of tests. So raw data is the unprocessed computerized file of DNA markers that some people will take to external websites and try to sort through that raw data for extra information.

Deepti Babu:
Thank you so much. That's really helpful to kind of almost put them into different buckets. Do some of these different options exist in the same test product, if you will? So like somebody could order a test that could tell them a little bit about ancestry and also traits or some combination therein?

Brianne Kirkpatrick:
It's becoming more common that a one company can offer multiple types of tests within the same... If you order a kit, you have the option of really opting in to see multiple things. Ancestry, My Heritage, and 23andMe, for example. They all offer ancestry testing, and in addition to that, additional information like traits and health and access to raw data files. So that is a more common and increasingly common option that consumers have.

Deepti Babu:
So those are a lot of details to keep track of. I know I, as a genetic counselor, have trouble. I'm imagining that consumers who are considering purchasing needs might as well. Are there resources to help people to navigate these options?

Brianne Kirkpatrick:
Yes, it is a lot of information. Each of the companies has built out additional information about their test results for the test users to find if they go seeking for it. So there's online information at the testing companies websites, the reports themselves often have more details, especially if you keep scrolling.
down or click on different tabs within your online report. Sometimes a medical care provider can also be a good resource to connect with. So maybe talk to your doctor, for example.

So let's say you have a test report that comes back showing you are positive for a variant for familial hypercholesterolemia. This is a relatively common genetic condition that leads to high cholesterol running in a family. There are some companies that will report if they've found a variance for that condition. It's not looking at every potential cause for that condition, but some of the companies look for a couple of dozen markers related to it. If you have a positive report, you might want to have your cholesterol checked and then take those results to a cardiologist to talk about whether taking a cholesterol lowering medication might be right for you and whether other family members should be tested. So a medical care provider, like a doctor or a genetic counselor, could be a good partner.

**Deepti Babu:**
Absolutely. So that's an example of a health risk related genetic test. That's a great tie in for this month, which is American Heart Month.

**Brianne Kirkpatrick:**
Good point.

**Deepti Babu:**
Where a lot of people might be thinking about heart disease or markers for heart disease and high cholesterol. You mentioned the expertise's invaluable. Maybe some doctors won't be familiar with DNA tests. So, in that case, a genetic counselor might be a good option. Did you want to speak a little bit more about that?

**Brianne Kirkpatrick:**
Genetic counselors are medical professionals who have specialized training in understanding genetics as it relates to health. Many of the companies that now offer at home DNA testing have partnered with networks of genetic counselors that are specially trained in understanding their reports and talking to consumers or testers that have had those tests. Sometimes you can connect with a genetic counselor that way, and it might even be included in the cost of the DNA test.

**Brianne Kirkpatrick:**
But also findageneticcounselor.com is a great place to start the search for a genetic counselor as well. This is a search tool website where you can put in your location, the specialty or the area of genetics that you're looking to find a genetic counselor in. You can search based on whether you're looking for a telephone genetic counselor or someone you could meet with in-person. Findageneticcounselor.com is a place I try to send people a lot when they have a specific type of question they're trying to answer.

**Deepti Babu:**

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That's a really great resource for people to be able to use. We know another audience that listens to this podcast are healthcare providers who maybe don't have that expertise in genetics and they're looking for ways to refer their patients who have those kinds of questions to a genetic expert, like a genetic counselor. Do you think that that's also a good resource for them?

**Brianne Kirkpatrick:**

There are so many different types of genetic tests, thousands of types of genetic tests, that it's impossible for any one person or any one provider to understand all the nuances of testing for all of those options. And so genetic counselors should be seen as a really helpful resource for healthcare providers and they should feel confident that they can refer a patient to a genetic counselor and say, "I don't know as much about this testing as a genetic counselor would. Let me help you connect with one." It takes off the burden on specialists that really know their area in depth and helps move people to the specialists that are really going to know about that testing the best.

**Deepti Babu:**

So, let's talk about genetic counselors for a minute because we're both genetic counselors ourselves. I feel like many of us in the field have real concerns about at home DNA testing. I'm wondering if you can help our audience kind of understand a little bit where we're coming from with some of those concerns.

**Brianne Kirkpatrick:**

Genetic counselors have privacy concerns, like many of the testers out there. We want to know, and we want you to know if you're going to have a test, who's going to have your information and what are they going to do with it. And another thing genetic counselors want people to be prepared for is the unexpected. What if you get news that you weren't expecting to find out about a genetic disease risk that you have? Or maybe you find out you have an unexpected new family member that you didn't know about, or you find out that your ethnicity, based on your DNA markers, is different from the one you've identified with. So, are you prepared for the unexpected?

**Deepti Babu:**

I mean, you have built your practice, your private practice, around supporting and helping people who do uncover that element of surprise as a part of their genetic testing. So, thank you for doing that. And we know that this is an issue, such that you have enough people to see just for that alone.

**Brianne Kirkpatrick:**

Right. Yeah. So, I think this was an unanticipated aspect of the home DNA test and using DNA to connect people to one another is we're going to find surprises. People are not expecting that, are not prepared for that, but who better to help people through that kind of discovery than a genetic counselor? It really just felt like the perfect combination of the skills, as a genetic counselor, that I had along with the interest in this type of testing and the acknowledgement that unexpected information really needs support and help from someone.
We really want people to have high quality testing as affordably as they can. So, we don't want people to settle for a DNA test just because it's the easiest for them to get to, or it seems to be in their budget. If there's a better test, we want to find out what are the barriers to you having that better test, and we want to take down the barriers. So, is it cost? Well, could we look into insurance coverage and make that an affordable test for you? Is it getting connected to a provider to order the test or to make sure you understand the results fully? Well, then can we get you connected someone over the telephone instead of trying to make an appointment in-person. It's not that we don't want people to have home DNA tests, and I think that's a misperception amongst the public that I run into frequently, it's that we want you to have the best test for you, not a general or a nonspecific test that the masses are having just because it's on sale for the holidays. We don't want you falsely reassured or unnecessarily panicked by your DNA test.

So, these are things that genetic counselors think a lot about that maybe somebody who's not thinking every day about the ins and outs of DNA tests, they're not going to be having those same concerns. But from the genetic counselors perspective, that's what's coming into play.

**Deepti Babu:**
And I feel like that goes very well with our training of helping people to make the decisions about testing or our genetic information in line with themselves and their families. So, whether it's about at home testing or genetic testing that you might get through your doctor, a genetic counselor will always be approaching it in a similar way, which is putting you first. Many genetic counselors have also taken these at home DNA tests. I mean, we're human. We're curious, just like all of you. So, can you talk a little bit about how that is the case? How we reconcile those?

**Brianne Kirkpatrick:**
There are some redeeming qualities of the test because it is sometimes the first time a person or a family finds out that they have a genetic variant that can have a lifetime of impacts, not just on them but other people in the family. So, there's some redeeming qualities to all of the different tests. We've got to just dig a little bit deeper and make sure that we aren't stopping short for someone who needs a more deep dive type of test.

**Deepti Babu:**
Right. I mean, some of these at home test companies are recognizing that need for extra help for consumers who choose their products. So, they make it available as part of the testing process. Sometimes that cost of the genetic counseling consultation is built into the cost of the test so the consumer doesn't see that. But how do folks know if they need to speak to a genetic counselor?

**Brianne Kirkpatrick:**
I feel like that would be an individual person-by-person basis. But I would say that, in general, if you get a result and you're just not sure what to make of it, or maybe you feel in a bit of a panic about your results after you get it, or you're wondering if maybe... What I was looking for and what this test gave me, I'm not sure that those are the same.

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So, I had a client come to me once because his home DNA test report showed a higher risk of a condition called age related macular degeneration. He came to me with the question does this mean I’m going to go blind? He was in a bit of a panic about it at that point. It was new information for him. He didn’t really have any family history of macular degeneration so it kind of came out of left field for him. So, I went through his report with him and showed him that the markers he has are common to his part of the world, and most people who have them do not end up developing macular degeneration. And that that condition really isn't blindness in the way he was thinking about it. And also explained to him that the test itself isn't predictive, it's just a risk assessment and that there was more information he could learn about how to lower his risks.

For him, it was a particular condition, a particular report, that he had questions about. But I feel like that talking about that one report and showing him how it worked, he was able to take that to all of his other reports and kind of work through those himself.

Deepti Babu:

So, I feel like you were just a fountain of information and so helpful. And I'd love to give listeners some good takeaways. What are some concrete next steps that they can do if they are sitting on this test that they've ordered, or they've already sent it in, or something like that? Could you offer some suggestions for maybe some of those folks? We can start with someone who hasn't sent in the test yet. Maybe it's still sitting in the plastic and they're wondering if they want to.

Brianne Kirkpatrick:

Yeah, very good point. So, let's say you got a kit for Christmas or Hanukkah or your birthday and it's still in its cellophane wrapper and you're just not sure that you want to do it. So, my advice is kind of think a little bit about what's holding you back. Is it that you're concerned about the privacy of your information? Is it a concern about finding out something that you're not ready for? Maybe you've seen some reports on the news about the government getting access or law enforcement finding serial killers in your family or things like that. So, know that every company's policy is different and that they change over time. So, take some time to visit the website of that testing company. Call the client care phone number that's listed or email client care if you have a specific concern. They can often point you to the FAQs on their website, maybe some videos on YouTube. There's different ways to find out about a test before you open that kit, spit in a tube and send it back.

If you just really are not ready right now, that's fine. There is nothing wrong at all with taking time. Maybe even giving the test to another person and deciding not to move forward with it. That's an acceptable decision as well. So, everybody's different, everyone's concerns are going to be different and that's okay.

Deepti Babu:

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I suppose they could also talk to friends and family, trusted people in their support networks, just to kind of bounce the idea around a little bit and kind of brainstorm on reasons to or to not do the test. And as you said, either one is a decision and completely valid.

Brianne Kirkpatrick:
Right. And these tests can have implications for other people in the family. So, I do think it’s worth kind of sitting back and talking with your loved ones and your relatives about it, maybe listen to their concerns. There might be a reason that a relative would not want you to do that testing and you just might need to give them a chance to tell you why. Yeah, don’t rush forward. But when you are ready, then you can move forward with the testing then.

Deepti Babu:
So, let’s now think about the person who maybe they asked for the test. They are curious. They’ve kind of done some thought exploration, if you will, into this already and they want to move ahead with it. What do you think could be some concrete steps for them?

Brianne Kirkpatrick:
I guess I’d encourage people to jot down their hopes and expectations, talk about those with their relatives, their family, their close friends and family, and then prepare for what they’re going to do if they get... Whether the results are unexpected or expected.

Deepti Babu:
Right. Yeah, I think that’s really helpful because I feel like, even for me, I can think about what I would do if I got what I expected, but it’s that surprise element that’s always going to throw me off the curb, so maybe someone else as well.

Brianne Kirkpatrick:
Yeah.

Deepti Babu:
I mean, I think we can maybe put in another shout out to the find a genetic counselor feature on the aboutgeneticcounselors.com website here because all of those things that you mentioned could lead to, "Maybe I should speak to a genetic counselor or speak to my doctor about seeing a genetic counselor or some kind of a health professional about this information a bit more at this stage."

Brianne Kirkpatrick:
Exactly. Findageneticcounselor.com is really the best place to search for a genetic counselor. Yeah, I’m glad that you brought that up again at the end.

Deepti Babu:
Well, thank you, Brianne, for taking the time to be with us today and to shed light on this really important topic that I know people are curious about and helping it be more understandable for us as well.

**Brianne Kirkpatrick:**
Yeah, it's been a great conversation, Deepti. I'm glad that we had it.

**Deepti Babu:**
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