**What Genetic Counselors Don’t Do**

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Deepti Babu: Hi everyone. Welcome to the third episode of the Genetic Counselors and You podcast series. My name is Deepti Babu and I am a genetic counselor and also on the National Society of Genetic Counselors Board as a director-at-large. I have been out in this field for over 20 years and I wanted to kind of set the stage for today's discussion, which is actually with my friend and fellow NSGC board member, Scott Weissman.

Scott Weissman: Hi, Deepti. How are you?

Deepti Babu: I'm good, how are you Scott?

Scott Weissman: I'm good.

Deepti Babu: I'm glad that you're joining me today.

Scott Weissman: Thanks for the invitation.

Deepti Babu: I wanted to kick off this conversation because it kind of hearkens back to some thoughts that I've had about our field since you and I have been in it for a little while, we've seen a lot of changes. When I applied for genetic counseling training programs a long time ago, I was definitely met with a lot of blank stares, including, you know, my friends and family. They just really didn't have a great idea of what it is that I was wanting to do.

Deepti Babu: And I think these days I feel like I'm seeing fewer of those as genetic counselors increase in terms of our workforce and our ability to see individuals for different reasons in the healthcare system and outside of the healthcare system. We're also involved in a lot of different things. I increasingly am aware that people don't necessarily have an accurate understanding about what it is that we do in genetics and genetic counseling.

Deepti Babu: So I feel like this is kind of a takeoff on the first episode from Amy Sturm, who is our current president and Erica Ramos, our past president, where they talked about what genetic counselors do, but they also touched on what genetic counselors don't do. And so I know that you have had a lot of experience where you've probably encountered some myths as well, and I thought we could bust some of those together.

Scott Weissman: Yeah, that sounds like fun, because actually yesterday we were together, prepping for this, and we were on a bus and the woman that was taking us around said, "What is the National Society of Genetic Counselors? What do you guys do? Do you clone people?" And that's something that we actually kind of hear a lot, I think when people talk about genetics. There's this perception out there of what their understanding of genetics is or what they believe somebody that is a health care worker working in genetics might do. So it's definitely great to have this conversation and talk about these issues.

Deepti Babu: Yeah. And those are really common questions and comments that I get too, because you know, genetics is sexy. And genetics and the term DNA is increasingly everywhere in marketing. And I think I encountered a DNA T in the mall like six months ago when I asked the person who was at this kiosk, what does DNA have to do with your product? And she couldn't answer. And it had this kind of feeling of ... it makes it feel like it has more importance than it truly is. But when you ask and you dig deeper, she didn't really understand what DNA was. And not ... to her credit, she really was trying to understand it, but she wasn't able to articulate that.

Deepti Babu: And I felt like that was kind of a loss and an opportunity for us to help educate people and bust some of the myths and make sure that when people use the term DNA that they're using it correctly and with the right intention.

Scott Weissman: Yeah, absolutely. Absolutely.

Deepti Babu: So I thought maybe, I know we've talked about a few of these things that we could bust together-

Scott Weissman: Right.

Deepti Babu: ... But it seems like a really common one is the term genetic counseling. What does the counseling mean, and what is a genetic counselor? And I don't know if you as listeners are seeing and have an appointment to see a genetic counselor. You might be wondering the same thing.

Scott Weissman: Yeah, it's a question that I think when I first started looking into this field was, I didn't even fully understand it when I started getting into the profession. And it's almost like the term like, genetic consultants, or something else may provide a better context for people because the counseling aspect of what we do is really, I think sitting and having really important conversations with people about how genetics may impact their health or their family's health and how they plan on integrating that information into their life. And really walking them through those conversations.

Scott Weissman: It's not necessarily the sense of counseling where you may think of maybe marriage and family counseling or mental health counseling. It really I think has a different angle in terms of how we use the word and so therefore I think people have an understanding of what the word means, but we as genetic counselors come at it from, I think, a different point of view.

Deepti Babu: Yeah, I totally agree with you. I feel like we are a professional communicators. So we're giving people a lot of information and we're ... I feel like a lot of what we do is translating it to the level at whatever the person is that's in front of us, or the family that's in front of us. And helping them adapt to that information.

Deepti Babu: But they're learning about themselves, but it's really dense starting material. It's like a cement brick that we have to kind of chip away with them [crosstalk 00:06:19] together, and get it to the point where we're all looking at the same pieces together and we know what they mean for each other, and then pulling those and stringing them together to give them meaning. I think that is all part of that whole counseling piece. And also I know that you're doing this too, you're recognizing if you see signs that there's something that someone needs a little extra support with because that's part of our training.

Scott Weissman: Yeah, that is totally a part of our training because again, we're trained in genetics and genetic disorders and psychology, but we're not psychologists. We're not social workers. We're not truly therapists.

Scott Weissman: And so when we dive deep in talking to people about how they think this genetic information may impact their health and how it may impact their relationship with a family member, when we do come across people that really there could be additional distress or this person is really experiencing or expressing signs of distress right now, we know what our limits are and may be able to say, "Look, I understand, I hear what you're going through, and I want to be able to help you, but this is really maybe outside of my scope and my abilities," but we also have a number of resources. We're connected to different people.

Scott Weissman: Again, social workers, psychologists, whomever, that can help you and let you get you to somebody that you can really speak to these issues with. Because again, I want to be able to help you, but I want to make sure you get the care that you need. And you know, I may not be the right person for you at this point.

Deepti Babu: Right, right. For sure. And I mean a lot of our conversations surround genetic testing and I have had people that have come to me and said, "So you know, I don't really understand why I'm here. My doctor told me to have this genetic test so I was going to give my blood sample or my saliva sample and be kind of done with it. Like another medical test. Why is it required that I come for this appointment and are you just going to kind of tell me what to do? Because if so, you know, let's get this show on the road."

Deepti Babu: And I think that's a really common and understandable kind of a way that someone might come to the appointment if that was how it was framed for them-

Scott Weissman: Yeah, [inaudible 00:08:18] every day.

Deepti Babu: ... Yeah. And so, I think I would love to hear what your thoughts are on your take when you get that kind of a reaction from someone, if they have this perception that you're going to tell them what to do.

Scott Weissman: Yeah, I mean it's always ... I think it's a difficult conversation to have because again, I think, like you said, people come in and say, "Well I'm here to get the blood draw, I'm here to spit in the tube, and I don't know why I need to talk to you." And I think once we sit down and explain to people, "Well, we really want to make sure you understand what's involved with genetic testing and what it can tell you. But I think more importantly, what it can't tell you," so that people really have a better understanding of what they may be getting into. So that they understand again, what it may mean for them, what it may mean for their family.

Scott Weissman: I think more importantly, since a lot of what we do is health based, what it's going to mean for their health. Because some people may hear about the options that we would make available to them if their genetic test results are positive, and some people when they hear those options go, "You know what, I'm really glad we had this conversation because I really don't want to do any of these things." Or, during the process of understanding why somebody is there, they may just say, "Hey look, my doctor said I need to come and do this, and I really have no interest in doing this but they said I have to."

Scott Weissman: And again, I think one of our roles is just like you started off this kind of conversation with is it's, we're not there as genetic counselors to tell people what they need to do. It's our job to really kind of understand who they are and why this information may be important to them so that we can help them in the decision-making process about whether or not this genetic test is right for them at this time in their life. And so we don't really kind of, again, we're not making medical decisions for people, but we're walking them through the process that they can make the best decision for themselves.

Deepti Babu: I really like what you said there about at that point in time too, because I know sometimes insurance coverage is an issue and they can only get this one shot to kind of come in and see you and that's an issue that's kind of separate unfortunately, and a challenging one for us. But let's say they have the opportunity to actually defer that decision.

Deepti Babu: I know what I've spoken to enough people who say that they just needed that time to sort of digest the information, and maybe come back to it later, and they didn't realize that they had that. So they felt all this pressure to make a really snap decision at the time. And some circumstances are such that they have to, but sometimes they can actually take a moment to just take a breath, talk to their loved ones that help them with these kinds of decisions if they didn't have them at the appointment and then come back to it.

Scott Weissman: Yeah, I [crosstalk 00:10:48] mean the biggest, biggest example of this that I come across, so I work primarily in cancer genetics, so a lot of people that have a new diagnosis of breast cancer or ovarian or whatever it may be, and sometimes the genetic testing can really help guide the decision-making process for what surgery somebody may be offered or what chemotherapy somebody may be offered.

Scott Weissman: And for some people, their doctor is trying to get them in right away so that they can have it and use it and make those important decisions. But some people really just kind of say, "Look, I'm, I'm so overwhelmed with this diagnosis. I really can't make any more decisions right now. I just need to kind of get this going and start with what my doctor thinks is really best. And I will come back to this." And that's a totally reasonable decision to make. But again, it's part of that kind of counseling process that ... we want to understand why you're here and what information that you're hoping to get so that we can support you in those decisions that you need to make.

Deepti Babu: Right, absolutely. And then communicating that back to their healthcare providers and their care team and giving them really focused recommendations so that they can use that information to their advantage going forward because that's what they were there for in the first place.

Scott Weissman: Absolutely. Yeah. Some people, when they look at healthcare providers, they just take what they say and go with it. Other people need to kind of process it, question it, and get other opinions to help make those decisions. There's not really a right or wrong approach, it's just there's different approaches and it's important that we kind of get that information back to their healthcare providers about why they're making the decisions that they're making. So that if somebody just doesn't necessarily feel comfortable saying no to a healthcare provider or I'm not ready for this, we can help them, we facilitate that process for them as well.

Deepti Babu: Mm-hmm (affirmative), absolutely. I wanted to ask you a little bit about when we get testing results back that are unclear, and we know that this happens and now some families out there listening you know that this happens, where it's kind of a gray zone result, like a variant or a change in a gene is found and we don't know the meaning of it medically at this point in time or scientifically.

Deepti Babu: Families I have experienced, when I haven't had an opportunity to tell them this was this possibility beforehand, are really shocked because the human genome project was completed in terms of our understanding of what the genes were roughly 20 years ago. That still is not the answer. We don't have the insights completely yet on how they work, whether they're all responsible and associated with a disease, how they work with each other, all this. It's just a lot we don't know, but the public perception is we've got this thing sealed. The book of life is known, know all the chapters-

Scott Weissman: You've watched CSI, you know they're thinking, "We can solve this in 20 ... In like a one hour episode we can figure it all out."

Deepti Babu: Yeah. And in 25 minutes.

Scott Weissman: Yup.

Deepti Babu: The whole genome sequence and all the answers laid out for you.

Scott Weissman: Right.

Deepti Babu: And we're being facetious, but this is what the mainstream media kind of has as ... because it's sexy. It's really interesting, and it's compelling, and the stories are naturally dramatic when you amp it up like that. And the truth is we don't have all those answers. And I do experience with families, this kind of frustration of like, "I thought this sort of ... in the era of precision medicine was going to be really accurate. Whatever you're telling me is ... You kind of told me something now that I don't have anything to go on. And I thought it was all going to be answered by this genetic test that my doctor told me to have."

Scott Weissman: Right. Yeah, and again, that's ... I'm sorry I'm like a broken record, but keep coming back to it, but that's where the counseling really comes into play so that people, when they come in and talk about genetic testing, they understand, again, what it can and can't tell you.

Scott Weissman: So we've just like you said, we don't really know all the genes associated with every different condition. We know that there are certain types of changes that can occur in your genetic code that our best genetic testing technology cannot pick up. So we know that there are blind spots to the testing and we can get these inconclusive results where there's a change found the genetic code, but we're not sure if it's actually going to be responsible for disease or predisposing to disease. And we're kind of left scratching your heads going, "Okay, well we don't know what exactly what to tell you."

Scott Weissman: But it really, I think kind of reinforces the need to sit with people and really talk about that family history and get all that information. Because even though the genetic testing may not be a positive, it may be inconclusive. We can still look at the family history and guide people in terms of different medical decisions that they need to be making, so we don't necessarily have to have all the information right now and maybe we'll never really truly get to that point, but at least if we have some information, positive, negative, inconclusive, we have enough to guide individuals to the best of our ability.

Scott Weissman: And sometimes we can do that even without the genetic testing, and just for people that aren't necessarily interested in doing it, we can say, well that's a reasonable decision, not everybody wants this kind of information, but based on your family history of x, y, or z, these are still some of the things that you and your physician should really consider doing, just in case there's something genetic going on for whatever condition it may be.

Deepti Babu: Yeah, I mean, I think for people it can be overwhelming and a little scary to be in a place of uncertainty when you're already talking maybe about your health. That is something you're uncertain about and you're trying to look for ways to predict or share information that seems concrete or have control over some aspect of the situation, and then to have this kind of thrown in the mix makes it a little bit tough. But I think the idea is that as genetic counselors, we can be a trusted partner in helping you navigate that, with the best tools that we have available at the time. And you can come back and things can change over time and we can continue to be a resource for you and your family.

Scott Weissman: Yeah. It's not necessarily a one time, you come see us get tested and then get the results and that's it. You're done. It's going to evolve. Our understanding of conditions evolve, the family history is going to evolve. And so constantly checking back in with that genetic counselor to get a sense of what is new, what else do I need to know, is important to have that kind of ongoing relationship to be able to have ongoing care as we learn more.

Scott Weissman: Because there is this idea out there about precision medicine and that, like you talked about a few minutes ago, that everything is getting towards precision medicine, but really it's such in its infancy right now that so few people actually truly benefit from what we would consider to be precision medicine. And it's primarily being used in the cancer world. It hasn't really made its way into a lot of other health disciplines.

Scott Weissman: And I think it will and hope it'll get there. But-

Deepti Babu: Can you define what you mean by precision medicine?

Scott Weissman: Yeah, thanks I should have done that. Precision medicine is basically this concept of looking at something in your genetic makeup, or maybe something in your tumor's genetic makeup that can be targeted with a very specific treatment or screening or something based on that genetic binding.

Scott Weissman: So a classic example is for certain types of cancers, if you identified certain genetic changes that caused the cancer to develop, there may be certain chemotherapies or other medications or drugs that can be used to target those tumor cells and take advantage of that genetic error, that is going to make the cancer more responsive to treatment and ultimately people having a much better outcome in ... and beating the cancer and surviving long term.

Scott Weissman: And so again, this is one model, but the hope would be that you can use this with other models, Alzheimer's disease, Parkinson's disease, whatever it may be, where you are looking at what is specific to that individual and their genetic makeup. Not necessarily something that they were born with, but maybe something that they just developed over the course of time and then really kind of giving them a very specific treatments in getting away from the one-size-fits-all treatment that we do now for a lot of different conditions.

Deepti Babu: Trial and error.

Scott Weissman: Trial and error, big time.

Deepti Babu: Yeah. Well, this has been a really an interesting conversation, Scott, and I want to thank you for joining me to take the opportunity to kind of bust some of these myths for people.

Scott Weissman: Yeah, I so appreciate the invitation. It was a pleasure talking to you this afternoon.

Host: Thank you for listening to this episode of Genetic Counselors And You. For more information about genetic counselors and to access tools and resources mentioned in this episode, visit aboutgeneticcounselors.com.