HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: PSYCHOLOGISTS ROUNDTABLE DISCUSSION PART 3

Guests: Lillian Hayes, Ph.D., Jennifer Hansen-Moore, Ph.D., Jackie Papadakis, Ph.D. and Jeff Garofano, Ph.D.

JOHN: *This episode of Hypospadias Conversations is brought to you by our sponsor, MyHypeLife.org. Wondering why you've never seen a TikTok, Reel, or Insta story about hypospadias? It's because they don't exist. Why? Well, it's because no one wants to talk about their privates online, let alone post a video blog about it. So, we found a workaround. At MyHypeLife.org, you tell us your story in private. We turn it into a powerful TikTok video recreated by professional actors. Your face and name stay out of it, but your story gets told in a relatable real way. Parents, girlfriends, guys with hypospadias, your story will help someone else feel seen for the first time. We need your help to tell it. Visit myhypelife.org to sign up and participate. That's 'myhype h y p e life dot org'. Let's put some TikTok stories out there for how to live a hype life with hypospadias.*

JOHN: *Welcome to Hypospadias Conversations with co -hosts John Filippelli and Bonnie Steinberg. We are members of the community that have experienced living with hypospadias and we want to begin the dialogue with members of that community, the men, women, and parents whose lives or the lives of those they love have also been affected by this common yet largely unknown condition and to create more safety to have these conversations.*

JOHN: Welcome to part 3 of our panel podcast discussion with our esteemed panel of psychologists on Hypospadias Conversations.

BONNIE: What if our sons, what if our young men are avoiding appointments with physicians, with healthcare providres out of shame, or fear, and I would add trauma. How do I break into that? How do I help with that?

JEFF GAROFANO, Ph.D.: Normalizing the Appointment, the appointment is, you know, it feels different than going to a dermatologist or going to your PCP. Just so that the nature of the differences, just talking about it as this is routine medical care that we are going to, to help you with this concern or that concern and encouraging them to talk about their concerns with you, to process it with them, process it maybe with their therapist or Psychologist. And then I think giving control is important in some ways. Maybe the doctor's office has different appointment days and times and offering to your son, "Hey, so we got four possible appointments this month. Which one of these works best for you?" Giving control is overall a big help for anxiety. Anxiety at its core is a lack or perceived lack of not having control over a situation or of an outcome.

So, if we can bring in some control, I think that could Help. If it's an option, if there's two parents in the home, which parents do you want to go with you to this appointment? Is there something that you want to ask your doctor? Those things are important. And then also to build upon that predictability again, maybe talking with, we do this a lot with our bladder exstrophy patients, telling them like what the appointment is going to entail. It could be days before the appointment. Are there going to be genital exams? Are there not going to be. Are there going to be blood draws? What's it kind of going to look like? And that can kind of help demystify what we're

actually going into. And in anxiety treatments, which might, you know, lead to avoidance, exposures are a really key component to kind of desensitizing the brain to anxiety.

And all an exposure is, is it's doing that fear provoking activity at a level that you can handle. And then over time, your brain starts to learn hey, I don't have to feel as anxious about this. I've done six doctor's appointments like this every year for the past six years. I know what I'm going through. Then the brain starts to realize, hey, you know, nothing super bad's happened. I kind of get what's going to go on with this. And then that arousal level decreases in the brain or that anxiety response. And then, you know, something that I heavily recommend across all child, teen, and I'd say adult behaviors is reinforce the behaviors that you want to see.

So, helping the child to, you know, prepare for the appointment, have some choice in that appointment. And then maybe, you know, hey, after this appointment, do you want to go rock climbing after? Do you want to go out? Where do you want to go to eat after? So, there's something to kind of look forward to. So, it's like, hey, I'm pushing through this, but there's a reward afterwards that I can kind of look forward to and kind of take my mind off of what's going on a little bit. And then the last one, too, is also letting them know I again do this all the time in session is letting patient and family know, like the doctors that you're seeing, this is what they specialize in. They see this all the time. Again, just to help normalize the interaction.

If there's touching going to be involved, definitely letting the patient know as soon as possible, hopefully earlier than the appointment. And if it's during the appointment, kind of the parent or the child can ask right off the bat. Are we going to be doing a physical exam at all? When's that going to happen? Ideally, we'd probably want that to happen, not right off the bat. We want that to happen a little bit later after we're already in the room, we're already exposed to the stressor of talking to a doctor, and then we can go ahead with that.

JOHN: Thank you, Jeff. Jackie, was there anything you wanted to add to what Jeff just shared?

JACKIE PAPADAKIS, Ph.D.: Yes, maybe I'll add a little bit more detail if that's okay, just because I think that's a very important question and something that comes up often. So, this question, how do we help our kids cope with doctor's appointments if there's gonna be a physical exam involved? And not just kids, but like how would you help a small child feel prepared versus a teenager? And then even as an adult, how do you feel prepared and empowered for that? So again, sorry if this is redundant, but yes, letting, especially kids, if it's the parent in charge of scheduling appointments, letting the kids know ahead of time when the appointment is and what to expect, that's very helpful. So, maybe a week or two ahead of time, it's reminding them, hey, next week you're going to go see Dr. So and so. And remember, the doctor will want to do a physical exam of your body, including your penis, and it's only going to last. A few minutes, but this is very important, right? Giving them a reason why this is happening.

This is very important because as your body grows, every part of your body grows, including your penis. And the doctor wants to make sure that your body is growing in a way that you want it to and that feels good for you. And so, you know, providing your child with an explanation of why this is necessary and then normalizing it, right? Men and women have physical exams for all sorts of reasons throughout their lifetime. If it was me saying it, I'd say, Oh, mommy's had tons of physical exams of her private parts and things like that to really normalize it.

And I would also note that when you're having this conversation, it's kind of a nice opportunity to also have a safety conversation about who should and shouldn't be touching or examining your private areas. That's a conversation parents should always be having with their kids at different touch points, that kind of body safety

and autonomy. But this is a good opportunity to do that. Doctors are typically in the category of these are safe people, and there's a good reason for them to do this. And then highlighting what Jeff commented on too, that the idea of offering choices can be really helpful to people of all ages, but especially to kids. So, deciding who do you want in the room for the exam? Now, mind you, oftentimes it's recommended that there be what's sometimes called a chaperone, especially for youth, but even for adults these days, they're kind of going towards a model of there's always a second person in the room. So maybe a doctor and a nurse, or a doctor and a parent, or a doctor or spouse. But letting them decide who that person is and then if they have any other requests.

So, I've had some kids say, I have a request. Like, I don't want anyone to talk during the exam. I don't want the doctor to comment. I don't want him to ask me questions. Can you just hold it? Because it's going to be awkward. And then after my pants are back on, then you can talk to me. And the doctor said, Okay, that's fair. I can do that. But something little that makes that young person feel very empowered. So yeah, so those are a few things I would add.

JOHN: Those are such important points, Jackie. And at what age would you say that a parent should hand over the medical conversations to the young man when he needs to talk to the doctor?

JACKIE PAPADAKIS, Ph.D.: Yes, so I think of this as a gradual process, and a child is never too young to be centered in a conversation. Obviously, the conversation is always about them, but for them to really be centered in the actual conversation. So, some Providers might be really good at doing this, directing questions towards the child, even young children. Some doctors might direct questions towards parents, that's fine. But you as a parent can always help facilitate that the child gets to answer questions and speak their mind. So maybe a doctor asks a parent a question specifically and you as the parent could say, "Great question, doctor. Son, what do you think about that?" And something like that, just to give your child the opportunity to speak first. Or as a parent, if you're answering a question, Well, this is what I think. But I really want to know what you think. And so everything that you answer, let's give them an opportunity to answer too. So, those are small things you can do. And then by middle school, certainly kids are capable, not, I mean, sooner as well.

But certainly by middle school kids are absolutely capable of having back and forth conversations and being pretty comprehensive and being able to answer any of a doctor's questions. But there are individual differences here. Like, you know, I know there are some elementary school kids who can just carry a visit by themselves. And then some other high schoolers who maybe they just have a quieter temperament like they're just a little bit shy and have a hard time making eye contact that might be uncomfortable for them. Like. It's okay if there's those variations. I think what's helpful as a parent is to be really explicit that the goal here is for the child to eventually have a lot of ownership over their medical appointments and their medical interactions. And that they are the one kind of with all the knowledge, they know all the history, they make all the decisions.

That's the goal. And so the whole thing here is for the parent to slowly hand it off. And so it could just be like okay son this next Appointment. I want you to kind of lead off and try to answer some questions. And if you don't know, I'll be back up and I'll answer or I'll chime in. And then as they get older. Allowing them space alone to talk with the doctor. And instead of asking like a teen, like, hey, do you want to talk alone with your doctor? Because your teen's probably going to say no, it's fine. It's fine. You'll just say, you know what? I'm going to. 'Cause your teen's probably gonna say, "No, it's fine, it's fine." You'll just say, "You know what? "I'm gonna step outside for five minutes, "just give you some time to ask your doctor "any questions you want, "and if you don't

have any questions, "then just knock on the door, I'll come back in." But you as a parent can absolutely do that to make sure that your child has that time with the doctor and feels like a little bit more empowered.

JOHN: Very cool, that's very cool. And Lily, I know you mentioned earlier about the pie metaphor, and I feel like this next question is really kind of the million-dollar question for a lot of people out there, which is what's the healthiest way for him to accept differences as part of his story without shame?

Lillian Hayes, Ph.D.: I'm gonna echo something Jackie just said which is that, you know, every kid is different and we want to be responsive to who they are and what they need. But I think that there's probably four things I try to keep in mind to help like build this foundation of confidence and accepting their differences as they grow older.

One is to normalize it. And I'll kind of talk through this a little bit more. The second is to avoid shame or secrecy by like opening lines of communication with them as they grow. The third is to let the child lead the conversation over time. And four is to keep it brief and simple and like be willing to repeat information over time as you revisit the conversation. When kids are ready and as they grow, we can give them more and more information about their medical condition in a calm and neutral and simple way. I know we've given some examples of conversations, but for example, if your son says, Mom, Dad, why do we have to go see Dr. so and so? We can answer for them and begin to build the narrative. For them about this and like give them language that helps them think about this and understand this.

So, a parent might say something like, that's a great question. Well, the truth is everyone goes to doctors sometimes and different doctors do different things. We go see Dr. So-and-so because when you were born, the hole where your pee comes out was in a slightly different place than other boys. Many boys are born with this and Dr. So-and-so knows how to help us with this. That's why we go see them every once in a while. And if you have ever any questions about it, you can always ask Dr. So and so or me and dad. And as they get older and have more questions, you can continue to offer information that's simple and calm and reassuring. I think we mentioned this earlier, but sometimes in our own anxiety, we tend to offer too much information before a child is ready to hear it and process it.

So, this is why I think it's important to let them lead those conversations and be consistent in how you respond. And so, you can open the door like when they're young by letting them know that they can ask you questions at any time. And then the key is to let them do that when they're ready. Outside of doctor's visits or when they ask questions, we want to try to not force the conversations. That's the time to focus on and cultivate the other aspects of who they are so they don't feel like this medical piece takes up like the entirety of who they are.

JOHN: Amazing. Thank you. And so, we're coming up to the end here. So, what we'd like to do is ask you, Lily, if you can share the, if there's a growing body of psychologists working in urology or medical settings and that they can advocate for this type of support. And do we know any resources for adults that might be helpful as well?

Lillian Hayes, Ph.D.: Definitely. So, the first thing I'll say is that all of us four got to know each other through through our urology special interest group, which is through the Society of Pediatric Psychology. And we started the special interest group, I think back in 2023, early 2023, with like 12 members, and now we have 33. And so, we've really almost tripled the amount of psychologists who are working in these settings or working with patients with urological disorders. I would say that like mainly these psychologists are located at major pediatric

institutes, but that some of us can see patients remotely in other states, or at least we use each other to try to find someone who can. So, if you have someone who you're connected with or have like, meaning a urologist you're connected with, they can always get in touch with us or you can reach out to us as well.

If you don't have a psychologist at your institution, please know that because these types of positions exist, you can advocate for your child's urologist about getting this kind of resource where you're being seen. That is like really one of the ways that we can build these resources where kids are being seen with this.

For adults, as we talked about earlier, sex therapists and adult psychologists connected with a medical institution are usually like my first go tos because sex therapists, of course, have this specialty. And at least like understanding sexuality and intimacy. And adult psychologists connected with a medical institution may have more knowledge about different medical conditions and how that affects people. But even if you don't have those options available, you can find a psychologist in your community. And if you build a good relationship with them, yes, you may need to educate them on what hypospadias is and how it impacts you.

But once you give that information, you know, they will be able to work with you using some of the general training and skills that we have. I know a lot of us will even connect with therapists in the community, or we may connect with, you know, your therapist can connect with your urologist directly so that they can hear that information too. And that means that you might not have to like be giving all of that information yourself if telling your story is—gets annoying after a while when you do it over and over. There's also support groups and communities out there. So there's the Hypospadias and Epispadias Association. And at least these are some that I'm aware of, the Hypospadias UK Trust. And so, there are communities out there who can provide support to you. And I would just encourage you to look online as well if you're looking for that type of resource with someone who also has Hypospadias or has a family member with Hypospadias, for example. Another great resource is My Hype Life, which includes videos of men with Hypospadias on a variety of topics. They're great for people of all ages to watch and get some advice about how to manage different issues that they might be experiencing.

JOHN: Thank you so much for that. So, at this point, I just want to thank everybody. I'll give everybody the opportunity for any parting thoughts or any promotion or anything that you want to mention. Don't feel obligated, but I want to give you that opportunity. So, whoever would like to share any parting thoughts or anything else, feel free.

Jennifer Hansen Moore, Ph.D.: I did have one thing that I thought about after we had already had our conversation. And that's something for consideration, whether it's romantic relationships or friendships is to make sure that when you do share that information about your condition, that it still feels empowering, and not like a cage, so not feeling like they need to stay in a relationship that is not going well otherwise again be it friendship or romantic relationship, just because they've now shared that information, it has been accepted. And I've worked outpatient with several young adults who have expressed that kind of intrusive thought of, "Who else would accept me? This person accepted me, so therefore I need to stay with them, even if the situation isn't so great." So that's just one other thing that I would highlight when it comes to relationships.

Lillian Hayes, Ph.D.: I would just add too that I think you know, all of us are coming here with our skills, our training, our knowledge, our experience working with patients with urological conditions. But I really truly feel like the times where I learn the most is when patients and families share with me about their experience and like what they feel like is important in the field, what research we need to do or what policies or procedures

should be in place or what resources we need, like handouts or talks or things like that. I find that like the best anecdotes I give other patients about coping is something that I've heard from another patient. And so please like continue to share with us too. We are on a team together that interdisciplinary Team most importantly includes patients and families. So please continue to speak up and we work together.

JACKIE PAPADAKIS, Ph.D.: I think I just really wanted to underline what Lily said.

JOHN: Jeff, any last thoughts?

JEFF GAROFANO, Ph.D.: My only main thought would be is if you feel like your son could benefit from mental health support, when you first feel that notion, consider it, look into it. It doesn't mean that you're locked in for weekly appointments for the next ten years, but it's usually better to kind of get some professional eyes on and get you on the right path. And maybe it's just a session or two, or maybe it's the start of a relationship. Usually just connecting with therapists and psychologists earlier is usually the best. If needed.

JOHN: Great, thank you. Bonnie, any thoughts?

BONNIE: I wanna just thank each one of you for pioneering in this work, for keeping connected with each other and hoping that this team keeps growing so the community of people with hypospadias can reach out more and more to people like you. And thank you so much. For giving this afternoon to us and to the wider listening community.

JOHN: Absolutely. I echo everything that Bonnie just said. I love the word pioneering that she just used. I completely agree. Each one of you is amazing. This is an amazing panel. And I just thank you all so much for sharing your time and your expertise, me and Bonnie and with our audience. Thank you everyone for listening. I wanna thank Dr. Lillian Hayes, Dr. Jennifer Hanson-Moore, Dr. Jackie Papadakis, and Dr. Jeff Garifano. For being part of our very esteemed Panel today of these episodes of Hypospadias Conversations.

Thank you all for listening. You can see all of our podcasts on Spotify, also on livingwithhypospadias.com. And if you have any feedback or questions for the doctors, please email us at hypospadiasbook@gmail.com. And we look forward to having another episode of Hypospadias Conversations very soon. Thank you very much.

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