HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: FOLLOWING UP WITH MOM ASHLEY

***JOHN**: Welcome to **Hypospadias Conversations** with cohosts Bonnie Steinberg and John Filippelli. We are members of the community that have experienced living with hypospadias, epispadias, the surgeries that are often used to correct for them, and we want to talk to people who are members of that community and their family and friends about many of the feelings and issues that we all have faced. We are not doctors we do not represent the medical community and we want to be clear that we are discussing our personal experiences—experiences that too often are not shared, leaving many boys, men and families feeling that they are alone. You are not alone. Our goal is to offer frank conversations about our thoughts, give many people company, give parents who are wondering what to do with their new babies that have been born with hypospadias or epispadias, some resources. to think about treatment. To think about parenting boys with this difference. The conversations are personal, frank, and we hope that you are aware of how vulnerable we feel, how risky it feels to open ourselves up in public. We hope to cultivate your compassion and understanding and create more safety to have these conversations.*

JOHN: Welcome to another episode of Hypospadias Conversations, I'm your co-host, John Filippelli, along with my co-host, Bonnie Steinberg. How are you, Bonnie?

BONNIE: I'm doing well.

JOHN: And it is our first podcast of the year, which is exciting. And we thought it would be a good idea to do an update from one of our previous guests. So, we are very glad to have Ashley back. Ashley is a mother of a son who's 20 years old. He was born with peniscrotal hypospadias and chordee. He's had at least 16 surgeries to correct complications from that, but Ashley's also a nurse so she has a very unique perspective on this situation from a parental viewpoint and also from a clinical viewpoint. So, thank you Ashley for joining us again today.

ASHLEY: Thanks for having me back.

JOHN: By way of update for for those of us that had a chance to hear the first podcast. How are you doing? How is your son doing? And how was his most recent surgery?

ASHLEY: Honestly, it is another failed surgery, probably going to be brutally honest, probably the worst failed to this point. And not expecting that at all. I mean, I guess kind of, you always have it in the back of your mind, but immediately failed within a couple of days after surgery. I mean, we're talking within the first 48 to 72 hours and just been kind of battling it since. He is still having complications from that and it's been an extremely rough time for him. Very, very rough.

JOHN: How did you or he realize in those first 48 to 72 hours, like what was happening that indicated that there was something not right?

ASHLEY: So, with this last surgery, they tried to, I guess, kind of bring everything together again, because the previous surgery, it had partially broken down and the skin had kind of ripped open on the outside there. So, they had tried to bring it back together again. And within, like I said, the first couple of days, where the catheter was, it started kind of just opening up along the incision. And we just noticed it immediately in one particular spot. And then within a few hours it was in a second spot and a third spot. And we were kind of just desperate there for the first week trying to utilize different techniques in how to keep everything together like as far as the wound. And we thought we had gotten a little like hold on it there and kind of stopped it in its tracks.
But then it over the last couple of months, it's just starting to basically wanting to go back to the way that it was, right. And so, it continues to, I guess, you know, there's definitely fistulas, it continues to open up on the outside, there basically is really no healing. It's been probably his longest recovery, just really physically struggling internally, externally, with the whole healing process. So, he's definitely had some fistulas. I think he's got some other complications going along with that. And that's kind of where we're at, because it's like now, we just—do we need to stop? You know, this is you know, what is God trying to tell us? Do we need to just stop and leave it alone? Could this get worse? We don't have a plan. I think he's there's a lot of fear of, you know, trying to figure out what the plan is, if there is a plan, you know, hearing that. Sorry, we can't operate or yes, let's go for another one it's just that you know it… both are really bad, right.

JOHN: And just you know to clarify I mean you've—you and your son have gone to multiple different practitioners.

ASHLEY: Yes.

JOHN: I mean around the country so this is not been just a one—you know one-off kind of event this has been… you've kind of been hearing the same things repeatedly with his complications, right?

ASHLEY: Yeah, it's kind of all the complications have definitely been discussed with us through all different practitioners. But I don't really think as a parent and maybe even as a patient, I don't think you grasp those until you are experiencing each and every particular complication. You know, you hear it, but it's kind of like, well, yeah, it's a risk, but hey, the benefit should outweigh it, right?

JOHN: I'm curious also. And then I'll let Bonnie jump in. But as a parent and your son's now 20, 21?

ASHLEY: he's 21 and he'll be 22 in April.

JOHN: Oh, OK. Great. Wow. So, I'm curious for you and for him, what was the post-surgical care regimen? Was it different, how was it different, was it things that when he was a baby or, or a toddler or, you know, uh, a young boy, do you remember having to do or not having to do versus now that he's older and an adult?

ASHLEY: So, when he was younger in diapers we would obviously—he still has had a catheter with every surgery, every single one. I don't think he ever walked away from a surgery without a catheter. So, we've always basically you know we would have to double diaper. I think they still do that now with the catheter coming out of the second diaper, you know, putting Aquaphor on. And that's kind of like, I just remember that it was very basic when he was an infant, a toddler, a young boy, it was just very basic.

Now that he's older, and maybe because I'm having to help him with those things, I feel like it's just more detailed. So as the recovery, the post-op has been definitely a catheter for two to three weeks for my son. And my son would, you know, like, you know, he has a dressing on right at post-op. Within a couple of days that falls off and then you immediately have to start putting on the Aquaphor Manuka honey. That's been a game changer for us.

I feel like even though he had the failed surgery, it was still helping him in the healing process. And he ended up pulling the catheter. He removes it himself after each surgery. And just a lot of baths, like a lot of soaking, a lot of creams, a lot of ointments, and definitely the pain medication, the antibiotics, the medications to prevent the erections after surgery, and the medication to prevent bladder spasms. So that's kind of his normal regimen for each surgery, and that's what it's been. A lot of, just a lot of those type of things. Obviously, as an adult, you're doing—you're doing that, multiple times a day, you're helping him, you know, and so it's just as the person who's caring for him and his caregiver, it's you're doing that for two to three weeks around the clock. And so, I feel like as an adult, I feel like he has a harder time, maybe because he can voice it, he can express it. His recoveries have been very, you know, just difficult, trying to physically feel comfortable, trying to maneuver around being medicated, his diet, it's all connected—

JOHN: Uh-huh.

ASHLEY: …In a sense. So, it's definitely just around the clock for two to three weeks.

JOHN: Yeah.

BONNIE: I've heard about going to this hyperbaric chamber to get the tissue ready for the surgery. The intimacy that is required between the caregiver and the patient in the post-op, for a parent to be involved like that with a boy after the age of five, six, ten, all of those issues. And when you don't live near the clinic, how does one keep making sure that the post-operative care is healthy?

ASHLEY: That's a good question. Because you're relying, you know, since we were out of town, we are relying on our local facilities to help us with that, you know. But with the hyperbaric, we are fortunate that obviously in California, we have facilities here that have the hyperbaric. So, we were able to do that prior to to prepare the tissue with every surgery. And we do the hyperbaric there in Texas. And we continue once we return in California, doing it here at home. But you know, the problem that we ran into with that, which the hyperbaric was great, it did help him, I feel like, but now you have the opinion of the wound specialist doctor that works at the hyperbaric facility, then you have doctor's opinion. So, you know, you're trying to listen to both in the healing process. And that was something I didn't expect is, you know, we were so gung-ho about the hyperbaric, but wait, wait, wait, now we have a doctor who's chiming in on, you know, what their perspective is.

BONNIE: Can you describe the process of going into the hyperbaric, going through that? What does it entail for the patient and for the caregiver? And what are the results that they expect from that? Do they expect the tissue to be much better through the surgery and the response in recovery? That the tissue will be more responsive?

ASHLEY: Yes, it's more oxygenated tissue. And so, we've been doing that, you know, pre- and post-op. You know, getting it, you have to first get it approved through your insurance. It's very expensive. They are the hyperbaric chamber or can they're what's called going in for dives. And they're 90 minutes long. I'm I don't know if the time differs with ages of the patients that are in there, but I know for my son, it was 90 minutes. And that's after you get it approved through your insurance, which is kind of a lengthy process. That's definitely done a couple months prior to starting the hyperbaric.

And once you're in there for your appointment, it's for my son, it was kind of a cross. There was a thin line between tiring and invigorating. If that—I know it's hard to grasp that, but you would go in, it was just because you have to do it every day and every day of the week prior to and, and, and so many after. So, for my son, it was 10 to 15 prior to surgery and 20 to 30 dives after surgery. And you're doing those back-to-back daily Monday through Friday.

BONNIE: So, it's 90 minutes a day?

ASHLEY: 90 minutes a day.

BONNIE: And you're in a chamber that is, so do you read? Do you listen to music? Do you watch television?

ASHLEY: Right, so luckily our two facilities that we have here locally, they offer television. You cannot read because you can only bring in a bottled water into the chamber. You have to wear a gown and you can't have any products on, no hair gel, no deodorant. You're just going in completely clean and you either sleep or watch TV. And so, for a 21-year-old, you can only watch—you're doing that Monday through Friday, you can only watch so much, you know... And so, I think it gets a little tiring in that sense because they don't have their phones. And if you want to, you can't bring a visitor, you can't talk to them. You can communicate with the hyperbaric tech if there's a problem, but yeah, just reading, sleeping. So, in that sense, it's that daily sitting in this chamber that only has, it's literally the width of a hospital bed. And you slide in and you're wearing a gown and you have different symptoms. Your body's trying to acclimate to these dives from the moment that the hyperbaric dive starts all the way up to the 90 minutes. And sometimes you can be nauseous, your ears, the pressure builds up. So, you need to make sure you can clear your ears. Sometimes you can—that's why they have the water so you can swallow. And so that was kind of his tiring thing of just being kind of stuck in this small confined space for so long every day.

But whenever he would get done with his dive, you feel, he said that it would just feel very like he would feel a little bit more energetic, like you just have all this oxygenation like just pumping through your body and you have a little bit more energy. So, he's just kind of that back and forth feeling every day. And so, it's great for the tissues, but you know, you have to, you have to keep in mind, I can't go in there with a cold, my ears need to be clear, if you have allergies, you can take allergy medication, because all those things affect it, you know, you can't take medication before you go in because you're going to get nauseous. So, all these little things that affect it, affect your body when you're sitting in this chamber, you just don't think about it until you're doing it.

BONNIE: So okay, so after the surgery, you're on a catheter, and does he have the procedure where they take material from your cheek to recreate a urethra?

ASHLEY: So yeah…

BONNIE: And you're eating…

ASHLEY: So, [a] majority of the surgeries, yeah, he's had the skin grafts, whether it's been an oral or the cheek or behind the ear, he's had it taken. He's also had it taken from his groin area. Yeah, he's had all that. And basically, yeah, I think that's where part of the complications arise from because they basically keep having to regraph certain areas along the underside of his penis. And that tissue just unfortunately is not taking as well as we wanted it to.

BONNIE: Parents out there really should talk to the surgeon. What is the donor site? Where is the donor site? What are the, what's the impact of having that donor site donate?

ASHLEY: Right.

BONNIE: So, for example, when our son was a tiny baby, they took bladder material, which sounded so logical, like, yeah, you're going to create a urethra. Let's take the bladder material. The consequences were that our son was in pain when he urinated for several months as the urine irritated that donor site.

ASHLEY: Uh-huh.

BONNIE: And it wasn't something that anybody ever said or we thought about or… We weren't aware.

ASHLEY: Yeah.

BONNIE: So that's something for parents. Yeah…

ASHLEY: And that makes total sense looking back on it, you know, and maybe it's not, you know, the symptoms that these—that these boys and men are having. It's not those little things maybe don't come into play when all that's being done. It's not thought about as far as what they're going to feel like internally.

BONNIE: But that was agony.

ASHLEY: Yeah.

BONNIE: Every time our son had to, you know, felt that feeling, it was really agony for several months. I mean, his surgery was in the beginning of August. He wasn't out of pain until the Thanksgiving period.

ASHLEY: Oh, I'm sure.

BONNIE: It's a long time. Yeah. So, what's it like to have the grafts taken from the inside of the cheek?

ASHLEY: Based on what I saw my son go through as an 18-year-old all the way up till now, it wasn't fun. It really wasn't. I'm not gonna say hell, but it was pretty darn close because especially—so the cheeks, the cheek is was more tolerable than the bottom of the lips. Sometimes they had to take it up here on the upper lip. Sometimes it's from the bottom lip. Those were the ones that were really painful. And then also when they did do it from the cheek, a couple of times they took it really close to the corner of his mouth, and that was extremely hard for him.

They prescribe an oral mouthwash that has lidocaine in it and I forget what else, and it basically kind of numbs it temporarily so you can eat. That mouthwash is started immediately after surgery. You can take it every so many hours, and we're talking a small amount. We're talking five mls of swishing that around or using a Q-tip on the graft area where it was taken. But poor guy, it was terrible. Anything hurt, trying to drink from a straw, everything just hurt. And then as that heals, those grafts heal orally, the inside becomes very, you know, your skin, everything wants to contract, wants to heal. That was hard because then you have this lingering tightness in your mouth. For my son, he cannot open his mouth fully without it being really tight on the corners of his mouth. And same thing with his smile. So now when he smiles, it's a little off because you can tell where it's been tightened and pulled and yanked. You can't see it from the outside, but you can just tell his natural smile is not there anymore. You know, it's been altered.

JOHN: Yeah. Ohh…

ASHLEY: So, for him, it bothers him because he, you know, that's your face. You look at it every day.

JOHN: Right, right. And it's your smile. I mean, that's your smile to bring joy, you know, expression, joy, all those sorts of things. And its hindering him.

ASHLEY: Right.

JOHN: And that was a very good point, Bonnie, because you had mentioned Ashley that most of your son's surgeries were three-stage repairs, right? Or two-stage repairs.

ASHLEY Yeah. Three-stage.

JOHN: So that's, that's an important distinction. I know for myself—the donor site was the groin area. So, I've talked about it and wrote about it, how it's hair bearing skin and over time, the hair continues to grow. And so that was issues for me, and I'm sure other men as well.

BONNIE: I would wonder if your son's response is pretty common, but there's no acknowledgement of that coming from the medical community. And unless people join an online group or something, there are very, very few hospitals, I would think that have support groups, even though they're supposed to, so that our sons may feel very lonely, but their experience might be much more common than—than is reported.

ASHLEY: I agree. It's a hush hush subject. And I'm sure I would imagine that many men feel especially with the ones that have the failed surgeries. Yeah, you just feel very isolated in it. And I think looking back, even just with all the doctor visits, you know, even just a general appointment of going in and having to explain this to any physician, it's very draining for these men. I would—I mean, like I can see my son. It's very draining to have to explain it over and over and over and over and again. And to really try to have someone listen to you and really hear what is wrong and what you're going through. And it's very degrading in a way, you know, it's a very vulnerable time and having to have pictures taken. And, you know, and and office staff is primarily female. So you know, it that was hard for him as well going into all this. And, you know, even I noticed that from like kind of just a younger—being a younger boy all the way up till now, it's very difficult to go in as a man and have everyone looking at your private area and taking pictures and having to explain it. It was just a very hard time for him to go through.

JOHN: What is your son expressing right now in terms of what the surgery or all of his surgeries have maybe affected him? And if he's expressing it to you, if he's expressing it to the doctors, and then I'd like to also hear if he has expressed it to the doctors, what any of the doctors are responding back to him?

ASHLEY: Well, first, I don't think that... I mean, I haven't been in some of his appointments since he's older now, if he's putting everything out on the table as far as you know, this is how you guys make me feel. I'm sure he's said a couple of things in a roundabout way, but I know that he feels like he's not heard almost like just very cold and insensitive. And I know he has a lot of fear, embarrassment, and no confidence whatsoever. It's a feeling that he kind of has nothing, you know, there's no reason to be here, basically. It's it's you, he's, he's had everything just kind of sucked away from him because this is his, you know, manlihood, right? This is everything. This, for him, defines what he could, you know, is he gonna have relationships? There's no companion. There's no—he's very lonely. So, for him, this is kind of like the center of his world right now. Everything revolves around it. And he basically cannot start living a life until this is corrected. But I believe that there's so much fear now with all the complications that maybe he… it's kind of forced him to, to maybe try to see, you know, well, what is my life going to be like, if I'm left like this.

And just to kind of jump back on the hyperbaric, we didn't anticipate that they would take pictures of him. It's a wound specialist, right, a wound doctor that looks over that. So, every so many months, they want to take photos, they want to see if there's any progress made. And that's done with a female doctor and a female nurse standing in the room. So, and sometimes they'll have male nurses pop in just to be that second person. And that's terrible. Like, you know, who wants to have a room with a couple of people in there staring at him?

JOHN: Right.

ASHLEY: And I know for myself, I've spoke with the staff at my local facilities and trying to make them aware. I've put in a letter, I've, you know, talked to managers, supervisors, and trying to make them aware of what these younger men are going through and what—how you're making them feel when you take these pictures and have other people in the room. This is not this is not a learning environment. This needs to be a private situation and they need to you know I've had that discussion and I don't know that it changed anything but there has been a few times to where we refused any pictures. It's not gonna happen today, sorry. And if this means we stop hyperbaric, then we stop hyperbaric. I just kind of wanted to include that in case there's parents out there that, you know, like what is involved in that? Well, if you have a younger boy, maybe 10 or whatever, there's gonna be pictures taken.

BONNIE: John, did we, I'm thinking that one of our previous podcasts, I had a list of questions for parents to ask their physicians and one was, will there be any photographs? And so, Ashley, what do you think the function of the photographs? I mean, you know, people now what's the function of these photographs? And do they help the patient? Or are they good for the chart?

ASHLEY: I think they're good for the chart. I know back when we first started when he was an infant and toddler, it was presented to us as more of we would like to take pictures, do we have your permission? Because you know, the hospitals had residents and they were training hospitals. So those pictures I felt like were a benefit, you know, like, hey, if this is not talked about enough, and there's not a ton of patients out there going through this — photo, sure would help the next patient or the next doctor. And so, I felt like in the beginning, that's how it was presented to us.

With hyperbaric, physicians that take pictures, I do believe they want to see a before and after. They want to be able to compare. But I definitely think it's for the medical staff and it's not for the patient. I mean, you know, that I see. I don't, I mean, maybe in some way it helps with the process and their plan and the ongoing care that's provided. But, you know, in the meantime, it's just very degrading for the patient.

JOHN: I could absolutely see why someone would be feeling less than… when that happens. And they're almost not feeling like a whole person anymore. Now, they're just like a specimen.

ASHLEY: You hit the nail on the head right there. Yeah, definitely. Like a science project. My son has mentioned that several times.

JOHN: Yeah. Yeah. And, you know, furthermore, I mean, I'm sure because I have dealt with these feelings, you kind of start to almost feel like—that almost is so counterproductive emotionally for someone, because really it makes them start to feel almost like kind of abnormal or freakish, you know. And that's the complete opposite of what we're shooting for here. I mean, we want people… I was so glad that you just said a couple of minutes ago, Ashley, if it means not going into the chamber today, we're not going into the chamber because you're not taking pictures. I mean, I hope that the people listening really heard that because there are choices. And I know how Bonnie talked about, you know, mutual decision-making. At the bare minimum, there should be a mutual alliance, to use that term, with the doctor. And I think a lot of people, especially when it's so vulnerable, it's such a vulnerable condition, a vulnerable spot, I know I certainly forgot that, that I could actually have a say in what's happening. And I hope that the parents, the individuals listening, realize that, that you can speak up, you can say, that doesn't work for me. And a good doctor should listen to that and respect that. Whether it's a parent with a small child or if it's a 21-year-old man like your son, they should hear that. I mean, I have friends through HEA and other places that I've spoken to. This is a lifelong thing. You know, this is something that people don't realize that and they don't realize with each season of our life, this is with us. And we have the regular everyday challenges like everyone else, but this is gonna be there as well. And the doctor you have today may not be the doctor you have or need down the line.

BONNIE: [For my] Master's thesis, my two readers were surgeons, were physicians. And one of them said, if our adults are having so many problems, wouldn't the doctors hear about it? And as I sighed, he got the message. He said, oh, you guys aren't telling the doctors what you're really going through. We aren't listening. And that I think is a crucial thing. I think I've met a couple more parents. We want to tell the doctors what we're going through and we really want them to listen and not discount us. …Oh, that's just a few angry people. And then we want to re-educate these doctors. Do we want to talk about the option of restoring the original urethra? I think that's something that we did an interview with Jim Lake, where he talked about that. How's your son's urological? How does he urinate during the day? What's it like for him?

ASHLEY: I think the urgency is there, just kind of like definitely more frequently urinating. That urgency I've noticed for the past couple of surgeries. And he also feels some resistance now, not necessarily a blockage, but definitely more pressure, more resistance. I think like a thinner stream. So, he's just really frightened that it's just going to kind of close up one day. But I know that there's a lot of inflammation internally and externally that he's going through right now. And you figure we're eight - nine months since the last surgery. I mean, it's been maybe not quite that long, but it's it's been a long it's been a number of months.

BONNIE: A significant number of months.

ASHLEY: Like, why are we having this now? So, I'm sure it's more scar tissue, I'm sure the inflammation, that whole healing process. So that's kind of where he's at now with it. And then he he does say that he feels kind of like this. Internally, he feels like it's tearing. But he's also at a point to where he's so just frozen in it. So numb, just of that fear of like, okay, what do I do that now there's no, there's no motivation for him to tell the doctor what's going on.

BONNIE: I was going to ask±—the physician that you, the surgeon that you've chosen is well known in our hypospadias-epispadias community. What's their knowledge? What's their awareness of what your son—what our kids are going through? And what are their suggestions?

ASHLEY: And so that's a great question. Because, you know, I haven't, I haven't had a long conversation with the doctor about all this. It's been mentioned. I've mentioned to him this is where we're at in the sense of emotionally and mentally. But you know, with my son being 21, I cannot necessarily speak for him anymore, you know. So, it's like you were saying earlier, like they're not being told of these symptoms. They're not being told how they are feeling in all these different areas of life.

BONNIE: The physicians are not being told of these symptoms.

ASHLEY: And I know for my son, it's very, it's, it's very like, well, why would I let them know if there's nothing else that can be done? If I'm continuously suffering from all these complications and nothing has changed and things just keep getting worse, why would I reach out? Because nothing's going to happen. And I know that recently, the, to kind of touch on all this of, you know, how the doctors are handling it. Unfortunately, there was no follow up for my son. This last surgery, I tried to initiate it with my son because he was older. So, he had to initiate things on his own with a post-op. There was no call from the office saying, hey, we need to touch base. It's been six weeks since surgery. We need to get those photos submitted, see how you're doing. There was no phone call, no follow-up. Until recently when I am, as the parent reached out and said, hey, this is what's going on. Can he get a refill on some ointments? No, looking back on it, we realized there was never a post-op appointment made. He needs to submit pictures and tell the doctor what's going on. Well, my son doesn't want to submit more pictures. So, it's just kind of we're at a stop now, because he doesn't want to submit pictures and tell the doctor what's going on and It's kind of like out of sight out of mind. I think with the doctor's office What are they gonna do? I guess is what I'm saying. There's nothing else that they can push on their end So unfortunately, he—my son does not feel supported in that area.

JOHN: Do they have any sort of like Therapist or social worker?

ASHLEY: They do actually. Yeah. A couple of years ago we were encouraged and I again, I tried to get my son to talk to the therapist that they have their own site. He has no interest, you know, so you got to meet him halfway, but my son isn't quite there yet. I actually did speak with the therapist there. He's great. And I think that's something that's like, I'm so glad that they have that, because I do think that should be started there with the younger patients. The younger boys definitely need to talk to him. But when my son reaches out to the doctor personally, because they exchanged several emails over the last few years, you're also getting, you know, you're talking to a surgeon. So, it's kind of just very matter of fact, very blunt, very black or white, you know, it's, it's not warm and fuzzy. So, I don't know if that's a good thing or a bad thing.

BONNIE: I'm feeling like it's a bad thing.

ASHLEY: Yeah.

BONNIE: I need to interrupt just for a second. We know that from these articles about, you know, hypospadias surgery, that the complication rate and the redo rate are often as high as 50. We don't have good statistics on this. And yet I think there's a feeling among the surgeons that our sons who have these repeated problems, your son, are in the minority and they're just the complainers and they're the bad healers or whatever. Ashley, during the hyperbaric and the preparation and the surgery, do parents meet each other and talk in the waiting room? Is there any collaboration or sharing during that process? Because going to your surgeon, I would assume that almost everybody who goes is going for the same reasons. It's not like one person's going because they have a urological, a [quote unquote] normal urological problem. I would assume that they go there for hypospadias repair and so everyone is kind of experiencing the same process?

ASHLEY: I was very much looking forward to that possibility when we first started doing these last several surgeries out of state, just because of the facility. I was really hoping to see other young men and other parents and people that I could talk to. That's a no, because I think it's like that maybe for some that have younger children, because our experience is there each and every time. It's just all younger children. We've never been there at a time to where there's been another teenager or adult male. It's always been, you know, parents that have a one-year-old or a three-year-old. So, I've never really initiated any conversations with them while in the waiting room, because I just, I'm in a different place with it all than they are. And I don't want to instill any fear, because you know, through the whole thing from day one, all you have is hope. So, I don't want to ruin that for them. I don't want to discuss any of the complications because they're in a different area of their journey with it. But yeah, unfortunately, we just haven't been exposed to a lot of people in our age group that are going there for that reason.

BONNIE: I just want to say that looking back on my experience, I really am stunned by the idea that for the first two years, our son urinated healthfully. And now since he was two, he has not. And I struggle with wanting parents to know that and physicians to know that and to think there's got to be another approach. There's got to be offered the approach of no surgery because the child is urinating healthfully.

ASHLEY: I agree. I agree. 20 years ago, that was not an option to not do surgery. It was very like, this is what we're going to do. We can easily fix this. life will be great afterwards. And that was it. And even back when he was through the third doctor, it was just very much like, okay, we're done, basically, like, I hope you have some closure. If you have any issues in the future, please feel free to reach out to me. It was never any discussion of even from the get go, it was never a discussion of, hey, this is what would happen if you didn't have surgery. But yeah, I think we're in a different place now. I think definitely more parents are speaking out, and they should because they are the advocate for their child. And if I could go back, I would totally just look at all those areas of what this journey entails, the surgeries, what they go through, what their life is like among their friends, you know, their relationships, their… how they see themselves, I would definitely be more of an advocate and say, you know what? Yeah, maybe what would life be like if we didn't do surgery? Or didn't do it right now. So definitely, I feel like there's more resources out there more parents speaking out on all of that.

BONNIE: Have you spoken to other parents?

ASHLEY: Just briefly through social media, but nothing to—nothing compared to our conversations. Because again, there's no other parents at least that I find in parents of 20 year olds that are out there talking about it. Yeah. And I know my son has gotten on to some support groups online, but I don't know how those are really going. It's definitely isolating. You have a very small group of people that are really willing to put themselves out there to talk about this.

JOHN: Without a doubt, it's still considered so taboo. Ashley, is there anything that you-

BONNIE Yeah, what would you like to summarize?

ASHLEY: Just being that advocate and really, really asking a lot of questions in the beginning. My heart breaks for some of these parents that I see as a nurse, when I am taking care of an infant, a newborn that I know was born with hypospadias. And I just think of what their future is going to entail—for the parents and for the patient. And these new parents have no idea what they're going to be involved in, you know? And so, I feel like if there could be more education on that part of, you know, physicians really talking to them about all of that, do your research, do your homework, just make sure you research both decisions, both ways, and really make sure that you have a good pediatric urologist. And, you know, do your homework with the physicians, because just because they're local doesn't mean that they understand this condition inside and out. You know, you really have to really look at these physicians who perform however many hypospadias corrections every year. That was a big thing that I didn't take into consideration back when my son was younger. So just a lot of homework, a lot of research, maybe a lot of meeting with doctors to talk about all this, having parents know what's available for them out there.

JOHN: That's great. Thank you so much, Ashley. We wish you and your son all the best.

ASHLEY: Thank you.

JOHN: Thank you for your time. Thank you, Bonnie, for being part of this important conversation today. And thank you all for listening. This has been ***Hypospadias Conversations*** and we'll see you next time.

***BONNIE**: The hosts of this podcast are not medical professionals, and the information presented during the podcast is not intended as a substitute for medical advice. If you or someone you love has a medical question concerning hypospadias, please consult your If you or someone you love has a medical question concerning hypospadias, please consult your physician.*