HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: DOCTOR'S ROUNDTABLE PART 4

Episode 18: Discussion with Doctors: Vinaya Bhatia, MD,
Lauren Corona, MD, Pankaj Dangle, MD, Christopher Long, MD, Hadley Wood, MD

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: Bonnie, did you want to ask Dr. Long a question regarding Dr. Canning?

BONNIE: You know, we really like Dr. Canning's—what we know about him, so congratulations for being in his chair. I'm sorry that he's no longer with us. You're on a national committee designed to improve the care of boys, and I hope men also, with hypospadias and improve the experiences of boys and men with hypospadias. Can you tell us about the committee, the work of the committee, how it was formed and what's doing?

DR. LONG: Of course. So the Society of Pediatric Urology put together a committee that's chaired by Mélise Keays. She's someone I've been working with for probably about 12 years now. And we've been partners in crime with this for a long time. And this is the third iteration of that task force and that committee. And so, really, what we're trying to do is—you know, a lot of the care is kind of isolated in terms of treating patients with hypospadias, and I think the primary goal of this task force and this committee is to try and unify everything in terms of how can we even define the outcomes for patients? You know, how are we going to get the patient-reported outcomes sort of mixed in with what we have traditionally focused on in terms of surgical outcomes? How can we collaborate across institutions so that ultimately, you know, if there are patients that are, you know, a little bit more challenging anatomy or maybe some patients may not be seen as often, can we decrease some of the care variation or technical variation that ultimately will improve the outcomes for patients? And so our goal is broad reaching, as you said. It's certainly something that would extend from childhood into adulthood.

None of us do this surgery in children with the expectation that they're gonna have problems as an adult. We really want this to work, have it be one surgery, two surgeries, and have this be a perfect outcome that lasts a lifetime of the child into adulthood. And so none of us have any sort of reservations about that. I don't think anybody wants to have a problem later on.

But breaking down those barriers, technology is a huge thing. I think being able to sort of either share pictures or video of how surgeries are done. I think that that is ultimately what's going to allow us, you know, moving forward to decrease that variability, allow everyone to sort of learn from previous mistakes so that we can all really move forward as a group as opposed to only one or two places in the country being able to deliver care for these patients.

DR. CORONA: Yeah, I think I failed to mention in my introduction, but I am at Vanderbilt in Nashville now and I do health services and outcomes research and in all aspects of pediatric urology, but the methodology overarching to everything is that I'm performing research that is meaningful to patients and caregivers. So you know the old expression of not everything that can be counted counts and not everything that counts can be counted. I'm trying to find ways to work together so that we can count those aspects that are seemingly impossible to count.

And so, I hope that over the next several years, we will continue to conduct research that will focus on making sure that families can receive clear, balanced counseling to make informed decisions, helping them to feel empowered rather than overwhelmed, and ensure that we're measuring what's actually important. So, measuring those outcomes that are truly meaningful to patients and to families.

DR. DANGLE: I may just chime in a little bit, share some experience from traveling to other parts of the world is, I think we are blessed that our patients are seen in that prime age, most of them, and we are able to offer all the surgical care to these families and the patient. And I've had patients who were 21 and above who've been sitting all their life to urinate. And when an operation for that particular young man goes successfully, there are only tears flowing everywhere, not only from the family, from the sister, from me and everyone. So I think it speaks truth. What we do now here will probably impact the the whole world of how we take care of these patients.

BONNIE: Can I ask a follow-up question, Dr. Dangle, to your international successes? When you leave, how do they get their follow-up care?

DR. DANGLE: Everybody can reach me directly to my phone number. So every patient has my WhatsApp number. They share their complications, they share their outcomes, how they're doing and what's going on. If there are any problems they face, the local providers have my number that they can reach. So it's a mutually agreed decision that if you face any problem, don't hesitate to reach out to us. Language barrier again becomes a big challenge. So, most of these reach out through the primary source, the local countries, and then the local surgeon reaches out to us to see if there's anything that we can assist them remotely to take care of the acute problem or the long-term issues.

BONNIE: Would it be good for our audience to hear a couple of the actual cases that were internationally—that's benefited from your interventions?

DR. DANGLE: Absolutely. This 21 or 21 and a half year old boy who I saw in October had been sitting to urinate all entire life and there was another 16 year old boy who had the similar challenge. Whether it's United States, India or Ethiopia, bullying is everywhere.

BONNIE: Bullying, yeah.

DR. DANGLE: Both of these boys were bullied in their school by their peers, et cetera. The 16 year old dropped out from the school. The 21 year old stopped going out of the house and having friends or relationship for that matter with anyone.

Being a father of two girls, it just made me cry. And it was very touching. And I said, okay, let's, we talked, you know, he had his, their whole family, his sister, everybody showed up to the clinic visit. And you could see in their eyes is how fearful they were. And when you hear a word that there is a surgeon who's come from America, you can imagine it's a golden word for them. And he's going to fix my kid's life. So the amount of pressure on you is just immense. And as you said, Bonnie, you operate and you leave. So you're leaving it to the trust and hoping that the outcomes are better and there is no complications. So, you put a lot more efforts to making sure that everything goes well.

Now, as you can imagine, the support system, the staff, the resources are extremely limited. And whenever we travel to these places and try to take care of these challenges… I was operating in Ethiopia. Throughout the day, every hour, the power goes off. I had someone hold a flashlight while I was doing the surgery. Simple example, we run out of a marking pen. Now what? So, you become creative and innovative. So I asked for a methylene blue which my ENT colleagues were using it a lot. Methylene blue is something which leaves a little kind of an outline as it does with a marking pen. So, you become creative when you're put in a situation and try to deal with these issues and come up with these little things that you do.

Anyway, to cut short the story, we did the surgery of these two boys. A week later, the catheter came out and both of them were able to urinate standing without any complications. Now, one boy had a opening, which was this right in the middle of the penis, with the penis bent like that.

BONNIE: Are you saying that after the surgery, one boy had developed a fistula?

DR. DANGLE: No, no, no. He started with the hole right here… And then we made the penis straight and moved the hole all the way to the tip. And was able to, first time, was able to urinate standing up with a good stream without any complications. The kid and his sister drew a picture of me and him and sent it to me by email.

BONNIE: By email? Yeah.

DR. DANGLE: That was very touching and that made me, again, cry. We are all humans, we all have emotions. So it helps us a lot to do what we do every day and it kind of give to our patients. So I just came from India two, three weeks ago and we did about 31 surgeries and the oldest kid was again 18 years old. He has had surgery for the first time in his life. So, he has been sitting all his life to urinate.

When I go back again, I will try to do the second surgery to try have him stand up and urinate for the first time in his life again. These stories are real, it's just that here in the States we don't hear those often because we see these kids at such a young age we never get to the point where what their real life issues and challenges are. And again, you don't speak their language, you're talking through an interpreter and the best you can make out is all our emotions that we speak through our eyes. And it helps us tremendously as persons and individuals.

JOHN: What a wonderful story, Dr. Dangle, thank you. And I just also want to just follow up with something that Dr. Bhatia mentioned about the training that you provide for local physicians in those remote areas. If you could talk a little bit about that as well.

DR. DANGLE: It's a collaborative effort. Again, these local physicians trust us. We work with them very closely, both during, before, and after surgery. We provide a kind of a pathway for them to continue to build their clinical expertise and practice over time. And as time goes by, we start becoming their assistant and their primary surgeon so that they can take the ownership of their surgical practices as they move on. So every time we go, we engage them more and more as the local surgeons become more and more senior, we try to incorporate their younger colleagues who would be wanting to do the same, provide the same surgical care as their senior colleagues or one would like to be part of. So, it's a collaborative effort and it works over years.

JOHN: Thank you for sharing that.

BONNIE: Dr. Long, you have provided your surgical expertise during some trips to Trinidad to treat boys with uncorrected hypospadias. Can you describe that? Can you tell us about those trips and the work there?

DR. LONG: Yeah, of course. You know, I've had the opportunity to operate in a few places. I've been in India, I've operated there, I've operated in South Africa and also in Trinidad and, you know, trying to, you know, set up a trip to go to Africa, hopefully within the next year or two as well. And so, I think the important thing there is we're not sort of going to these places and just flying in, doing some surgery, and then disappearing and sort of doing the ostrich effect where we sort of put our head in the sand and just assume everything's going okay.

All of these surgeries were set up with local either pediatric surgeons or pediatric urologists. And when we traveled there, it's a partnership. So, they have patients that they're taking care of and they sort of identified a need where, hey, you know, hypospadias surgery is pretty difficult. Are you able to come so that, you know, we can sort of work together to do these surgeries side by side and hand in hand so that I'm going there, we're helping them, but they're also learning at the same time.

And so, again, I get to the technology where, you know, when I was in South Africa, we were able to kind of broadcast some of these surgeries and, you know, there were 40 other surgeons there that were sort of watching and sort of were talking and discussing things. And I think it's invaluable to kind of make it so that, again, the world's a little bit of a smaller place and patients can stay locally and get excellent care. And so, for me, being able to go there, being able to stay in touch with those surgeons afterwards to hear how those patients are doing, sort of see pictures and just kind of make sure that the outcomes are good.

And even talking to them afterwards, where they say, some of their trainees will be like, well, during the workshop, we didn't do that. So maybe we should try this other way that we learned during the workshop and to kind of, you know, just get the techniques so that, you know, something that might work a little bit better. But it's really a great experience. I mean, I think being able to extend, you know, our experience outside the walls of CHOP is something that's part of our mission and something that is very important to us. And so I really enjoy that.

BONNIE: I just want to ask, you talked a little bit about follow-up care, but once you leave, those are far away places. How do you help with follow-up?

DR. LONG: So, the phone, you know, the phone is a beautiful thing. It's a blessing and a curse, I guess I would say. But WhatsApp is something that we can basically use across the globe. And so, for these patients, the surgeons are in touch with us afterwards, you know, what things look like when the catheter came out, you know, what things look like when they came in follow up. So, we're able to really kind of do that and kind of continue care beyond when we were there.

Now, Trinidad, we went twice. Now we were set to go back again, but we were limited by COVID. Unfortunately, that was kind of what's gotten away there. And, you know, a lot of elective surgery was delayed in Trinidad for years beyond—well beyond COVID well beyond well beyond what we had here in the United States. So unfortunately we weren't able to kind of get back there, but I've been in touch with them and we still go over patients that we haven't even operated on. And they would just ask like, how would you manage this patient and et cetera. So, it's been great.

BONNIE: What should adults do if they don't live near centers of excellence?

DR. WOOD: Fortunately, hypospadias is a condition that most people who do a good amount of urethral reconstruction have some experience in because it's a really common reason why we see urethral problems in adult life. And so… There are urethral reconstructive surgeons in, I would say, most academic urology departments these days.

There weren't 20 years ago when I came into the field, but fortunately, we, you know, the specialty has grown. And so, I would say to anyone out there who's saying like, I think I might have a problem or I see drainage coming from a hole that's not, you know, the tip of my penis—to look at the hospitals around them and see if they can find a, you know, reconstructive urologist at that location that could evaluate them.

I want to say to anybody out there who has hypospadias who thinks like, 'there's no hope for me or I'm defective' or anything like that, that this is part of who you are. And there are people out there that want to try to get you to a point where you feel comfortable being out in the world with your genitalia the way it is or make revisions to it. And so, I hope you don't lose hope in that. And part of this is acceptance that there's a spectrum of quote unquote normal across the whole population. And the second is that there are people out there that really, really want to help you. So please don't lose hope.

JOHN: Thank you so much for that.

Dr. Bhatia, can you tell our audience about some of your research and what is the ultimate goal of your study?

DR. BHATIA: It's a big question. So my research is really about correcting the gap in our communication with our patients and with our families and making sure that we are defining surgical success based on patients' lived experiences. That's the ultimate goal. And making sure that our definition of success in the patient's eyes is also durable. And that requires long-term regular follow-up, regular conversations, open conversations early, all things that have been emphasized in our discussion here today.

We have developed an application with patient and multidisciplinary physician input where you can go in and enter symptoms across a multitude of kind of—clinical and psychosexual domains related to penile appearance, voiding and sexual function, social interactions, and of course psychological function and communication with your clinician team.

The idea is that if we are able to capture concerns in any of those areas, that we can actually give you a list of questions to send to your care team. They can actually review those questions in your chart and they can even make referrals potentially based on the recommendations that we provide. Our hope is to see that if we create this infrastructure to improve our communication with families and improve *our* understanding of what families and patients are experiencing, that we can be very patient-centered, patient-specific, and proactive about concerns as they arise.

Could this potentially answer several of the questions that you asked today? One, when do we do surgery? Maybe we look at symptoms, right? Especially in these milder cases of hypospadias where there's not curvature, the opening isn't too narrow. Can we allow families to wait and still have a good outcome and let the patient be a really active, engaged part of the decision-making process? Can we redefine surgical success? Can we compare different surgeries that are performed and look at our functional and psychosexual scores and say these surgeries had a durable improvement in functional and psychosexual scores, other techniques, maybe we need to tweak them so that they can achieve similar scores. Can we identify areas or centers of excellence where people can go and train so that they are prepared to give those really durable results in terms of functional and psychosexual support?

And this training may not just be surgical. It may be in the coordination of the clinic, perioperative counseling, referral to psychological services, identifying the right experts. Maybe that's what a center of excellence is. Maybe it's not just looking at the surgical experience alone in, you know, kind of isolation, but looking at over time, who was supporting their patients the best, right?

And then adopting those care models at other centers or adapting them to what resources are available at local centers to get it as close as possible to that. The idea is that successful, durable outcomes should not be kept at one center only, right? The idea is that everybody should have excellent access to the best quality of care for their hypospadias. And that's the overarching goal.

JOHN: Amazing. So how do you plan to get a wider sample group and perhaps even get other hospitals to collaborate to get wider data?

DR. BHATIA: Yeah, this is a great question. So enrollment in our application is going to be open as soon as we complete our pilot testing. We just have to make sure that it works before we send it out. But patients will be allowed to enroll by simply being given access to a QR code from their clinicians, either a primary care doctor or urologist. And we are going to open this more widely in phases. So, we'll start at a few test sites after the pilot and then we will be disseminating it at our national symposium. So multiple physicians across multiple specialties can get access to the QR code to have their patients call us to enroll.

And our hope is to really centralize the process of enrollment and even the app experience so that we're not asking for significant resources from collaborating hospitals, but rather kind of allowing the patient to kind of be the person interacting with us, sharing their experiences and giving us the data and then giving us permission to share it in a de-identified fashion with their hospital system so that the hospital knows. Patients will be given the option to share their results directly with their clinical care team though. So, if they would like it to influence their care, it absolutely can. So that's the plan for dissemination at this time.

JOHN: Great, and what advice would you offer for smaller practices to be able to provide some of this type of holistic care that larger hospitals like yours can provide?

DR. BHATIA: This is such an important question. We are actually looking at different dissemination models to be used in urban and rural settings. So giving kind of a Wi-Fi enabled iPad to some rural clinics to see if this improves engagement and ability of patients and families to enroll in our application. And so our hope is that by doing this in a mobile format, it can be accessed on a phone or a tablet or a computer. It's compatible with all of those that once patients are enrolled, they can easily access this information from home, wherever home may be, as long as they have a Wi-Fi connection. And so that's really our hope for improving accessibility.

JOHN: And how can doctors and hospitals who are invested in hypospadias research get funding for more research?

DR. BHATIA: Oh, this is a super important question and a timely one. I think we need to remove the stigma on talking about problems with genital perception and concerns about genitalia. This is where a lot of the problems arise is that disease states like cancer, they're very visible. People talk about them. They're not afraid to talk about it, right?

But with hypospadias, which remains one of the most common congenital conditions in the United States, nobody wants to talk about it, right? That was the one thing that came up in every phase of development for our interview studies was people want to avoid disclosure. I think there are some pioneers in this area, like the rapper Little Dicky is his moniker. He is kind of a champion for hypospadias and he's been very open about about this. What I'm hoping to see is that by introducing discussion aids to help people communicate with either a family member, their child, a potential partner, that we can help destigmatize these concerns so people aren't afraid to talk about it.

That will increase awareness, even in industries like the NIH, right, where they are thinking more about, like, what diseases matter to people, right? They don't know that this matters to a lot of people because we're not talking about it, even though it's prevalent. So I, you know, in my previous grant applications have invested quite a bit of time and effort into crafting background materials that emphasize the commonality of this disease state. And really, I mean, do we call it a disease state? Do we call it anatomic variation, right, as a part of our effort to really destigmatize it because that's what it is, right? But it's anatomic variation that matters to people, right? And so, I think once we make that more part of our conversations on a regular basis, which is exactly what you're doing in this podcast and in your book, I think that all of these efforts are slowly kind of a grassroots push to make this something that people are aware of and want to fund.

BONNIE: It's really great that you discussed the idea of using the word disease, where it's really not a disease, it's an anatomical variation. That is a great transition.

DR. BHATIA: Thank you for saying that. And I think that we are trying to emphasize this to our trainees now as well. This is something that has been discussed in kind of the variations of sexual characteristics space, but I think hypospadias is tangentially related to that. And so that's all we're doing is we're looking at anatomic variation, but we wanna support quality of life, right? And hopefully that reduces the sense of urgency to do interventions before patients and families are ready for them, right?

JOHN: It's fantastic. And once you have the research data, where will you take it?

DR. BHATIA: Yeah, so our hope is that this application will be used to create electronic health record infrastructure. So, any patient who signs up to receive care for, you know, hypospadias or other genital variations in the future, we hope to expand this like kind of model of care that they will be able to kind of enroll, regularly enter experiential data, design a care plan based on that, that allows them to be more efficacious, like communicate their concerns very clearly with their care team early and often so that we can be more proactive. So that'll be one thing we wanna do is, you know, integration into electronic medical records.

The next step is really looking carefully at surgical outcomes. What surgeries are supporting the concerns that are bothering people, right? What surgeries and what care team coordination is supporting functional and psychosexual quality of life? Those are the care models we want to emulate to have places be called centers of excellence. Ideally in a world of great access to care, everywhere is a center of excellence, right? So that's the goal is to make it something that we don't have to worry about having a center of excellence, everywhere is excellent, right? So that is the hope is that we're gonna be able to kind of train the trainers based on looking back and saying, okay, these centers are doing a great job. Let's copy these guys. Let's learn from them. Let's figure out how to make this accessible to everybody. That's where we're going to take this data.

JOHN: It's so exciting. It really is. I can't wait for it to come out. So looking forward to it.

Dr. Bhatia, in your 2024 paper for *Urology Research and Practice* called “Advancements in Hypospadias Management, Trends, Techniques, Training, and Patient-Centric Outcomes,” which was written with Dr. Long, among others. Patient-reported outcomes were emphasized in conjunction with surgeon-reported outcomes. Can you talk about the importance of how that approach leads to a more holistic understanding of expertise? And also, how does this approach play a role toward long-term health-related quality of life for patients?

DR. BHATIA: This is such a critical question, and it's basically what I have been trying to understand for the last five or six years. So I think that surgeon-reported outcomes were previously *intensely focused* on penile appearance. We were so focused on cosmetic appearance of the penis and we had these definitions, you know, kind of a cone-shaped glands, a straight penis. And then we said, okay, well, maybe patients have a sense of this too, since it's their body, right? Let's ask them, let's create these tools. So, our tools only ask patients those questions, right?

But then when we looked at the bigger picture and we just asked patients, what are you feeling, right? Their concerns were so much more complex. They had concerns in all the domains that we've talked about, psychosexual, psychosocial concerns, and then obviously penile appearance, but also voiding function, erectile function. It was just, it was a Pandora's box, right? That we opened.

And so, I think our goal is now to *change* the surgeon reported outcomes a little bit. Make sure that we are asking the right questions on a regular basis. And that's kind of what this care plan we've developed is intended to do.

In order to support health-related quality of life, which we showed in another different paper, really encompasses all the things that I just talked about. We have to be asking those questions and addressing all the concerns, not just the stuff that's related to perceptions of appearance. And as we kind of discussed earlier with our other members, you know, having this be about the patient's perception of appearance being considered paramount and the surgeons kind of coming to meet that rather than the other way around.

So, I think that this is how we can actually support long-term health related quality of life. And I also think multidisciplinary care teams are required, right? And care conferences between clinicians, maybe including multiple surgeons, may be also required to provide great care because every patient is different. Every patient's needs are different. So that's where this is going, is really patient-centered, but also patient-prioritized, patient-individualized care for hypospadias. I hope that answers your question.

JOHN: Oh, it definitely does.

BONNIE: I'm so appreciative of the approaches. So I don't know what to say, but thank you. And I hope to continue these conversations and to see the work progress to helping more and more people.

DR. BHATIA: Thank you for saying that, but I should also thank you and John for the phenomenal work you've been doing to kind of increase awareness, destigmatize, as we said, an anatomical variation and support patient and families to do better, to feel better informed as they make these really sensitive decisions. And so, we're really grateful to you for this opportunity. I know this meant a lot to me and my colleagues to even be able to talk to you about it. So thank you.

BONNIE: The honor really is also ours.

JOHN: Oh, without a doubt, without a doubt. This was such a pleasure to hear such insight and expertise shared with the audience. It was amazing, an amazing conversation. Thank you.

DR. DANGLE: I echo what Vinaya just said about you two. It's just very, very important for personnel like you to destigmatize a very important aspect of these boys, and especially with the social media and the access to the social media with these boys I think it is our job to make sure that they have the right information for them to have a normal life.

JOHN: I mean I know for myself too I mean I don't know how I would have coped had I grown up in an era when social media was so prevalent. I don't know if that would have made it a lot easier in some aspects or a lot harder. I'm not really sure. I grew up in the 70s and the 80s where we didn't have the cell phones and all that. So that had its own unique challenges at that time.

But this is just so amazing that there's doctors out there that are doing this work and improving the quality of life every day for some of these men. I've met so many different men now, you know, from HEA, the Hypospadias Epispadias Association and other organizations. And to your point, Dr. Dangle, there's men, I've met men from all over the world and they shared so many common experiences with this and so many common emotions that they finally meeting each other gave them the opportunity to share those things with people that understood and they're going to be thrilled to hear this conversation to know that there's doctors out there that understand—that understand these issues and are doing everything humanly possible to make things better. So it's amazing work that you're all doing without a doubt.

DR. DANGLE: Yeah, thank you. It's a once in a lifetime opportunity.

DR. BHATIA: It really is.

DR. DANGLE: That we have, yeah.

DR. BHATIA: Thank you.

DR. CORONA: Thank you so, so much for having me. I think it's so important, this work that you're doing, reaching out to families and patients so that we can do just that. I think this is a big part of it. So, thank you.

JOHN: Thank you. Dr. Dangle, would you like to share any parting thoughts?

DR. DANGLE: I think it is phenomenal that you both have been involved in doing this. And I applaud Dr. Bhatia for doing what she's doing and continue to do for the families and the patient. There is so much to learn from her work and it's just amazing with the many aspects of the care that she is looking into and it is very empowering to the families and to help tremendously to all the future generation of surgeons and people like me who are very, very humbled for a request for me to be part of this. So, thank you again for everything you guys do.

DR. LONG: Thank you both. Thanks for some tough questions. I appreciate it. It's good to talk about it.

DR. WOOD: Well, it's been an honor to be on.

JOHN: Thank you so much.

***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.*