HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: DOCTOR'S ROUNDTABLE PART 1

Episode 15: 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.*

BONNIE: Welcome everyone to Hypospadius Conversations. I am Bonnie Steinberg, a retired rabbi who wrote a master's thesis for my bioethics program on hypospadias treatment decisions. Co-host John Filippelli and I met at a walk-a-thon for hypospadias and we started having these great conversations. John is a licensed social worker who wrote this really unique book called ***Living with Hypospadias*** and then we started this podcast. We are not medical professionals. We are not allowed to give medical advice, but we have questions as you do, and we ask questions that we wanna share with you all through this podcast format.

For our episode today, we are very fortunate to have a panel of highly respected pediatric urologists with us who are gracious enough to spend time to discuss some of these important issues related to the treatment of hypospadias in children and adults.
John…

JOHN: Thanks, Bonnie.

And with that said, I want to thank Dr. Vinaya Bhatia for organizing this esteemed panel together today for us. Dr. Bhatia and I met at the Pediatric Urology Fall Conference in Louisville, Kentucky last year and have really had some great conversations about her research regarding quality of life and standards of care for those affected by hypospadias.

So, if I could, what I'd like to do is have Dr. Bhatia introduce herself first, and then the other doctors can introduce themselves as well. So thank you for being here, Dr. Bhatia.

DR. BHATIA: Thank you so much, Bonnie and John, for having me. It's such an honor to be able to learn from you both and work with you. As John mentioned, I'm a pediatric urologist and clinician researcher at the University of Wisconsin, Madison. I became interested in the care of people with hypospadias as a resident and kind of carried that research through my fellowship and now into the first four to five years of my career. And it's been an honor to kind of be able to learn from my patients and my colleagues in the process.

I do wanna comment that all of the perspectives shared in this podcast are our personal impressions from our careful investigation of the literature, working with patients, but they may not reflect the views of our institutions or the larger pediatric urology community. So, I do want to kind of start with that caveat. But it is such an honor to be here and to be able to speak with all of you.

JOHN: Dr. Dangle, if you'd like to introduce yourself as well.

DR. DANGLE: Thank you, John and Bonnie, again for a lovely introduction. I am Pankaj Dangle. I am a practicing pediatric urologist and associate professor of urology at Indiana University. I practice at Riley Hospital for Children. And I'd like to thank Dr. Bhatia to make me part of this. I agree with her. These views are our own individual views. It does not represent the entire pediatric urology community here in the States or across the globe.

I have had the opportunity to travel for the last 14 years to many places in and around the world, mostly in Africa and in India, partly in Southeast Asia, in Vietnam, and I've learned a lot about the special population. And over time, I have changed how I approach these patients and the families based on what I've learned from them. So I value that experience a lot, trying to learn from patients and trying to change our practice to kind of a patient-centered approach. So thank you.

JOHN: Dr. Long.

DR LONG: My name is Chris Long. I'm a pediatric urologist at the Children's Hospital of Philadelphia. Spend a lot of time focusing on hypospadias research and improving our outcomes. So hypospadias is something that's near and dear to my heart and a primary focus.

JOHN: It's great to have you here.

DR. LONG: Yeah, great to be here.

JOHN: Dr. Corona.

DR. CORONA: I'm Lauren Corona. I am in my second year of practice as a pediatric urologist at Vanderbilt in Nashville. So I finished fellowship in 2023 in Chicago. I grew up in Michigan and that's where I did my residency training as well. I see everything in pediatric urology, but I am also one of two urologists in our intersex or differences of sex development clinic also. So I do see a fair bit of more severe hypospadias in that clinic as well.

JOHN: Dr. Wood, such a pleasure to have you here.

DR. WOOD: I'm Hadley Wood. I'm a professor of urology at the Cleveland Clinic, Center for Genitourinary Reconstruction and my area of clinical focus and research focus is on adults with congenital anomalies. So that includes patients with hypospadias.

JOHN: As practicing urological reconstructive surgeons, what do you consider the most important issues regarding hypospadias treatment today?

DR. BHATIA: So, I would say that creating better strategies for perioperative counseling would be high on the priority list. In addition to improving our instruments for long-term follow-up of patients. I think there is also a lot of really exciting things on the horizon to improve how we even approach surgery itself when we do it. So, these things include better simulations for our trainees and even our kind of junior faculty entering the field, better replacements for urethral tissue. I have some really talented colleagues out on the West Coast who are working on this, and better ways to assess curvature that patients may even be able to use at home. Again, being worked on by some of my very talented colleagues on the West Coast. So, all things to kind of keep in mind and stay tuned for.

JOHN: Wonderful. And, Dr. Dangle?

DR. DANGLE: To me, I think just like any other medical illness, hypospadias is very important to the patient and the families in terms of not only the short and the long-term outcomes. And as Dr. Bhatia mentioned, there are many new things on the horizon which will help us tremendously to take care of this special population.

I would quote one thing is each patient is unique in its anatomy and how each patient should be managed based on their individual anatomy. So, no two patients get similar surgery in my short, limited experience that I've had. I also feel the incidence and the prevalence of hypospadias is on the rise in last 10, 15 years. And it's been looked at national databases in last few years, not only here in the States, but in other parts of the world too. Traveling to other places, especially where you have language as a big barrier, it's very critical for us to be very honest and humble about our outcomes and our ways of managing these patients. And I pretty much apply the same in my practice.

But what's striking to me is the understanding and the knowledge base the families have. And it's hard to really know exactly how much they comprehend or understand when we talk to these patients. So, I really would love to understand that aspect of the patient care from the family perspective is what can be done differently when we communicate with the families, both preoperative, intraoperative, and postoperative.

JOHN: And I'm curious, Dr. Dangle, is there any literature that that says why the prevalence has increased recently in the in the last few years?

DR. DANGLE: Not particularly, but there are many things which have been kind of associations rather than causality, and many things which are similar to other aspects of medicine where the number of cancers are gone up so it's a lot of those combination of things which have caused this and I think we are seeing a surge of patients who have complex medical conditions other than hypospadias and more and more patients are born with a lot of other medical comorbidities who have quite extreme complex hypospadias. So it may be that we are having more and more premature babies who are coming, are being able to be, kind of, make through the life and have a diagnosis of hypospadias too. So we're seeing more complex hypospadias these days.

DR. CORONA: So yeah, I agree with what everyone has said so far. And I think definitely doing a good job of communication with families pre, intra and postoperatively. But I think especially we can make a difference in that preoperative counseling realm. Research has shown that we know that, you know, decision on uncertainty regret is increased if patients or families feel uninformed about the procedure, its goals, the range of possible outcomes. And we know this can be minimized with a shared decision-making approach that incorporates the values and goals of the family. But I think it's really hard to know how to do this well. I think it's very easy to say that we need to empower families with knowledge and align their treatment plans with their values and goals. And we can use all these shared decision-making buzzwords, but how do we effectively actually do this in practice?
And I definitely don't know the answer to this, but it's something I think about often.

And I think one way to get to that answer is just talking to the community and talking to patients more and more and making sure that we're capturing all the voices. Because I think oftentimes maybe a vocal minority are the voices that can be heard, but we want to make sure we capture the whole range of experiences and understand really what matters to all families and how do we tailor the counseling to meet that family where they are and provide whatever that specific family needs to make the best decision they can make for their son. And so it's kind of about providing the necessary information, but without burdening the family because I think everyone feels a little bit differently too. Some people wanna know everything and some people don't feel that same way. So how can we tailor it to that specific family to support them to make the best decision for their son?

BONNIE: What would you like parents to know if their child has been diagnosed with hypospadias?

DR. LONG: Boy, that's a big question.

BONNIE: We only ask the serious ones.

DR. LONG: Yeah, so it's a great question. I mean, I think, you know, for me, when I see families in the office, it's typically, you know, everyone on my team knows that it's going to be a long visit just because I tend to talk a lot with families. I think, you know, education is so incredibly important. I mean, the first step for me is always talking about this is the anatomy. This is kind of what we're looking at for that particular patient, for their son.

You know, I talk about things being a spectrum in terms of severity, and some patients are on the lower end in terms of the severity, and some patients are on the extreme end of that severity. I think it's very important to say and put it forward that it's not—every patient does not need surgery. I start every single conversation with these are maybe some of the considerations why we would be more likely to recommend surgery, and these are the considerations for not. Certainly, try to have that conversation with families that you can have the opportunity to sort of defer until patients are older if they want them to be involved in whether or not to make the decision for proceeding with surgery. And so, you know, that's where a lot of it starts.

Like I said, there's a lot that we can talk about. A lot of families will ask about fertility in general. I think as long as both testicles are descended, the fertility potential is very high for patients. I try to bring in a lot of the research that we've done in terms of why we use certain approaches or might not use other approaches or we do things a certain way just because, you know, we look very closely at our patients and the outcomes and, you know, we wanna move the needle. We don't want this to be a flat line in terms of patients are not getting better or surgeries are not getting better. We wanna, I would love it if in 10 years from now, our complication rate is zero. And that's, you know, that's what we'd love to do. It's not where we are now. And I convey that to families. There's, I don't think anyone on the planet is doing this with zero potential complications. It's incredibly important to convey to them as well. And so I think there's a lot. Typically, it's two visits with families before we even get to surgery, if that's what they choose to do. And so really try to run through everything in terms of all considerations there.

JOHN: And just to follow up on Bonnie's question too, Dr. Long, are there other concerns or fears that families typically present to you aside from fertility that are very common that they're asking you about regarding whether their child should have the surgery?

DR. LONG: Absolutely. I think they get concerned. I think the most common question is fertility. The number two is always anesthesia. You know, the recovery is a big one in terms of how they're going to tolerate the stent, how they're going to tolerate the pain. You know, a lot of families will ask that, you know, when you cross broad age ranges, you know, I think there is a big difference between the infant period versus the adolescent period versus, you know, teenage years versus adulthood.

I think there's very different sort of processing by the patients in terms of their recovery, in terms of what things look like and what the outcomes are. So, I think that, you know, we talk about that a lot, talk a lot about what the appearance will be. And I think that what I find very challenging in terms of the interaction with families is trying to give them a sense for what things are going to look like. You know, I think on one hand, it's hard. You know, we see a lot of patients that, you know, are infants and or, you know, are very young children.

And as urologists, pediatric urologists, we see a lot of patients at that age. So we can compare that patient across, that patient across tens of thousands of patients. And for the parents, they're seeing they might have one son, maybe they have a couple boys, maybe they have a couple of nephews or cousins for their children that they can see, but it's nowhere near as often as we're seeing them. And so, for us, if something looks 95% normal or 90% normal, especially given what things look like from the beginning, you know, we can have a good sort of perception of that and understanding of that. But I think that's harder to sort of convey to the families in terms of what to expect. So I think those are probably the main considerations in terms of things that families ask.

JOHN: Thank you for that. Dr. Corona?

DR. CORONA: We don't completely understand what causes it or why that's happening and also that it's not their fault. I think some parents come in with those questions. But most importantly that it's not an emergency that we have time to make these decisions for their child. It's very natural to feel overwhelmed right at the beginning and there's really no rush to making a decision.

So, our focus as urologists caring for this individual is not just on surgery, but it's on the quality of life of that child. And we wanna ensure that they grow up with a healthy urinary function, with a healthy sexual function, and with an appearance of their penis that is satisfactory to them. And every child, every family is different. And within the limitations of what I already discussed, I think trying to understand what is important to them, what their priorities are before making a treatment decision.

So, I love to see patients for my first consult with families early and then bring them back closer to five to six months to give them some time to process everything and have another discussion and that, you know, my hope is that I can guide them and support them with all questions. And if I can't, that I can provide them with resources for someone that can.

BONNIE: What is it that you want the families to know that's hard to communicate?

DR. CORONA: I just want them to know what to expect when the regret happens is if a surprise happens. You know, if there's something that they didn't hear could be a possibility. And they said, if I'd had that information before making a decision for surgery, then I would have made a different decision. So that is what I want to try to prevent from happening. And so, I think that's done through information and through discussing all the range of possible outcomes.

But I also think it's about maybe supporting them in different ways, too. Maybe getting them in contact with an affected individual who's already had the lived experience, or more than one, that can share these experiences, or psychological support, if that's needed, to try to take some of that initial distress away from, ‘oh my gosh, I have to make this huge decision for my son’.

JOHN: So, it's a very patient-centered approach.

DR. CORONA: Exactly, absolutely, that's so necessary.

DR. BHATIA: Really patient-centered, but also patient-prioritized, patient-individualized care for hypospadias.

DR. WOOD: Well, I think a lot of what we've talked about today is really understanding which patients should be recommended repair in pediatric life and which ones maybe we can put aside and let them be part of the decision-making down the road or maybe not even offer reconstruction to because we do know that some of these patients get somewhat catastrophic experiences from having hypospadias repair in infancy.

And that's a really important area of thinking for me and Dr. Bhatia, who's also on this podcast. So, we'd like to understand a little bit better what the risks are of not correcting different types of repairs in childhood. And something I'm focusing on right now, and we're working on a multi-institutional trial, is looking at late effects, psychological late effects of patients who've had hypospadias repair in childhood. Do they have medical PTSD? Do they have higher than normal rates of anxiety? And if they do, can we develop a trauma-informed approaches to these patients so that when they come to our clinics, we're equipped with the skills to help screen patients who may be in that higher risk category and get them the resources they need to navigate the health care system in a way that serves them.

I think this is really important and I think so many of these patients have been so impacted by this. It probably impacts not just coming to see the urologist about a problem they might have related to their hypospadias, but maybe seeing all kinds of doctors. So I worry about patients who have trauma from pediatric medical conditions, you know, not getting colonoscopies and not getting routine health screening and not getting their lipids checked and those types of preventative measures that will allow them to live long and healthy lives, not to mention the psychological impact and support that they may need going into their adult lives and treating that as soon as possible so that they cannot have that impact partner seeking and their general wellbeing and their ability to maintain jobs and all these other factors that are so important to people feeling whole.

JOHN: That's wonderful. Just curious, is it common for urologist offices to incorporate like a mental health professional, social worker, therapist?

DR. WOOD: I would say it's very uncommon and I don't have a social worker. I think in pediatric clinics, there's more access to those things. In adult care there just really isn't. Anybody who's been out there in the world trying to find a psychologist or a psychiatrist in the past five years knows that these professionals are very limited and this corner of the of psychiatric care, psychological care, is even smaller, right? It's not very well appreciated. And so I hope in the rest of my career, we can start to chip away at that and understand it better and also build some resources around it.

JOHN: That’s wonderful.

BONNIE: Dr. Wood, you have given our community such hope for the future.

DR. WOOD: But it is again, like this observation that patients that have pediatric—have had pediatric care, particularly pediatric genital care and lots of procedures, having a lot of anxiety and emotional response to even something as simple as a physical exam is something that lots of us have noticed. And identifying it, characterizing it is the first step, and then building out resources to help patients be more able to get themselves cared for is just so important. And I hope that we can continue that work in the era of decreasing NIH funding and that sort of thing, but it is a very small corner of medical research. We've really struggled to find a psychiatric partner that can help us build out some of these investigations, and you need to have both expertise. We have the patients, and we have a lot of people who are interested in doing this work, but finding someone with any expertise in medical PTSD has been really challenging.

BONNIE: I'm intrigued by the fact that you work with adults because so many of our adults will want to know about that.

DR. WOOD: Yeah, well, I mean, this sort of stemmed back to when I was in medical school. I had a very influential pediatric urology mentor who did a lot of very complex reconstruction and I was really interested in the work he was doing. But I always wondered like what becomes of these patients when they have all these like really, really specialized care needs, urologic care needs, and they have this really unique anatomy, which quite honestly is in the purview of pediatric urology.

What happens to them when they become adults? And then I had the advantage of coming here where we had a very prominent urethral reconstructionist. And all of a sudden, I saw all these patients showing up in his clinic, just sort of hypospadias patients and other complicated congenital anomalies. And I was like, well, we don't really have anybody thinking about how to take care of these patients holistically within the context of their past.

And for many, many young men with hypospadias have been really their lives and their willingness to interface with medical specialists, particularly urologists, has been really shaped by their childhood experiences of pediatric operations, of genital operations, and that's a really unique need. So that's what sort of inspired me to build out a practice that's specifically focused on patients who come from pediatric life into adult life with ongoing care needs.

BONNIE: Well, first, let's thank you for doing that.

DR. WOOD: Oh, sure.

BONNIE: We often refer to Douglas Canning's editorial where he said that the handoff is not always that efficient or good or helpful for the patients. So, thank you.

DR. WOOD: Yeah, well Doug was a great mentor and friend of mine and he really helped me actually put together this concept of like building out people with expertise in adult life. I will say also urology changes from pediatric to adult life. You know, the things that happen to men as they go through puberty like concern about cosmesis and genital function and fertility. Those are all things that I would say most pediatric urologists don't have that top of mind and they become really relevant. And I've never met a young man who hasn't been thinking about those things, but I sure have met a lot of young men who's never had a meaningful conversation with their urologist about what risks may be out there, how they might be able to get help, et cetera, et cetera.

JOHN: How can parents of adolescents or young men themselves who are aging out of care navigate the process of finding adult urologists who specialize in hypospadias?

DR. BHATIA: So, I may start with this question, if that's okay with the panel. Doctors Long and Wood are gonna talk about two very mature transitional programs for patients with hypospadias.

We have started a newer program here at the University of Wisconsin that starts in the pediatric phase of care actually. So early adolescence, we start assessing symptoms and transition readiness and kind of talking about what the long-term looks like. I think we're going to be talking a little bit more about my ongoing research towards the end of the session, but I have developed a care planning tool that is intended for national dissemination where we can register our patients in this tool. They can answer questions about their active symptoms. They can receive a care plan that summarizes who they need to see across multiple specialties. And they are able to look up active adult providers in all of those subdisciplines at a local institution using their zip code for a search function. So we are working on opening our pilot for this here. And I know I don't sound very excited about it, but I am incredibly excited about it. It's just hard to voice that after seven years of working on it and then hoping it'll actually function. But yes.

JOHN: Definitely looking for the rollout for that. Definitely excited about that as well.

DR. BHATIA: Thank you.

DR. LONG: For the past 10 years at CHOP, we have had the benefits of having an adult urologist that spends 20% of their time with us on the pediatric side of things. And so, you know, the person that was our division chief, Doug Canning, he was in charge for a very long time. And I think he had the foresight to sort of see the need for these patients and transitioning them into adulthood.

And so his name is Caleb Covell, and that's the physician that works with us over at CHOP. And so, I think the benefit of having him there with us in our clinics is that, we can talk about certain things, how we manage certain things. I think management of penile curvature is a great example. I think we also talk about how, some of the outcomes, like some patients have had a lot of surgeries and at a certain point, you're not gonna achieve the perfect outcome for them, but you wanna have something that's gonna balance their expectations and also the function. And so sometimes the approach or the procedure that we might perform or the question of whether we even do a procedure comes down to that.

And so I think what we have the benefit of is we can operate together. So he sees the experience that we have on the pediatric level. We're operating on infants. And then, as patients get older, we have the opportunity to talk about some of the adult issues, sexual function, reproductive function, something that we not might not have as much in our foresight or talk to patients as many times as he does just because, you know, in the pediatric population. And so being able to have his influence there and have his ability to sort of work together is very important.

Now, outside of that, obviously, some patients have the opportunity to come in and sort of visit in Philadelphia. Others don't. You know, we see patients in New Jersey, New York, Delaware, kind of all over the place. And so I think you know, Dr. Covell is trained as a reconstructive urologist, and so I think he has a special training in terms of dealing with these patients. And there are the reconstructive urologists, there's a lot more out there now, so I think that there's a lot more interest in focusing on these patients.

So, I think, for patient-wise, I think it's very important to find a reconstructive urologist, talking to their urologist that they've spent a lot of time talking to, sort of to identify someone they might be able to transition to. So, I think having an open conversation about that is incredibly important.

Typically what we recommend to families is that we see them at least through 18 years of age, and we have certainly seen patients beyond 18 years of age, and that's not a problem, I think, especially if it's a situation where something needs to be addressed. But once they get to be 18 and we're able to have a conversation with them, like, there's going to be a low likelihood of having an issue as you get older, or in terms of, they’re going to move across the country or they're going to move out of the area where we're sort of watching them or, you know, they start to be—they're mid to late 20s, we're going to transition them out to an adult provider. I think it's very important to sort of have the patient sort of talk with the, you know, urologist to see, hey, are there any concerns from your end? Is there anything that I need to know know moving forward.

I think if it's a hand-to-hand handoff, if that sort of makes sense in terms of, you don't want to fumble the handoff, I guess, is the way to say it. And so, if there is a patient that does have some complexity there or does have an unaddressed issue, then I think it's going to be incredibly important for, number one, to get the records from the prior institution, from the prior surgeon. Those are invaluable in terms of if there's going to be a new provider that takes over and is going to make a decision about how to manage things moving forward, is another surgery going to be indicated, you know, having that history available is incredibly important.

But otherwise, you know, I think it's incredibly important to find a reconstructive urologist, you know, they're specifically trained in these issues to sort of deal with patients that happen to have questions or potential concerns there. So I think going to the right person is a very important part of that process for patients.

Our discussion will continue with part 2…

***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.*