

HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: INTERVIEW WITH JIM LAKE (follow up)

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

JOHN: We're very happy to have another episode of **Hypospadias Conversations** for you and especially pleased today to be doing a follow-up podcast with one of previous guests, Mr. Jim Lake, who is the former Executive Director of HEA. Welcome Jim.

JIM LAKE: Hello John. Hello Bonnie. It's good to be back, I realized, oh my goodness it's been a year, or just about since we did the last podcast. A lot of things have happened. Again, John basically introduced me. I was previously the Executive Director for HEA. I will continue to do annual walks, so I will schedule one soon and keep him abreast so he can advertise it. I'll advertise it, too. I don't want to go into a lot of my history because you can listen to the last podcast and get that information so we don't spend a half hour just talking about me, even though we'll probably spend the next half hour just talking about me.

BONNIE: At the end of our last conversation, Jim and John, I felt it was really important to focus on the story, Jim, of you having your surgery where the surgeon brought you out of the anesthesia to offer you the possibility of restoring your original urethra. I think people need to hear that story in more detail and how it's gone since then and some of the details of that. So start where you would like.

JIM LAKE: Wow, okay. And that's very true. My current doctor, who I still see, and I still have weird things happen with my body. [laughter] I think I had seen him a couple times, and we had scheduled the surgery, yet again, a total re-build of the urethra tube using the buccal mucosa. And after he put me under, yes, a little bit later, he woke me up and said, Jim, I really want you to think about this and would you like to discuss alternatives? And it's like I had no idea that I had any alternatives. My whole life has been doing whatever the doctor said and respecting that authority and sometimes getting angry at that authority, actually quite often. My doctor is Nejd Alsikafi.

BONNIE: And where does Nejd Alsikafi practice?

JIM LAKE: He has a few offices but in the suburbs of Chicago. It's called UroPartners. And there are several urologists that have different specialties all in that group. So, he did wake me up when he was about to do surgery and actually he didn't talk to me in depth at that time because of course I was under and just coming out of it. But when I did come out of it, he asked me if I had ever heard of a perineal urethrostomy and of course I had not. And so, he said, Jim,

you know, the odds of you—of this surgery being successful with your track record, you know, it might last two or three years and then we're back at it again. And he said, with this, it takes your urethra back to the original place when you were born and you'll be able to function basically as you were. The difference will be you will be sitting to pee, your ejaculates will come from the bottom as well. And, you know, actually that was a little bit freaky to think about, but what I really liked was the fact that I had the opportunity not to be sick because, and I don't know what John's been through recently, but I know for me that every, about every three years, all of a sudden, I'd be getting UTIs again. All of a sudden, I couldn't, my stream would narrow. I didn't do self-dilations like a lot of my friends do their own dilatations and things, and my doctors always warn me about it, probably because of all my scar tissue. So, I thought about it and we rescheduled for not too long after that. It was December of 2016 and so yeah it hasn't been actually that long ago at all when I think in dog years. [laughter] But I had that surgery and I woke up and actually I walked out of the office, I got in the car, my healing was like almost instantaneous. It was very little pain. I want to make it akin to having a colonoscopy. It was like I woke up and when I came out of anesthesia, I was ready to go. Yeah, could I feel a little bit of discomfort? And was there a bandage there initially? Yeah, but just for like a day or so. So...

BONNIE: Was there a catheter or anything?

JIM LAKE: Not at all. Not at all.

BONNIE: So, let's just focus on this for a moment.

JIM LAKE: Okay.

BONNIE: I have been, I thought, and so I was once told, like 20 years ago, that you can't go back. You can't get the original urethra back. And here you are after some 27 surgeries, and your physician offers you your original urethra. Sphincter control?

JIM LAKE: Yes

BONNIE: You have had many operations with arduous, arduous recoveries, and here you are walking out of this thinking it's almost easy like a colonoscopy. Focus on that just a little bit more. Inform us.

JIM LAKE: I well I mean let's face it... I whenever I come out well actually just going into the operating room it's almost PTSD. Whenever I come out of anesthesia it's almost PTSD. It's like you know those smells, you know what to expect, and your body is letting you know that all of it could happen. So, when I got up, it was like, you know, aren't I supposed to be hurting? [laughter] It was like, wow, this is different. I did feel some sensation down there. The neat part that happened was for the first time, like, when I would urinate from all the rebuilt urethras, I'll put it that way, you know, I really had urgency. When I had to go to the restroom, I had to go. The nice thing about this is I can hold it forever. That is so nice. It's such a good feeling to be able to have some sort of bladder control. Not that I would because I know that will cause UTIs,

but if I have to, I can hold it for a little while. So that makes me actually very happy. As far as recovery, it was like three years in before I got my first UTI. And so, to me, that was like, uh-oh, what's going on now?

JOHN: It must have felt like, why is this happening after I had this done?

JIM LAKE: Exactly. The whole purpose was to avoid that.

JOHN: Right.

JIM LAKE: And that's when I learned about a woman's anatomy somewhat, because I went to the doctor's office and learned that I was wiping wrong. And I'm like, well, then why didn't I get sick beforehand? You know, I didn't know you were supposed to wipe from the front to the back. I had always wiped from the back to the front, because that was just the way it was done. So now I know that that is wrong. It was a severe infection, actually. I've always battled E. coli and things like that, but with that and with the antibiotics, that was the only time that that's ever happened. So, I'm very glad about that. I might've had another one, but it seems like cranberry pills will take care of just about anything that comes my way. Actually, I just take cranberry every day.

JOHN: So, I was just gonna say so there's no like preventative antibiotic dose that you take or anything like that?

JIM LAKE: No, and as I think we just sort of touched on that last time that I'm wondering if all those years of antibiotics weren't something that contributed to my appendix bursting and you know now my gallbladder issue or then, who knows what long-term things do to things due to our bodies. So, I'm not here to downplay or disagree with whatever doctors have done. I know that my doctors now are there to help me live a more healthy life and I do appreciate that.

BONNIE: How often do you check in with your physicians?

JIM LAKE: He asked me that I just saw him two weeks ago. He asked me do I want to come back in three months or six months and because of what I had, all of a sudden, I got the worst thing I have ever experienced, worse than any recuperating from surgery, and it was called epididymitis. And all of a sudden, my left testicle like, grew bigger than the Grinch's heart. So, [laughter] it became very hard. It was extremely painful. And so, yeah, I called my urologist right away. So, the interesting thing was that all of this is connected. You know, one thing is connected to the other, to the other, the nerves are all connected. And so, my urologist basically told me, and it was funny, because I sort of read the HEA chat room like a few days earlier and several members always list that you know they sometimes get this syndrome so I asked my doctor about that he said yeah among hypospadias and epispadias people it's way more common than people that don't have those conditions. You know I'm 64 and a half so I'm like why would it wait until now to do this to me. So, I was not happy. He gave me medication. He gave, well he gave me, you know, the Z-Pak basically and a couple of antibiotics, some more

steroids, and then he gave me silodosin and basically what that did was keep me from having orgasms or ejaculates the entire time that I was using it. But I wanted to give it the college try and I wanted to do what he said to do. So yeah, I was on this medication for six weeks before my follow-up and I told him what was going on and he said, is your epididymitis gone? And I said, oh yeah, it's gone. I was so busy worried about my other side effects and I totally forgot about that. But yes, I'm all better now.

BONNIE: As a parent—

JIM LAKE: Yes.

BONNIE: —who regrets having given our son the surgery, but as a parent, I have two questions, or two comments, or two thoughts.

JIM LAKE: Ok.

BONNIE: Parents kind of need to know that if they begin with hypospadias and epispadias surgeries, that the long-range scenario might be someone who's in need a lot and can't get a lot of those problems solved and keeps draining the resilience battery. So, parents kind of need to know that that's a possibility. The other question that I have is, your temperament seems so good. How does, what does one do with the fight and the anger and the regret? How does one continue to work and throw oneself into one's work life or, you know, regular life life and go through all of this?

JIM LAKE: Those are interesting questions, Bonnie, and it hasn't been easy. And I think it's genetics. I think it's, you know, I think we're all given a personality at birth, kind of. And as long as that isn't tampered with, like, you know, we're not beaten every day. You know, as long as we have, like, a fairly normal upbringing, I think we're going to become, you know, personality-wise who we are. And that's, again, just my thought. It's funny that, you know, you were just talking about your son and then John; and I am a licensed clinical professional counselor and I achieved that later in life. I actually was on what I laughingly called a 20-year college program. I put myself through college, I got a job, I took a class here and there and there and there until finally 22 years—when I was 40 years old, I graduated with a bachelor's degree in business. Six years later, I got my master's in counseling. That was through a different cluster program, so I was glad that I could do it. And again, looking at that, those are accomplishments. So, you have to have goals and you have to be able to move forward. One of my issues lately has been recovering from COVID. And it's not me personally recovering from COVID. I'm looking at the world and the way we live. I am having problems at work because of the fact that I don't like working from home all the time. I'm a people person. If I'm a manager, like I manage nurses and social workers who are in the field. That's very hard to do like we're on Zoom now, but over the phone, not in person, I'm not catching those things that I need to know that, you know, that they're dealing with. It works much better in person. Not being able to see the members or what we call the members, the patients, is another hindrance. They're in the field now, but me trying to manage them without having all those, like I guess I'm very sensory and I'm very

hands-on, so typing isn't my forte. So, I'm a very fast typer, but I would rather be working with people, not machines, is I guess what I'm saying. And COVID has caused like all these huge businesses and skyscrapers and offices to close. A lot of people are working from home and you just said your husband was still working. So that I understand. So yeah, I work from home Monday through Friday 8 a.m. to 5 p.m. or so and so it's too unless I get called in the office for a meeting. So, it's been kind of isolating along with everything that I used to do has closed and a lot of my friends have moved. A lot of my support system is no longer available except for by phone. And so that is difficult. So now we have to navigate this next part as well as contact—for me, and, again, those that are listening, I'm at a different stage in my life. I'm trying to figure out how to retire (laughter) because I'm 64 and a half, but it's like, you know, how do I do that? What does it look like? My ideal dream isn't sitting at home and typing all day. So...

BONNIE: The changes in work because of COVID are a huge issue in our society. How it dovetails with all of the surgeries that you've had. Did you have COVID? Would you be in a worse position because of all of the surgeries, all of the health care that you've had, all of the antibiotics, would you be in a worse position to fight a COVID?

JIM LAKE: Well you know I had five COVID shots and I had no reaction to them whatsoever. I was one of those lucky people who didn't get sick. I'm the same way with flu shots, I'm the same thing with anything. That might be because I'm a professional patient. So, it's like, it's a shot. But, no, the only thing that COVID did to me, and, you know, a lot of people know that I used to smoke, I quit smoking. So that was good. That was very positive.

BONNIE: That was only recently in the past few years?

JIM LAKE: Its been two years ago—right.

BONNIE: Wow.

JOHN: Good for you.

BONNIE: That's supposed to be one of the hardest things to do.

JIM LAKE: And my health is fine. It was like, you know, you can't breathe. It's like, well, what a great time to take advantage of that. (laughter)

JOHN: Right. So, like, you know, it's hard to smoke a cigarette with the mask on, right?

JIM LAKE: Exactly. I didn't quite get to the mask part, but, you know, it's like, why would, you know, this is crazy. Yeah. So, I just took advantage of that and was able to quit cold turkey and I haven't looked back. So, I'm glad about that. That was the very positive thing that happened.

JOHN: That's great. So, as we're talking here, Jim, I mean, we were talking earlier before we started the podcast about this idea of resiliency and, you know, your reserves are kind of hit

when you have even just one surgery, no matter what it is, let alone a medical history like yours. And what you were just saying as well, I mean, if you could address that, but also the idea that it's not just the physical recovery, you know, there's an emotional recovery involved. There's a lot of times the financial recovery that is involved with these things. So, I'm just curious your thoughts about that idea through this journey that you've had, especially most recently, where your mindset is now in those regards as far as resiliency, reserves, in light of the experiences you've had recently.

JIM LAKE: You know, and then I have to think about my caregivers during all that, you know, have I worn them out?

JOHN: Mm-hmm.

JIM LAKE: It's like, no, not again, Jim, because we look at people who constantly go through things and it's like, well, we just want you to get better because that's what our society does. We want this problem to go away so we can do other stuff. I seem to have not gone away lately, of course, yes. But as I know, other things come up. On the other hand, though, as far as my general health, I'm great. My blood pressure this morning was like 113 over 70. My blood sugar, my A1c is less than 5. I'm, you know, I can walk, I can do whatever I want. So, you know, in that respect, that's great. We were talking... I think one of the problems that I've had to deal with is comparing myself others, to my peers, my friends, all who seem to be way more successful than I am. Not that, you know, how do you judge success? How do you look at yourself and say that you're successful?

JOHN: So, if you were to, you know, kind of compare and contrast, I guess, you know, to your quality of life before you had the reversal to post-reversal, could you point out maybe a couple things that are better, some things that are the same or that are challenges, pre and post reversal?

JIM LAKE: It's kind of difficult because of my age and I look at things through stages of life. And like I said, I'm 64 and a half now, so what am I supposed to be like? And the other joke that I, well, it wasn't a joke. My staff look at me and they say, there's no way you're that old. So, I'm happy about that. I'm happy that I supposedly wear it well. But challenges have been, one, dating. You know, my partner died right before or actually right after my last surgery. He died in 2017. Since that time, dating has been very different. I try to disclose to people that I'm different, my anatomy is different, and they don't comprehend that. And on the occasion that I let somebody see it, then they go, oh my god, what is that? It's like I said, I have what appears to be a vagina and then I have what appears to be a penis. So, I still have, you know, the glans, the penis, that looks normal, nothing comes out of it, everything comes from the bottom. And maybe it's because I'm different, you know, I know there was some things going on previously regarding, you know, whenever we joined the intersex groups. I really don't feel intersex at this time. I feel like a man who has an opening at the bottom of his body. And then at other times, but—I just want to be Jim. So that's been hard, you know, it's like how do I even tell people what I'm going through? My friends all know, and I think I voiced that last time, that

my close friends and family have been through all these things with me and I still have the same close friends that I have back when I started that. So, you know, way back in the early '80s when I started having these reconstructive surgeries again, unaware that I had all those surgeries as a child. So, I do have that support system, and I don't know whether I'm just becoming an old codger and just want to be left alone. So, we'll see. (laughter) But dating has been a challenge. I'll just put it that way.

JOHN: Well, it's very interesting to hear that because when I think of people that have been very open and forthright about their situation, you're at the top of the list as relates to hypospadias. So, to hear that is very interesting because this is a big part of having hypospadias. It's a life-long condition and [for] a lot of us, what you just described has been at the forefront of anxiety-producing thoughts. Right... And, you know, it's in one way it's very sad to hear, but in another way it's kind of like, no, we're not alone because, you know, because of associations like HEA, relationships like we have where we are familiar with each other's situation and stories. I guess my point is that, you know, when I hear what you're saying, I hear that I don't want to say at least because that's invalidating sounding, but we're at the point where we can be forthright about it and we don't have to worry like, can I muster up the courage to talk about this? We're past that point. We're talking about it. So that part's good. It's, as you said, getting other people in today's day and age to comprehend what we've been through or what we go through in that way. So, I'm curious, does that kind of resonate at all? Or has it gotten easier? Has it gotten harder as time goes by?

JIM LAKE: Now that you say that. Again, I don't know whether it's my age and whatever. But when I look back at both of my long-term partners and even partners prior. You know, if I look at what would be today, I think that either one of them would still accept me. I've often thought that there are people who like really get into sex and just want to see how big you are and how you perform and da...da...da...da. Then there are people that I always called sexually blind. They just liked me. (laughter) I'm like, wow, really? And I've been lucky enough to have met those people in my life.

And maybe since COVID, I've just shut myself off for a while. So, you know, a good thought for me, maybe I will consider doing some counseling and I'll look at some options. I think the other issue is just what am I going to do about retiring? Do I really want to pull anybody into all this stuff that's going on right now? What am I going to do about, you know, work? What am I going to do? There's just a lot going on. So, I think sometimes I just become protective of self and just stay quiet. And then when it's time I just go and become me again. I don't know.

BONNIE: Parents, physicians and health care providers often assume that parents are anxious and that's why they want their kids to have surgery. But the parents are anxious about all these social issues and future psychosocial things and the surgeries will solve. And parents need to know that the surgeries don't solve. So that's a huge issue. I want to just tack on one more question and you can address both. And are you available to counsel younger hypospadias men who might be considering returning to their original urethra?

JIM LAKE: I think just because of my life and...and just because I'm not the executive director of HEA doesn't mean I'm not involved. And I am a clinical counselor. I am only licensed in Illinois so you know it's funny because I became a counselor in order to help what I call our people. And then it's like I can't charge them. They're going through what I'm going through. So, I work for a company that pays me. And so therefore, that's how I do that. I need a license to do what I do, and then I can spend my time working with those who need the help or who just want to bounce things off. Because again, I let them know this is their life, and thank you for sharing that with me. But you know these are decisions you're going to have to make. I can't make them for you. And hopefully they have had that resilience to get through. Unfortunately, I've known a number of men who did not and who did commit suicide. And you know it's an option that I don't think of for myself. But and you know thank goodness because of HEA and because of people like John and yourself, I have people that I can talk to you know to reach out to, so that's very good. I don't know if I've answered your question.

JOHN: I'm curious can you recall if any other surgeons throughout your life had ever suggested reversal and it was something that you just weren't, you know, prepared for a long time ago, or was this the first time that it was ever really brought up that you seriously considered it?

JIM LAKE: It was the first time I had ever been told that, was in 2016 in December. Before that, everyone else was a world-renowned physician, the best in their field, and every single one made me worse and worse and worse. And after that many, you know, surgeries, there's just a lot of scar tissue. I know there are doctors who say, you know, I don't care what you've had in the past, we can start from square one and you'll be fine. I know several of these doctors personally, and I think for my peace of mind, I'm happy with where I'm at now. I would much rather be, you know, again, my health issues, I don't know whether things just happened. Again, whether they happened because of prior surgeries, whether they happened because of prior medications or the amount of, but it happened, and it happened to me and I survived it. So that resiliency part is still there. Do I sometimes just get tired more? Yes. Again, is that because of my age? Possibly. I know that I can't like dance and go all the way to the ground like I used to and do the limbo So, but hey, I'm still dancing. (laughter). So...

JOHN: Yeah. And that's the most important thing. I mean, still showing up, still doing it and helping other people at the same time, advocating, you know, it's, it's, it's, it's so commendable, Jim, it really is, you know, in light of your, your medical history. And as Bonnie pointed out earlier, I mean, your, your demeanor about everything, you know, your, it's just very, you know, I think a lot of people are going to be reassured hearing what you've been through and, you know, and that you're still here, resilient and helping others. And that's huge. It's a huge thing. So, I can't thank you enough for your time, you know, not just tonight, but in general, that you've done such a yeoman's job of trying to educate and advocate regarding hypospadias. So, I, for one, have, you know, learned so much from you, you know, in our relationship over the years. So, I appreciate it.

BONNIE: I'm so moved by the story. I was going to ask, is there anything that you want to say to parents who are making the decision or to young men who are making continued medical decisions with urologists?

JIM LAKE: You know, that goes back almost to that argument of should I or shouldn't I? And, you know, you're damned if you do and you're damned if you don't and I see where you're coming from and I see where my parents were coming from. It's like all of a sudden here's this person and in my case they couldn't identify the sex, and so yeah you freak out it's like what's going on with my child; so my mom decided I was a boy right off the bat because I was covered with hair from head to toe, which I still am. You know, I'm glad she made that move because I would not want to be on all those hormones or steroids or whatever everybody's on. That's another good thing about what I've been through is I haven't had to take any medication as far as that goes. I don't have any daily medication. They did what they could. And they, you know, I still believe that if I would have known about it, I would have dealt with it. The secrecy of the '50s and '60s, and even now, I'm hearing more and more that my parents never told me, or you know, I had this happen. And once again, I've known people that have had no surgeries that feel different, and I've known people that have had 40 surgeries that feel different. And we all have this bond and we're all over the world. But for the parents to make that decision, that is so personal. So just a lot of things that would have to go on.

Tiger DeVore has always said, and I'll say this too, anytime you cut, you're cutting into nerves, you're cutting into tissue. It's going to scar, there's going to be some amount of nerve damage. Because regardless, anywhere on your body, if you touch it or whatever, you feel it, right? So, if you cut that and it heals, there's going to be a scar and there's going to be a difference in the way that it feels. So... multiply that by major surgery over and over and over again. And yeah, I think that sometimes my body gets confused on what's being touched or what it should feel.

JOHN: Well, like you said earlier, I mean, you know, it's kind of a PTSD. Our bodies kind of almost instantly revert back to, 'oh, here we go again. I remember this. We're having something done again'. And that all has to be taken into account, I think. You know, when parents make the decision, when individuals are, you know, at an age that they're making the decision for themselves. Just beyond the anxiety and emotional component, it's taking into account of, like, I used to, I don't want to say argue, but I used to argue with my mother about, I didn't believe that I was a quick healer. She would insist that I was a very quick healer. She remembered me being a very physically healing quickly over illness. I felt the complete opposite, you know, that it usually took me so long. Like I always, my body took its time, you know, and those are—something like that, you know, no one knows our bodies better than ourselves. And, you know, so I guess my point in bringing that up is that down the line for any procedure, for any future surgery, hopefully not, but—those are calculations that someone has to make, I believe. Someone says four to six weeks, I may be looking at more like eight weeks, in my mind. And if it winds up being four weeks, great, then I'll be pleasantly surprised. But I have to kind of go by what I've experienced. And generally speaking, I feel like there's always been some sort of, it's been stretched out somehow. Something's happened here or there, where I didn't feel 100% bounced back yet. So, I imagine, you know, everybody's different, but at the same time I feel

like we all can kind of feel that, you know, we know our bodies, we know how it kinda operates, how it works. It's very, very complex.

JIM LAKE: Right, but I can't tell you how you're going to feel going through the same thing.

JOHN: Right.

JIM LAKE: So I always make that point clear.

BONNIE: One of the things parents are told, I don't know if they're still told this, but I think it's mostly for the convenience and the denial of the physicians who are doing these surgeries. The babies heal really well. The babies heal really well. The dismissal and the convenience of the doctor to say, we like to do these surgeries on the young, young children because they bounce right back. I think parents also need to think about that.

JIM LAKE: I don't think, you know, the parents are there with shock. This child was just born, they don't know what to do because they've never heard of this condition. But I've also seen, like from going to conferences, we have so much more information than we did when I was a kid. My parents had no information. They were reliant on whatever the doctors at Walter Reed or, you know, John Hopkins or wherever we were at, at the time would let them know. I did want to say, and I think I might have said it before, but Barb Neilson always told me to get checked for something called BXO. And it's a skin condition where surgeries will always go bad after a while.

BONNIE: BXO?

JIM LAKE: BX, like X-ray O.

BONNIE: BXO. Are surgeons routinely checking for this?

JIM LAKE: Not at all. I was never checked for it. I still haven't ever been checked for it.

JOHN: What is it?

BONNIE: How does one check for BXO?

JIM LAKE: Well, let's Google, shall we? (laughter) But there's evidently a test, and again, Barbara was in Canada, and Canadians do a lot of things that we don't do. So...

BONNIE: It's lichen sclerosis. And do you want to talk a little bit about who Barbara was and her legacy? I never had the honor of meeting her.

JIM LAKE: Oh, I am so sorry. Barbara Neilson was the head of social work, pediatric social work for SickKids Hospital in Toronto. She started their program, she developed their program, she

mentored social workers as they were students, she advocated for several of us, and she also got me in to see some doctors that, different doctors all over the place, including in Toronto, a doctor now that's in Abu Dhabi. So, I've seen lots of doctors.

But anyway, Barbara and I formed a special bond and whenever we would have a conference, we would go together. We went to several conferences together. We went to several types of conferences together because she would also do the bladder extropy conferences and sometimes we would join those. She would also do the intersex conferences and I would go to those a lot and I would go to most of the conferences, especially years ago because I was just curious about myself. I wanted to know where I as a person, where my boxes were checked and I saw commonalities in all of those people.

So, Barbara was at, like, I want to say the second HEA conference, and we connected right away, and we stayed friends until she passed away almost, I don't know if it's been three or four years now, but I want to say it was '20, it was right before COVID, January 2nd, that she died of pancreatic cancer. So, it was very fast and, you know, it just robbed the world of an incredibly amazing woman. I still know some of her students who are also doing wonderful work.

JOHN: So important. Such important work.

JIM LAKE: Yeah, because the United States doesn't do what they do. I know there are some hospitals that are starting, but even most urological practices, even the centers where I was younger, they didn't have the social work aspect of it. And I think that's so important.

JOHN: Absolutely. When you say that now, I'm just thinking about, you know, one of the doctors in my book mentioned that and said, as surgeons, as doctors, we're just, you know, involved with the plumbing, so to speak. I mean, having a social worker in the practice would be an enormous boost for a lot of practices for all ages, whether it's pediatrics, adolescents, adult. I mean, I think I could speak for most of us when I say that when I was younger, that would have been an enormous help. The surgeon that worked on me as a kid was like the only doctor in the area that was doing longitudinal follow-ups, you know, to say, how is he doing, how is he adjusting? And this is, you know, going back into like, you know, the late '70s, early '80s. As you were saying before, now today we know so much more, and the doctors know so much more than we did back then or in the '50s or '60s when you grew up, but that there were so few options back then, you know, so having a doctor do this type of follow-up and get a reading on the pulse of, how is this person adjusting to this? You know, this is such a private, personal thing, but it impacts so many everyday common things at the same time that we have to do, like going to the bathroom. We all have to do it, things like that. So, Barbara was an incredible person for that work, and it's very, very interesting that there's been so little, but now that this conversation is being a little bit more in the forefront and open a little bit more. I think that's one thing that is different today, that people *can* talk about it. This podcast or this conversation may not have taken place 20 years ago.

JIM LAKE: (laughter)

JOHN: It wouldn't have. Yeah, it wouldn't have. So, I mean, that alone is just progress. I don't know. What do you think, Bonnie?

BONNIE: I'm honored to be part of this conversation. I don't know how to summarize it. You know, I feel sort of like when I hear Jim talk about his Barbara, I feel like you're my Barbara, John. Welcome to the conversation, Jim. There are so few people that I talk with—this kind of openness and honesty, including significant people in my personal world.

JIM LAKE: I'm trying to think if I have any pearls of wisdom. My heart goes to the parents. My heart goes to everybody involved, but something you said, John, about the surgeons and the plumbing, that's exactly right. And almost all of my surgeons, like they all would sit and talk to me just because I was one of the interesting cases. But for the most part, their job is to go in and fix it. So, for them to say, no, I'm not going to do that, probably is among the lowest percentage.

My doctor looked at what I had been through in the past, where I don't think a lot of doctors had done that previous to that. So, I got lucky this time. Or did I? Would it be neat? I mean, I think what Tiger DeVore used to say is every time I would wake up, I wanted, you know, the perfect penis. I wanted to get up and there it was. And it's like, to be one of us, that's not gonna happen. There are some good outcomes. I have not had one, but that again is just me. But, you know, have I had good relationships? Yes. Do I maintain work, yes. Do I have good friends, yes. So, there's some good and bad. We all are given our cards. We can look at how our life compares to other people's lives. But at the end of the day, I feel that maybe I was given this life because I'm strong enough for it. And a lot of other people couldn't deal with what I've been through. Just like I can't deal with what a lot of other people go through. I look at some of the things that, you know, I think I work with a bunch of mensas. They're so smart. I'm like, well, no, I'll just talk to my staff. But yeah, we all have our genius and we all have our things that we're not so good at. So.

JOHN: Yep, for sure. I guess the other thing, real quick I'd want to ask you is, knowing what you know now, what would you recommend in terms of how to increase the chances of a good result? Is there something that you wish you knew?

JIM LAKE: Well, it's not to increase the chances of a good result. It's to have the open communication with your parents and doctors and not the psychology of the '50s and '60s. I think when I was questioning that my parents, instead of ignoring me, should have talked to me in an age-appropriate way. I think as I was getting older and had questions, they should have done the same, but instead I had to go out and wait till I was old enough, leave home, and find my own answers. And unfortunately, that started everything that it started. I'm glad that I had the wherewithal to be able to be independent, maintain myself, etc., etc. So, you know, I'm still here.

JOHN: Well, thank you, Jim. Thank you for your time tonight.

BONNIE: Thank you, thank you.

JOHN: Thank you, Bonnie. And thank you everyone for listening to this episode of ***Hypospadias Conversations***. And we will see you next time on. Thanks, guys.

BONNIE (MUSIC): *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 physician.*