

TERESA KOBELT: Welcome to, "From my Perspective". This is OCALI Family centers weekly podcast. Each week you'll hear from people with disabilities, their families, friends, and others in their lives. You'll hear about everyday life, their passions, their interests and opinions. You'll be inspired. You might laugh or cry. But most importantly, we hope you'll better understand what life is like from our perspective.

On today's podcast, I'm joined by Patrick John Hughes and Patrick Henry Hughes. A father and a son from Louisville, Kentucky who just wrapped up their keynote at OCALI con. There was so much about your story and what you all shared that I loved. And I think, Patrick John Hughes, how do you guys talk? Well first, let me ask that? So, Patrick the dad, you talked about initially when Patrick was born having this period of time where you guys were really grappling with kind of what was going on. But then at some point, 8 or nine weeks, you said there was sort of this turning point. And do you remember that time, kind of what was it that helped turn that corner?

PATRICK J.: I don't know if there was a specific incident that threw us from in the why us mold. Why did this horrible, awful thing happen to us? We play by all the rules and then all of a sudden we're like OK we're going to-- I don't know if there was a snap sort of thing. It was more a process. But certainly, people ask all the time, the hardest parts about raising Patrick. What was the hardest part about raising your son? And really I think it was those first couple of months where you're just trying to get your arms around. Going down all these roads and paths that you didn't imagine going down. And giving up so many other-- giving up not really the right word, but thinking that all the dreams that you did have weren't possible. Which, as we know, as you saw in our presentation, a lot of the dreams I had for my son came true, just in ways we can't imagine when you're going through that. So I don't think there was a moment, per se, where we just both made the decision my wife and I that we're not going to become withdrawn and collapse. And you know, it was more a process. I say eight or nine weeks because I know there were a couple of months of crying ourselves to sleep and saying why us. But we loved our son, this is our baby, and my wife and I think it was really great that we had each other. I don't know if I'd made it if she wasn't so strong and maybe vice versa. But it was just kind of an evolving decision that, you know what, he's our son. Yeah things are different than we planned, but life goes on. And you know we've got to, as we had planned on doing before Patrick came in this world the way he was, we've got to make Patrick the best Patrick he can be and give him opportunities to succeed. And be whatever he is going to become. And so

that's what we did and, you know, here we are.

TERESA: Patrick, you described school and not really realizing that you were even blind until preschool when somebody told you that. What was school-- what's that school been like for you, school experience been like for you?

PATRICK H.: You know, overall I think I had a really good school experience. I had great teachers throughout the years, and I always had an adult with me. I had a vision teacher who basically knew Braille and knew how to get my work in Braille. And I had an instructional assistant that was kind of

like my eyes and legs, and made sure I got where I needed to go when I needed to be there. And the children were great as well. To tell the truth, I was always more of an adult oriented person, because you know I had an adult with me pretty much all day. But you know I did activities with the children as well. You know they'd invite me to birthday parties or school dances or things like that.

TERESA: And how about now, do you have a social life? Do stuff with friends? Are you busy traveling?

PATRICK H.: Yeah we do a few speaking engagements, probably one or two a month I guess. And you know I generally try to keep myself busy. If I'm invited to events then I'll do my best to try to make sure I'm there.

TERESA: How much time do you spend practicing or even just doing it for fun for your own pleasure?

PATRICK H.: Usually I'll do maybe a couple hours of piano practice every morning. And then, anywhere from 30 to 30 minutes to an hour of trumpet practice. And then maybe on occasions, go over there and and either play for fun or even just to listen to music is always a pleasure.

PATRICK J.: Amazon Echo has been the greatest thing for him. He bought like a music package. So he loves music and history of music and all sorts of things so he can go to her. And Is it Amazon Echo? Did I get that right?

PATRICK H.: Yeah that's the product.

PATRICK J.: Alexa. He can go to Alexa and pull music from all over the place. Unlike in my day when I had to find the album and the record player.

PATRICK H.: Good stuff.

TERESA: That's great. And you mentioned that you had two brothers who are also musical. Moms kind of musical. Do you guys ever perform together? Do things together?

PATRICK H.: The five of us, not really, no. Sometimes dad and I will do a duet. Either piano and violin, like for churches, you know weddings, funerals things like that.

PATRICK J.: And sometimes I'll play piano and he plays trumpet for the same event, but the younger two boys, they were fine musicians. But when they got to high school, their band, their marching band was really involved high school marching band. And it made it impossible, kind of, to be in both band and play sports. And they chose sports. One played football for four years, and the other one was a swimmer. So they kind of went that way. But they've got some musical talent. They just didn't pursue it We never made anything a contest. We never said, well Patrick makes straight A's, or what. Why don't you make better grades? Or Patrick can do this. That never happened in our house. Patrick, as I said in our remarks, he taught me that it wasn't about what I wanted my kids to do. It was what do they want to do? So the best thing for Patrick's younger brothers, was that Patrick came first and changed dad and my philosophy. We presented just like we did Patrick, we presented all three of our sons with several different with music and with sports and with whatever. We could find and let them choose. What do you like and what do you want to do? And then of course once they chose something then, Mrs. Hughes was the enforcer that you will stick with it. There's no, there's no quitting. So, but yes they did what they wanted to do. And they all, they've all turned out well. They're all better than I was as a son. So I'm very blessed.

TERESA: That's what every parent wants. I've interviewed both people with disabilities, and families, and one of the common themes that comes out, especially with parents, is this idea of they just want to put their child into the world. They love this child and are amazed and impressed and proud and how to do that in a way to let the world know that. And so I think even some of what you have described is that similar to Patrick and so how do you get the world to know and see Patrick?

PATRICK J.: There were a lot of roadblocks. And And that's not saying that people are bad. It's just people don't know, so we chose, my wife and I said we're not going to not give Patrick opportunities just because people are afraid. We're going to push Patrick in front of them and change their

thinking process. That yes, you might be uncomfortable, and you're afraid, you know they're afraid they're going to say something that's offensive or whatever it is. Just not knowing not out of not out of line out of meanness. But just nobody wants to say the wrong thing. So we pushed Patrick out. And yes we got some odd questions, and some stares. And we just learned to deal with all that. And sometimes people stare too long and we just roll Patrick right up in front of him and say, meet Patrick. This is Patrick. This is our son Patrick. You look like you might have a question. So you know, it could be awkward. We were somewhere where Patrick was performing as a very young person singing the national anthem at a softball tournament or something, and this little boy just, he came up and got right in front of Patrick and just kept staring at him. And I was there, and I was watching it all unfold. And I was prepared, you know, for whatever this little boy might ask me about my son who looked a little different. And he bowled me over, he said, what's wrong with his hair? And as of all the things he could have said was like what? There was nothing wrong with his hair. But it was just like see so you know you're afraid of what people are going to say. And people are afraid of saying the wrong things, and nobody says anything. But then it might just be something like that little kid who just wanted to know something about Patrick's hair that day. So he's got to take a chance. You know there was a chance to fail miserably in the marching band in front of 50,000 people on a Saturday afternoon. Right, I mean what a what a disaster that would be if I didn't make the move or made the wrong turn and you know and ran over to another player, or stop the whole formation. But you know and you just you just do it anyway. You got to get out and you got to break out of your box out of your safety zone, and make things happen. Take a chance. And the worst thing that can happen is that you fail. And then you get up and you forge ahead.

TERESA: Patrick, has your dad had any ideas that you thought-- any ideas about ways to put you out into the world that you were like, you've got to be kidding me.

PATRICK H.: You know, maybe a few here and there. But I mean none, none really

TERESA: And you guys spend a lot of time together? A lot more time than probably most fathers and sons.

PATRICK H.: Probably ever since I was little. You know, he was my first piano teacher. And I remember there were days when I was little that you know I wouldn't just want to play piano. I'd want to play piano with dad.

TERESA: I feel like this is an example of the kind of thing a lot of times people think about disability. And think about loss. But one of the things that I've noticed is how much it can actually bring to people's lives. And I think your guys' is relationship strikes me when you talk like you you maybe wouldn't have had this.

PATRICK J.: Being a music major and somebody that was in music his whole life and always had the battle between I want to play sports. I don't want to go to music lessons. I want to go to the football game and the basketball game or the baseball game whatever sport I was playing in school. And but then I look back on it, when Patrick was born. You know thank god my mom you know had the strength and the will to keep pushing me through all these music lessons. And she accommodated for sports as well. You know she made the sacrifice. She drove me all over the city, getting me from point A to point B for all this stuff. But you know when Patrick was born, I wanted to make Patrick an athlete. Right, my first born son had that mentality. And obviously that probably wasn't going to happen. But you know, thank god we had the music thing. And what a gift like you say. If he did become an athlete, then he would have been out on the field doing whatever, and I'd be in the stands cheering. But with the way things worked out, what a great gift for a Dad. And what's really cool, and you can tell this story, about our motivation how we talked about that years later. How I was motivated by you.

PATRICK H.: Right, and then dad, when he when we were doing classes and marching band and things like that, he also had a second shift job. Third shift actually. Yeah I was thinking during those days where, you know, I didn't want to go to classes, or marching band practice, I'd just have to realize that dad's doing all this on what? Three or four hours sleep a night. And you know I got a full night's sleep.

PATRICK J.: It wasn't planned. It just kind of fed off Patrick. I thought, you know, I sure am tired, and you know I don't want to go to school. I want to sleep in today or whatever. And and but you know I worked with guys that worked. They did the same work I did on the night shift at u.p.s. And then went to a full time job during the day trying to make ends meet. So I'd always immediately adjust my thinking if I was feeling downtrodden or overworked. It's like look how lucky I am to get to go to take my son to school and participate with him in the marching band. That always, you know, energize me. And we've talked so many times, it's all about your perspective. You know, do you want to be somebody that's beat up and downtrodden? Or do you want to find ways to motivate yourself? And think of all that you're lucky to do. Because what are there 7 billion people in the world? And in the United States we've probably got it better than I don't

know 6 and 1/2 billion of them as far as opportunity and hope. You know like for like for people with special needs. Children in America. Imagine trying to do what you do in another country, where they don't have the Americans with Disabilities Act. And they don't have all the lawyers and the people to make sure we're getting services and things we need for our children. So there's always good to find. Sometimes it's a little harder than others and there's days where it's harder to recognize and others. But it's always there if we choose to embrace.

TERESA: Can I ask about some of your other musical favorites? You played Ray Charles, right, so he's a favorite.

PATRICK H.: Oh yes. To tell the truth, I really prefer country music above. And I especially like some of the modern artists, but I really like a lot of the earlier artists. I like Johnny Cash, Conway Twitty, Hank Williams sr., Jim Reeves, people like that. But I've actually been very blessed to get to meet several of country music artists that I like. And I've even befriended artists like Pam Tillus, the band Lone Star, Chad Brock, lady named Layne Brody, just to name a few.

TERESA: You play piano and trumpet. Right. Do you prefer one?

PATRICK H.: No, they're both fun. But I guess if I had to pick it would be piano. Yeah, it would be piano. Because to me, the way I see it, piano you just have to worry about making sure your finger hits the right key at the right time. Whereas trumpet, you have a whole list of things to worry about. How to hold the instrument, kind of how much to put into it, what kind of sound you want to produce, things like that.

TERESA: Do you have other hobbies outside? Not that music is a hobby.

PATRICK H.: I guess another thing I'm really big into, I really like television game shows. I hope to host one day. And you know I've been a fan of game shows for quite a few years. And you know love those of today as well as some of the classics from the 70s and 60s even to the 50s.

TERESA: If you could bring one back and you were the host which one would it be?

PATRICK H.: I actually had a dream of bringing back the Hollywood Squares, but in a different format. I was going to call it Nashville squares, and have country music stars in the squares. Yeah, I made an attempt and it hasn't happened yet. But you know never say never.

TERESA: I think you guys are the epitome of never say never.

PATRICK J.: We gave it a try and we went outside the box, and spent some money and you know tried to get the Nashville squares thing rolling. But, it's very difficult to break into into that world. And you know on most game show host didn't start out as game show host. They did something else first and then eventually it happens. But who knows? We don't ever give up. We just, there are setbacks and you keep trying and you attack from another angle and see.

TERESA: So another question I usually ask the parents but I'm kind of curious in this instance. Patrick, I usually ask what your proudest parenting moment is? But I'd feel like I'd be curious to know what your proudest moment of your dad is?

PATRICK H.: Us performing at OCALI con.

TERESA: That's a good answer.

PATRICK J.: Yeah that's right.

TERESA: Is there another one?

PATRICK J.: I don't know. That's a good question. He's never been asked what's his proudest moment of his dad, so he'll have to think on that and get back to you.

TERESA: OK, how about you? Oh, you thought of one?

PATRICK H.: Well, actually it would be, not with dad so to speak but well I think my proudest moment period for me, especially looking back and being the country music fan that I am, was getting to perform on the Grand Ole Opry, which I actually did twice. Once with Pam Tillis whom I mentioned. And then a second time with Lone Star. And then to be able to enjoy the artists of yesteryear, so to speak that I enjoy. And you know knowing that they performed on the Grand Ole Opry stage.

PATRICK J.: There's obviously been so many through the years. Probably one of the earliest proudest moments was Patrick's first crusade for children performance. It was a live performance, actually, that kind of did a play on it in our movie. They showed me backstage, you know, cheering him on and he did a great job and I was a nervous wreck. But he got in front of the audience and played and sang. He had all these the lyrics that he sang in the song that we wrote for the crusade for children, which is a local charitable telethon. And I was standing just behind stage with the lyrics in case he got stuck, but he just nailed them. And the audience went crazy jumping out of their seats. Because everybody in Louisville it's kind of like the

movie The Truman story everybody watched Patrick grow up on TV and in our hometown of Louisville, Kentucky. And but to be honest just be offstage and watch him nail that moment. I guess you were 10 eight nine. Nine, I was close. So but Yeah I'll never forget that feeling inside of me, of that moment about how proud I was. And how great I felt in the audience. You know rising to the occasion as well. It was just the culmination of so many great things. And has gone on to do so many people going on the field with him the first time in the marching band was obviously a very proud moment. How many parents get to do that? March with their son in a major college football game. I mean it's ridiculous. So that was another moment. A lot of these speaking engagements we do in front of thousands of people. You know they're always you know I'm always so proud of him. He's never he's never let me down in one of these type of minutes he's just a great entertainer. So I could go on and on.

TERESA: Yes, I didn't realize that you write your own music too.

PATRICK H.: Yeah, I've sort of dabbled in it a little bit. I guess I've written maybe about 20 or so songs. But mostly I do all covers.

TERESA: Well you do it well. It's really been a pleasure to hear from you. I looked around I will admit myself. And as I was looking around the crowd, lots of big emotions in the room today. Really great to hear stories of hope.

PATRICK H.: We enjoyed it.

TERESA: Yes. Thanks so much. Safe trip back.

PATRICK J.: Thank you.