

DR. DARREN SUSH: Hello, and welcome to Holly's Huddles, a podcast series created to help people at every stage of the autism journey. My name is Dr. Darren Sush, Cigna's Head of Autism and Psychology. I will be joined every session by actress, activist, and mother of a thriving autistic son, Holly Robinson-Peete. So let's jump right in and learn more about Holly's journey. Holly, thank you so much for being here, thank you for joining us. Would you please share a little bit about your autism story and the discovery process for your son, RJ?

HOLLY ROBINSON-PEETE: Well, first of all, I'm so so excited to get Holly's Huddles kicked off, it's something I've wanted to do for a long time and thank you so much, Dr. Sush, for helping me realize this dream. To be able to talk about autism in this way. So my RJ is now 23, but when he was three, 20 years ago, he was diagnosed with autism and it was a really difficult diagnosis for our family. Very, very difficult for my husband and I. My husband was an NFL quarterback at the time. RJ has a twin sister named Ryan. And that diagnosis was tough. I think mainly because of the lack of resources that we were given upon diagnosis. So it's one thing to tell someone that their child has autism, it's another thing to basically give them no hope moving forward. And that's what I saw back then. And it was a tough time. That was one of the reasons why eventually I wanted to talk so publicly and openly about RJ's journey, because I wanted other families to have the hope that I didn't have.

The day that he was diagnosed called it the "never" day. And it's because he was told he would never do so many things. Speak, mainstream in school, have friends, have a job, self-advocate, drive, and a lot of those things at 23 now, he has done. He has checked off. And so the journey has been -- it's hard to believe it's been 20 years. Like, when I think about that, it's -- it's a head scratcher. Like, wow. Because there were times when I didn't know what the future would look like, and I didn't have a lot of hope for the future.

DR. DARREN SUSH: Right. And I think so many families, even today, experience that same thing, even though there are so many more resources available now than there were -- then there was in the past. But there is still all those question marks that just are faced -- that parents face when they -- when they receive or learn about that diagnosis. Along your journey, what were some of the challenges, the triumphs that your family experienced together, and especially with RJ?

HOLLY ROBINSON-PEETE: I always say the number one challenge was acceptance with trying to figure out how to live with autism, how to have hope with autism, how to thrive with autism, and what did we want to do to help RJ get along in this world? The other challenge, the extra challenge, I think, was my husband's inability to accept the diagnosis, which I'm sure anybody who has to experience this will understand, that denial is a real thing and it's very difficult to overcome. Fortunately for us, we were able to do that and my husband ended up not only overcoming it, but writing a beautiful book about his journey, which I think has been very helpful for a lot of dads who sometimes process the autism diagnosis very differently than us moms. Not always, but sometimes. And that was probably a hard part of the journey was navigating my marriage through all of this. My husband was on the road playing football. And he had all of these issues about, well, you know, my kid is the only kid that's not running around the locker room asking for autographs. He's twirling and standing and flapping, and he's disconnected. And it was difficult for him to process.

And then along the way, we just met so many great people and stories and families that we were able to share with. And those were the -- the lighthouses if you will, right? That gave us hope and gave us a sense of, okay, we're going to get through this. We don't know what it looks like yet, but we're going to be okay. And then also, remember he had a twin sister who talks often about how she felt neglected. How she wasn't the squeaky wheel, so she didn't get all of the attention. So that's another challenge along the way, having other children in the house. I eventually went on to have two more. And the dynamic of making sure each kid gets their "squeaky wheel" time.

DR. DARREN SUSH: Right. Right, and -- and, you know, one of the things that you mentioned is I think, so impactful, in that, you know, there's -- there's resources and we talked about there's supports and there's services and there's therapies, but having those connections, whether it be within the family, or friends, or just other people who can give you advice and information, is just so important for a lot of these families, because you don't know where to look and it -- sometimes it's just not easy to find those answers. So someone, especially like yourselves who have been down these roads before and had these struggles and figured out some answers that work, that's just so meaningful for so many families. So -- so thank you again, I mean, for sharing your story and just being that resource for -- for people out there who just, you know, are looking for some place to find some -- some answers and some support.

HOLLY ROBINSON-PEETE: Well, I'm glad to be thanked, because I didn't really have a lot of those people around me back in 2000. I was very lonely in my diagnosis. And didn't have the resources that so many families have today. One of the things that I tell parents, that if you just got a diagnosis, be thankful that you have so many resources. And there are so many places to go you don't want to say to somebody, "Oh, you know, you're lucky, because, back in my day, I didn't have this, that, and the other, there is something to be grateful for. That there are so many resources. Even a forum like this, did not exist back then. There were maybe some chat rooms and a couple support groups, but this type of platform to reach so many parents and have conversations, didn't exist. So if you got the diagnosis today, or yesterday, or recently, I would say, the good news is, you have so many resources and there is a lot of hope and a lot of help out there.

DR. DARREN SUSH: Right, and so many families, you know, when they receive that diagnosis of autism, obviously there's -- there's questions, there -- there is struggle, there is concern that comes up. But in some way, also that -- that diagnosis gives direction. Okay, now I know where we are, now I know something that we need to do. And -- and especially as you mentioned today, there -- there's not enough, but at least there's more resources and supports and services out there that -- that can be of help. How is RJ doing now? What's -- you know, he's -- he's a -- he's a grownup, you know, he's an adult now. So how's -- how's he doing?

HOLLY ROBINSON-PEETE: Well, I still cannot believe I'm saying he's 23 years old. Because like, I told you that "never" day really did take the wind out of our sails. And he's checked so many of those "nevers" off the list one of the things we were told he would never do is have a job. He doesn't only have a job; he has his dream job. He is a clubhouse attendant for the Los Angeles Dodgers, which means he takes care of all of the players' clothes and uniforms and makes sure everything is washed and -- now, this is the boy, mind you, that doesn't do an ounce of laundry at home, but somehow, he can manage doing laundry for an entire major league baseball team. So, go figure. But it's an amazing job and this is a kid who had literally no

friends growing up, and now he's got all of these major leaguers and these clubhouse guys, and even people from the front office that are just so loving and supporting to him. The Dodgers understood that by hiring someone with autism, that they were not just helping RJ, but they were helping the autism community, and they were really helping their own workforce their team is better because RJ is there. I get emotional about the World Series, which is really amazing, and RJ gets a ring, and that is pretty awesome. But every time I go on social media and see one of the players, I go on this long crowd clubhouse Mommy rant about, "Oh my gosh, thank you for being so nice to my son and raising him, and you don't know what it means to me for him to be able to self-advocate and have, this sense of pride in -- in his life and value." And they always tell me the same thing, they say, "Mrs. Peete, it's your son who makes us happy he brings us the sunshine every single day." And so RJ is doing great. He's a little bored right now. He's been furloughed for a minute because of the pandemic. He's really struggling with not knowing what's going on in his employment situation. But the job has been a gamechanger, and hopefully when things get a little more back to normal, some of the anxiety and -- and issues that he's experiencing now will go away. But overall, I mean, it's a really beautiful story and I like to share it, because I think so many parents need to hear something like that, when they are looking at their 3-year-old and they don't know, or they've been told he'll never do something.

DR. DARREN SUSH: Right. Well, and it's such an amazing thing too, not only that he was able to achieve one of those things that you were originally told was going to be a "never" thing, but also that as -- as -- as an adult, he's able to have that kind of impact on so many people's lives, to show, number one, for families who are going through similar things, that what your family went through, that it's possible. And also, to raise awareness and raise acceptance and make connections to people who might not otherwise have had an understanding of what autism is. And what autism looks like. Or maybe they've only seen it in -- in TV shows and -- or they have a -- it's a mystery to them. So what a -- what a great service really, he's providing to -- to raise awareness, and acceptance, and understanding.

HOLLY ROBINSON-PEETE: He's an interesting guy, and you'd love him if you met him, and you wouldn't imagine that he struggled his whole school life with no friends, and no social connections, because he's so gregarious and loving, and connected right now. And a lot of it is just from his therapies and being able to understand how to move in the world. But you're absolutely right and that is one of the reasons why we did a reality show. That was not, like, on my BINGO card in life that I was going to do a reality show, but one of the reasons I really wanted to do these shows, is I wanted to show the world that this is a -- a success story a story of a kid that -- and show the possibilities of life. Because that's just one thing I didn't have when we got the diagnosis. It was so bleak and dark. We've got to have hope. We have to have hope. And I wanted RJ to be able to be sort of that beacon in a way. He doesn't always enjoy that role, but he does understand the value of it. He understands how it can really help, because people are always walking up to him in places wherever it may be -- in an airport -- and saying, "Thank you, RJ, for sharing your story, because it's helped me and my family."

DR. DARREN SUSH: That's great. Any tips? Any guidance that you want to share with families who are supporting loved ones who are on the spectrum? Or things that have worked really well for your family that -- that you can spread the word on?

HOLLY ROBINSON-PEETE: I always maintain that all of our kids are different, and what works for one child is not going to work for another, but for me, I don't even know how to

describe my early days. My sleeves were rolled up, my boxing gloves were laced up. I was a autism mama. I was gangsta that's the only way to put it. There was nothing I wouldn't do for this child. I was constantly fighting and advocating for him. And I think a lot of moms and dads can relate to that. You've just got to go to bat for your kid. Again, many more resources now than there were two decades ago, but the good news is, people understand autism a little bit more in the world. Not everybody, obviously, but people understand. So now when you say, "Oh, my kid has autism, or he's autistic," you've got a few more references than just Rain Man. You have places you can. You can go online; you can see kids like RJ doing amazing things. And then a lot of people who have autism as adults that have never really shared that, have come out and shared that, and that's been helpful too. So, my advice would be, roll up your sleeves, advocate like crazy, you've got to thicken your skin a little bit. And I think kindness goes a long way. Now, I'm not saying this from experience, because I -- there were times when I was less than kind to people who were not understanding of my son's experiences, especially on planes and places that I've been. Out in public. But I find that when you treat people like they don't understand something, and give them an education, it really, really helps. And you don't talk down to them, and then they are more likely to be more understanding about what your son or daughter may be going through. So treat them with -- kill them with kindness.

DR. DARREN SUSH: Well, thank you so much, Holly, and thank you to our listeners. Be sure to listen to our next podcast in this series, where we will discuss getting a diagnosis and accessing services.