

DR. DARREN SUSH: Hello, and welcome to Holly's Huddle, a podcast series created to help people at every stage of 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. And today, we're going to chat with Cigna's Consumer Health Engagement Medical Director and pediatrician, Dr. Matthew Keller, an expert in autism diagnosis. Dr. Keller, thank you so much for joining us today, appreciate it. Would you mind sharing a little bit about your background and your experience? Especially with helping individuals diagnosed with autism.

DR. MATTHEW KELLER: Yeah, thank you so much, Dr. Sush for -- for having me. I've been a pediatrician for over 16 years in clinical practice at a large independent pediatric group. During that time, I took care of many children with autism spectrum disorders from infancy through adolescence. The autism community is really tight-knit and my following of patients on the spectrum grew really by word of mouth. For pediatricians in primary care taking care of patients on the spectrum is really part of what we do every day. We're there to help guide families from initial diagnosis and evaluation all the way through into adulthood.

DR. DARREN SUSH: Thank you. Thank you so much for sharing your background. And Holly, would you mind speaking a little bit about RJ's diagnosis experience?

HOLLY ROBINSON-PEETE: When RJ was two years old, I noticed that he had some degree -- we noticed a period of regression. He was hitting all the milestones that his twin sister was hitting, and saying his first words, and then there was this needle on the record moment, where he just regressed into his -- himself. I knew as a mom, as you've all heard about the "Mommy gut" that we all know certain things about our kids, even though I was a rookie mom, my first kids, and two of them to start off, I knew instinctively something was different about him, when he was two. And it really took me a year to get the diagnosis. This was 20 years ago and a lot has changed as far as awareness and resources and even doctors understanding how to connect and talk to parents, but back then it was a little more difficult for me to get a doctor, our pediatrician, to even really acknowledge that there was something going on. I was told, oh, he's a boy twin, boys -- don't compare him to his twin sister. Stuff like that. So as a mom, it was a little bit frustrating, but when he was three, I was able to get an appointment with the developmental pediatrician, and she diagnosed him. Actually, very few people know this, but she diagnosed both of them on the autism spectrum. But my mommy gut, again, told me that that wasn't right. She ended up changing that diagnosis. But what happened in the evaluation was that Ryan, my daughter, was mimicking everything her twin brother was doing. I felt like it was this sort of moment of solidarity. Like, if you're going down there, I'm going with you. That's how we talk about it now that they're 23. She ended up not having autism, or not getting the diagnosis, but he did. So it was a little difficult. It was me sort of feeling something and not being able to articulate it and not being able to get the answers that I needed at the time. It was tough, there weren't as many resources. So, when I hear sort of several people's autism diagnosis journey, now it seems it's a little bit more streamline. We definitely had some hurdles and some -- some little pitfalls that we had to get around to actually get to diagnosis when he was three. Even though I knew there was something happening when he was two.

DR. DARREN SUSH: Yeah, and Holly, one of those things that -- that you mentioned is, you know, needing to rely on that Mommy gut, especially when you're meeting with professionals

and especially, you know, even if they have a whole bunch of letters after their name, sometimes things just don't feel right in that conversation. Ideally, I think when you -- when you meet with a doctor, a pediatrician, an expert, a specialist, you're getting really supportive advice and a really intuitive ear. But sometimes that's not the case. So Dr. Keller, do you have any thoughts or any advice for families who might have had a similar experience to Holly if -- if they want to -- if they feel like the information they're getting is just not -- not enough or doesn't feel right?

DR. MATTHEW KELLER: Yeah, absolutely. Holly, as a pediatrician, I always take parent's concerns seriously and I think that mommy gut really goes a long way. As healthcare providers, we get short little windows to see children. You know, 20 minutes, 30 minutes at a well visit. But you as the parent or caregiver, or grandma, or a teacher, really is with that child all day long. And so if there is a concern there, those should always be taken ser-, seriously. You know, one thing that -- that parents should never accept is, "Oh, he's just being a boy," or, "let's see how things are at the next well visit." I really would encourage parents to be an advocate and push for that formal evaluation if they're concerned.

HOLLY ROBINSON-PEETE: Absolutely, I would too. I tell anyone who wants to listen to me, that you have to listen to your mommy gut, and also, I encourage parents to write everything down and really document everything. This is 20 years ago, I mean, we were videoing and stuff, but it wasn't like it is today, where everything gets video. We didn't have iPhones yet. But document, document, document. I think that's so good, because down the line, as you see progress, or there's regression, you can have a sense of some kind of marker. And so, I think we can be statisticians, we could document, we could do all that stuff, and I think that eventually really helps. It's a big piece of advice that I like to share.

DR. MATTHEW KELLER: That's great. I think videos can be really helpful. There are lots of great milestone tracker tools out there as well. And one that I often recommend is the MChAT, or Modified Checklist for Autism in Toddlers. It's a great screening tool that can be found online for free. It's a quick, 20 question assessment geared towards children 16 to 30 months, that really just says, hmm, is there something here that needs more evaluation? And so that's just another way of collecting that data, if that gut instinct is that there's something that may be going on.

HOLLY ROBINSON-PEETE: I will definitely be recommending that. That is a tool that I did not have, and Dr. Sush and I have been talking a lot about how the resources are so much more plentiful now than they were many years ago. And that's the first plus that I think I give to parents who are just getting the diagnosis, there are just so many tools and resources at your disposal. You've got to roll up your sleeves and look for them.

DR. DARREN SUSH: You know, Dr. Keller, one thing that -- that Holly was mentioning, was her experience in getting some challenges in finally accessing information related to that diagnosis, and I would imagine for a lot of families, part of that challenge is just knowing who to go to. Who is a professional that they should seek out if they have a concern related to language or development or a potential diagnosis of autism? So I don't know if there's a typical path, or a typical journey of who the professional might be, but are there -- is there anyone that families should look toward in general for getting evaluated for an autism diagnosis?

DR. MATTHEW KELLER: Great question. I really recommend starting with your pediatrician or family doctor. There's a lot of information, resources, out there for providers that there

wasn't 15 or 20 years ago. And I do think that most pediatricians and primary care providers are geared up to start on that path and journey. Like you said, Holly, it does take some time to get that diagnosis. And oftentimes pediatricians will refer to a child psychologist, a psychiatrist, a developmental pediatrician, or a child neurologist, to do a formal evaluation in order to get a diagnosis. That doesn't mean that nothing is happening during that period of time and I strongly recommend that if there is any inkling of not just some spectrum disorder, that parents reach out and start with an early intervention evaluation, and early intervention programs are run by the state and those evaluations are free. And your pediatrician or your family doctor can start that process and guide parents into that path, so while we're waiting for those specialists, which sometimes can be a really time-consuming and long wait to get an appointment, that things are still moving and happening, such as starting behavioral therapy, or speech therapy, occupational therapy. So that time isn't lost. We know that outcomes are better when interventions are started earlier for kids on the spectrum.

HOLLY ROBINSON-PEETE: Yes, I think that's the number one best piece of advice I ever got early on, was there's a very a tight window of time that you want to exploit, you want to get in there and get that intervention started, even if you do have to have that long wait for a doctor's appointment. And that kind of gets back to that mommy gut again, about getting things going, it certainly can't hurt. I would love to ask you both a question, if you wouldn't mind just sort of just describing some signs or possible symptoms of autism, what to look for. I know from my experience, but I have to take advantage of being an autism mom, sitting here with two amazing experts in your field, and just hearing from you. What would you say would be the signs or symptoms of autism that parents should look for?

DR. MATTHEW KELLER: Yeah, I think the -- the number one thing that you said in regards to RJ, was regression. Things were progressing and then all of a sudden you saw a stop and even backwards in skills and things that he was doing. That's really always a red flag and something that parents should always bring up with their pediatrician. Remembering that -- that autism spectrum disorder is related to differences in social interactions, and communication, those are the areas of development that parents and pediatricians should be paying special attention to. So, things like lack of a social smile, or joyful expressions by 6 to 9 months. If your child isn't responding to their name by 12 months. If they are not pointing at objects to show you, like an airplane in the sky, by 15 months. Not engaging in pretend play, like feeding a baby doll, or zooming a car across the carpet, by 18 to 24 months. Those are some of the -- the big red flag signs that we look for as pediatricians. And -- and hope that parents will reach out to us in those cases. I think it is important to remember that all children develop in their own unique way, and that if one of those milestones that's in a parenting book, or on one of these checklists isn't there, that doesn't mean panic. Be vigilant and bring it to the attention of your pediatrician or family doctor.

HOLLY ROBINSON-PEETE: Yes, Dr. Sush, would you add to that?

DR. DARREN SUSH: Yeah, I think just echoing what -- what Dr. Keller was mentioning, is that it is important to -- to know that every kid, every individual is going to be a little bit different and, you know, a slight lag in maybe a milestone or one of those areas that Dr. Keller had mentioned, that doesn't necessarily equal oh my -- oh my gosh, we have a diagnosis on our hands and now we need -- we need to go get all of these services available. But what it might mean is, let me take a look at this. Let me try to pay a little bit more attention to this, and then

let me at least let the professionals who I have a relationship with, know that I'd like some additional focus in these areas. You know, the CDC has a really amazing website that lists a lot of the red flags that Dr. Keller was mentioning, with different developmental milestones and areas where we typically see progress by certain ages. And they have one specifically related to signs and symptoms related to autism spectrum disorder. So I would definitely encourage parents to check out that website, look at those red flags that are listed, see how much it might compare to their trial, and keep track of that. And the MChAT, like Dr. Keller mentioned, also is a great way of kind of validating, or looking into some of those concerns.

HOLLY ROBINSON-PEETE: Thank you. I know that's so helpful for parents to hear.

DR. DARREN SUSH: Holly, do you mind maybe speaking a little bit about your experience when you first received that diagnosis for RJ? What was it like going through the process? And then ultimately when -- when that diagnosis was made?

HOLLY ROBINSON-PEETE: Well, when we first got the autism diagnosis, we were a little gut-punched -- a lot gut-punched, because we just didn't really know anything about autism, and we were just really living this pretty amazing life. And I was on a hit TV show, my husband was playing football, for the NFL, quarterback, and it's just -- kind of this fairytale life, just took this real crazy weird U-turn. So it was -- it was kind of jarring and we just had to adjust and pivot. I was a little bit able to pivot better than my husband. He went into denial and struggled mightily with that, and thank God he -- he pulled -- pulled through that and came around, because I couldn't imagine this journey without him. With that said, he was struggling a lot with -- with denial and what he was going through. My first goal was just to roll up my sleeves and get him to all these therapies, right? Had to go to all the T's -- PT, ST, TO, I was around town, running around, and all I kept saying in my mind is: one day, when I'm, you know, further down the line with this, and I've got RJ on a good track, I'm going to build a giant place where all the T's are under one roof so you don't have to fly everywhere around the world to go get this stuff. I remember that day very much, because L.A. traffic is crazy. So we were just driving around to all these different places. But my -- the biggest thing I did was just really almost -- maybe over the top, and I like, overloaded RJ's schedule, because I wanted to really, really exploit that window of time. I felt like, you know, to be honest with both of you, that I felt like I was really really late on it. Because, remember, I saw this when he was two. And then I spent a year trying to get a diagnosis, and that was frustrating for me. I felt like I lost a long intervention of time. And I just really had like a kitchen sink type of approach, where I really wanted to do it all and see what -- see what would happen. But it was very difficult because I was working and trying to manage all of the things, my first thought was, wow, what if I didn't have this terrific job, or what if my husband wasn't this fancy football player. We have resources. What about families that don't? How do they approach this? And that was when we knew we had to get into this non-profit world, and help support and use our platform to support others who didn't have as many resources as we did.. And it was very cathartic because we were going through our own situation, but we were able to help others get through theirs. I remember my husband going, "Really, you want to start a non-profit in the middle of all of this?" And I was like, yes, because I can and because I don't have enough on my plate already. But it was really super helpful and it allowed me to interact and -- and interface with families and see what they were going through that's what we talked about. Who was your doctor? How is he helping you? Are you getting good information? What information are you getting? And again, a lot of this was without the resources that we have today. So that journey in those early years, I just remember talking to

families a lot, running around to different therapies, trying to do a whole lot. It's kind of a blur, but the biggest thing I remember was just the people that I met along the way. The lighthouses of people that were really helping us get through this. And then we wanted to be that for other families as well.

DR. DARREN SUSH: Well, thank goodness that you did, because you're right, a lot of the ways in which people access these supports, whether it be all the T's that you mentioned, or just getting to that early diagnosis, is going to be -- gonna come because someone else knew the path. Someone else walked that path before you and helped you get to that correct person along the journey. So thank you for doing that. And Dr. Keller, thank you so much for your participation today. Holly, thank you again, and thank you to our listeners, and please be sure to check out or next podcast in this series, where we're share tips for caretakers to balance supporting loved ones, work, and of course, play. Thank you, everybody.