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Brian Martin: From UPMC Children's Hospital of Pittsburgh, welcome to That's Pediatrics.

Carolyn Coyne: I'm [Carolyn Coyne](#), I am a scientist in the [Division of Pediatric Infectious Diseases](#).

Brian Martin: And I am [Brain Martin](#), Vice President of Medical Affairs here at Children's.

Carolyn Coyne: Joining us today is [Kishore Vellody](#). Dr. Vellody is the medical director of the [Down Syndrome Center at UPMC Children's Hospital of Pittsburgh](#). The Down Syndrome Center provides families with the tools they need to become educated and strong advocates for children and adolescents with Down syndrome. Dr. Vellody also hosts his own podcast, [The Down Syndrome Center of Western Pennsylvania podcast](#). So you have to make sure you check that out as well. Thank you for joining us today.

Kishore Vellody: Thanks for having me. I am glad to be here.

Brian Martin: So, Kishore tell us a little bit about, one of the things we like to do, is just sort of open up and learn a little bit about your background. What brought you both to Children's and your current role, and your history and what maybe even drew you to medicine in the first place.

Kishore Vellody: Of course, I'd be happy to. So I grew up in Chicago. Actually the son of two doctors, which made me realize I did not want to be a doctor when I grew up. Actually, very interestingly, my older brother has Down syndrome. I had accompanied him to a lot of medical visits and also just over time, realized how awesome people with Down syndrome are. So then, I went to medical school University Of Illinois in Chicago. I done my residency in Milwaukee, at Children's Hospital of Wisconsin. Then came out here because I wanted to be a hospitalist. I wanted to take care of children who were admitted to the hospital and I did that for about 4 years.

In 2009, due to the untimely passing of Dr. Bill Cohen, who used to run our Down Syndrome Center here. They asked, "Who would ever want to work in a clinic this big and this established and jump into these big shoes?" I said, "I'll do it." So that's how that started back in 2009. It's just been a really exciting way of giving back to my brother and being able to see hundreds of children each year. Just indirectly give back to my brother every time.

Carolyn Coyne: I was wondering if you could talk about that because having a personal experience, and more insight into personal relationships, how that could influence you. If you could tell us, how your interactions, and experience having

an older brother with Down syndrome, just influence your ability to either be a doctor or just to be able to maybe talk to people when they're understanding this.

Kishore Vellody:

I think that's great. There are so many studies that I didn't even realize, that I fit into that mold of a sibling of a child with Down syndrome or a person with Down syndrome. We are so used to, as siblings, working with our sibling with Down syndrome, and working with them, teaching them and having that patience to know that if I could just do this in a different way if I could figure out a different way of explaining it or showing it, that slowly but surely, they will come to get it. Then, that exhilaration that you feel that when they finally do get it, all that work you put through does come to fruition.

I think, that one of the things that has helped me with in general, just being a doctor is helping me be a little more patient that I probably would have been otherwise. The other thing is specifically in my work, in the Down Syndrome Center is, many times parents will ask me a question and there is no answer to be found on the internet or in a textbook. I will say, you know what, I have seen that a millions times. I know exactly what that is. It just gives me that confidence to be able to share with them after having, not just my brother, but so many friends growing up that had Down syndrome that, I am kind of part of the group even though I don't have Down syndrome myself.

Brian Martin:

Can you share with us a little about the Down Syndrome Center? Can you speak a little bit about the structure of what that looks like here at Children's and how that optimizes care for patients with Down syndrome, and their families as well?

Kishore Vellody:

Yeah, it's an extremely unique situation we have here in Pittsburgh.

This Down Syndrome Center was created by parents. Actually, this is our 30th anniversary of the center. Thirty years ago, or probably a little bit longer than that, the families got together and said "We've got some great pediatricians in the area," and we do, still to this day, the challenge though becomes, if you have a small population of children in your individual practice that has something like Down syndrome, it becomes really hard to know what's the latest guide lines and what's the latest research that's coming because there's so many other things that you have to focus on as general pediatrician. So the families got together back in the mid-eighties, probably. They got together and did some fundraising and came to Children's Hospital of Pittsburgh back in 1989. They said "Hey, we would like to have a clinic, and we would like to have a physician, where that's all they do, take care of children with Down syndrome in their clinic practice." The hospital said "well, that costs a lot of money." And here the families said, "well we have done all this fundraising."

What makes this so unique is that early story, you might find it in other places, but that fact for thirty straight years, this has been an independently financed clinic. Not only is the local parent group still our major donor, but we have

several other donors that have gotten on board has allowed us to really grow and do what no other center in the world is able to do.

To do it in a way that serves the families so that I don't have to feel rushed when I am in with a family, I can say this portion of your visit, this is all fully funded by the people who have come before you. The parents who have come before you. So I don't have to rush through my visits, I can answer all the questions they may have. The families consistently remark on how important that is for them as well. Medically it allows me to make sure all the potential medical issues could arrive are being addressed before they ever become a problem. To me that is very fulfilling a physician to be able to give that type of service, not taking over the primary care doctors roll, but supplementing what the primary care doctor is already doing and allowing the child to get the comprehensive care they need.

Carolyn Coyne: I think, a lot of people are familiar with Down syndrome, but tell us a little bit more about it. I think there are aspects of it, that people probably don't appreciate and understand. So maybe educate us, educate our listeners, just about down syndrome in general.

Kishore Vellody: So, Down syndrome, when it was originally described was back in the mid-1800s, it was described by a guy name Edward Seguin. He recognized that there was something different about people who had Down syndrome, but it didn't have a name. He didn't put his name to it, that came to John Langdon Down, about 30 years afterwards. Between then and between the 1960s, no one really knew what caused Down syndrome, it doesn't seem that long ago. To think that they didn't know what caused Down syndrome and it was actually Jerome Lejeune's lab where they discover they extra chromosome 21 is what leads to Down syndrome. How that exactly happens is up for debate.

Nobody really knows exactly why it is that the extra genetic material from the twenty first chromosome leads to all the potential issues that come up in Down syndrome. There're some theories out there, but nobody has really fully conclusively determined that. We do know that people with Down syndrome usually have a little bit of a higher incident of cardiac issues. They also have incidents of thyroid related problems, iron deficiencies and anemia, things like that. Atlantoaxial instability in their necks, in the cervical vertebrae of their neck, sleep apnea, these are just some of the many things medically, that we think about, that require a lot of time and a lot ability to really know what types of questions to ask, to uncover those things. Then what type of testing should be done to uncover those things as well.

With the right type of care, what we have discovered is that the average life span for somebody with Down syndrome in the nineteen forties was 15 years. The average life span now is in to the mid-sixties. That's only increasing and if you think if we, the general population, had the same percentage increase in our life span, we would be living until we are three hundred. What it shows is, adequate medical care, when its provided, allows people to really thrive,

including people with Down syndrome. That is kind of sad to think, we didn't really recognize that earlier, than we should have probably as physicians.

Brian Martin:

That is an incredible statistic. I'd like to gear shift a little bit towards community. I'd love it if you could just expand your experience here with the Down Syndrome Center UPMC Children's about the role of the center and about the role of the community of families of patients that have Down syndrome. I was fortunately, close friend of mine has a son with Down syndrome, I participated in the Down syndrome walk. It was a super powerful experience. And really, what I came away with was a profound respect for the way the families can now communicate, using social media and other vehicles. I'd love to hear your perspective and experience during your career with those activities and issues.

Kishore Vellody:

Yes, the community here in Pittsburgh is so united and so strong when it comes to families and people with Down syndrome in general. The way they all love to get together, you were describing the buddy walk that happens every year. It also has been called over the years, The Dash for Down Syndrome here in Pittsburgh. It's a tremendous opportunity that happens every October, September-October, depending on the weather sometimes. It is a beautiful time for all of the families to get together. Somewhere over two thousand people can get together in one little area and share commonalities with each other. That's just one example.

The Down Syndrome Association of Pittsburgh which is the local parent group does such a fantastic job of putting together, almost monthly now, some sort of gathering. Just last week, on March 21, that is World Down Syndrome Day. That's three, March "3," twenty-one, which is a nice way of having World Down Syndrome Day. I was able to go and be a part of the Down Syndrome Association's dance that they had. Oh, my goodness, the kids, the adults and everybody getting together, and having a good time. For us, as part of our center here, many of us have a family member with Down syndrome who work at our center. So, we are a part of this community already, so whether I run the Down Syndrome Center, or I didn't, that would be where I would be, at those types of events. It's so much fun to be not only the physician, being able to care for so many children in the area, but also to be a part of that community.

There's a huge community event that I want to make sure we touch on too. That is coming up on the last week of June. I am the president of the National Down Syndrome Congress, which is a national organization that provides for the needs of people with Down syndrome, really all over the world. There's a convention that moves from city to city to city. It just so happens its coming to Pittsburgh, the last week of June, at the convention center. This is going to be a tremendous family gathering, we actually call it the family reunion. Where all of these families from all over the world, six continents are usually represented at the convention. Including all of our local families being there. We are talking about four thousand or so people, that will be all together at the convention center, learning more about Down syndrome, and experiencing something you

can't really experience anywhere else, which is that community feel, from all over the world, all coming together in one place.

Carolyn Coyne: Well just thinking about community, education, and the need for education. I think, I would hope as a general community we've come a long way in understanding Down syndrome. But what do you see as some of the challenges we still face just to kind of the education, or maybe the lack of education level as a community, with respect to people that have Down syndrome?

Kishore Vellody: Yeah, I think we have an entire generation of people who, did not ever grow up around people with Down syndrome. Unless, you had someone in your family, your school might have had a room and the door was closed, and there was no interaction even during the schooling system. So, naturally, what is not around you is different, and different, especially when you're a child growing up that means there is must be something wrong. That's changing, it's slowly but surely changing now that we have, many governmental pushes towards making sure there's inclusive education for people with Down syndrome. Now an entire generation is growing up with people with Down syndrome in their classroom. Suddenly now, we are finding that, the studies are clear, not only does that benefit the person with Down syndrome educationally and developmentally, it really impacts the people who don't have Down syndrome in the classroom.

Academically as well, there's a theory that probably when you see someone else that needs a little bit of extra help in your class, and you're providing that extra help it lets you learn the material that you may not have learned as well. Because now, you have a role, not only learning it yourself but also helping someone else along as they learn the material too. It's a positive on all ends. We still have a long way to go societally though. We do. The employment opportunities are not where they need to be, for adults with Down syndrome. Even, the education as we get to higher levels of educations, into the high school systems and things like that. We don't have what we need. There is still an active need for the advocacy efforts, that go on locally and nationally for people with Down syndrome. From a society perspective, I think we're moving in the right direction, we just have a little bit of a way to go.

I think the needle is definitely pointing upwards when we see all the changes starting at an early age. I even look at my own children, and see how they interact with other people, whether they have Down syndrome or just need some extra help for some other reasons. Just the compassion that they show, that I don't recall seeing when I was their age from my peers.

Brian Martin: I think that's a great point. I'm seeing, my children as well and their school, there's an entire movement of the "be the kind kid," type of movement. That is really refreshing. It is really good stuff. I got to ask you, what type of topics are they requesting for your podcasts?

Carolyn Coyne: Competing podcasts (laughter) trying to get in on the competition.

Brian Martin: Well, we are definitely not going to steal anything I promise. It's not competition. It's just I'm just sort of interested, so what kind of questions, or what are you taking? How do you solicit your topics for your podcasts?

Kishore Vellody: So, our audience is totally different, for our, for The Down Syndrome Center Of Western Pennsylvania podcast. So, what happened was, I was sitting in these patient rooms, realizing that every family had a similar question. What happens after the baby's cardiac surgery or how do I toilet train my child? Or what is the best way to transition them from pre-school to kindergarten? All these questions kept coming up and I kept answering the same things always. And I thought, wouldn't it be great if there was a way to just send the information, quickly, to the families that we were taking care of.

So, I did a quick iTunes search, I typed in Down syndrome. There were two podcasts, one was no longer updated and the other was a group of dads that got together just to talk about their dad experience. There was nothing on medical care for people with Down syndrome. I said, "Well I got a microphone and a I have a computer." So, I sat down and recorded our first couple of podcasts, and I was just overwhelmed by the number of downloads. The thing that's amazing is, we've had I think fifty-seven or fifty-eight podcasts that have been released over the last two to three years, and they are all geared towards families.

I thought I was going to impact our Pittsburgh community, only 25% percent of my downloads out of the thirty-five thousand downloads we've had, only 25% is from Pittsburgh. 85% is from outside of this region, and to further to blow my mind, of all the podcast, 20% are outside of this country being downloaded in areas where they have no medical care for people with Down syndrome.

Carolyn Coyne: Do you think that some of that might be, because it sounds like the center you created here at Children's, for at least the local community, it's probably a fantastic resource. That's maybe the reason the local people aren't listening because they have that resource through the center, through the community. So maybe you are impacting communities that don't have that kind of resource, that maybe don't have friends, or people that are close to them, that could ask those questions to, which is really amazing I think.

Kishore Vellody: I definitely think that's the case. You also asked, Brian, about where do we get the topics from. Families will email us questions and say "hey could you address this on your podcasts." So we will try to find an expert in the field, and if they are far away, I will just do a telephone podcast, which isn't the greatest audio quality, but it gets us there to the information. Or we will just bring in experts from here at Children's, and we will talk about very common topics that families will ask us about. Sleep studies, sleep apnea, cardiac, all those topics we might run into we address them on the podcasts.

Carolyn Coyne: So it sounds like this podcast is really a great resource. You mentioned before the large convention that's coming to Pittsburgh, so is that convention geared,

you mentioned families, but what about clinicians? What about the people that want to come and learn more?

Kishore Vellody: Yeah, no thanks for that. The large part convention is for families. We love the fact that families are going to be there. On the Friday, which will be June 28, on that Friday we have what is called Down syndrome medical interest group meeting. Which is only for physicians and other providers, PA, nurse practitioners, physical therapists, occupational therapists, any people who work in a medical context with people with Down syndrome. We have an all-day CME event, that's provided at the convention, that Friday, at the convention itself, all you would have to do is google, type in Down syndrome Medical Interest Group. You'll find a link for how to register for that. That is an incredible opportunity to really learn from all the experts from all over the world about Down syndrome from a medical perspective as well.

Carolyn Coyne: Oh wow, that's great.

Brian Martin: Fantastic.

Well thank you very much for joining us.

Kishore Vellody: Thank you for having me. Yes

Carolyn Coyne: This was great.

Brian Martin: You can find other episodes of That's Pediatrics on iTunes, Google Play Music and YouTube. Be sure to subscribe to keep up with new content. Leave a review and tell us what other topics you would like our experts to cover. Thanks for listening.