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In this episode Taren Grom, Editor in Chief of PharmaVOICE Magazine meets with Wendy White, Chief Patient Officer, Vitrisa Therapeutics.

Taren: I'd like to welcome Wendy White, Chief Patient Officer at Vitrisa Therapeutics. She's also Chair of Global Genes and a PharmaVOICE Red Jacket honoree. Hi Wendy.

Wendy: Hi! I'm so glad to be here, thanks Taren.

Taren: It's our pleasure. Wendy you've had an amazing career. You're an entrepreneur, having built a digital agency. You're a two-time Chair of Global non-profit association, the Healthcare Businesswomen's Association and now Global Genes. You're an author, you've sold a company and now you are one of the few chief patient officers in the industry.

I've noticed that the common thread throughout your journey is your passion as an innovative leader working at the intersection of advocacy, technology and business in the rare disease space. For those who don't know your incredible story can you please tell our listeners why you re-centered your start up company Siren Interactive to become one of the breakthrough entities in the rare disease space and why the rare disease space continues to fuel your passion?

Wendy: Yeah Taren, Siren Interactive was my second company. I had already started working there and had several healthcare clients. My third child was born in 2001 and when she was born it was clear that there was something wrong, didn't know what it was, so 10 hours after giving birth I checked myself out and followed my daughter over to the teaching hospital where they had sent her to meet her hematologist/oncologist to try and figure out what was going on.

She spent about a week in the ICU and they did all kinds of tests and they asked us all kinds of questions, couldn't figure out what was wrong. She had half her blood volume, she had a club foot, they couldn't figure it out. They gave her a transfusion and they finally said well you know what, she's better and they sent her home with me. And then I went back every two weeks to meet with doctors.

And after about four months I made a comment to the resident, because at that time of course we're seeing the resident, and I said it's so funny having a daughter after having two sons that she has dimpled knees. And that rang a bell for him, I guess, back to

medical school, because apparently no one's supposed to have dimpled knees and we started doing a whole bunch more tests, one of which was an MRI. So when the pediatric orthopedic surgeon called me and told me the results of the MRI he said well she's missing her patella and we don't really know what that means or what that's related to. She'll probably walk, but she might never climb stairs.

That was a hugely pivotal moment for me. So I'm already running a business. Now I have a child who we don't know what's wrong with and I spent all my time going on the Internet back in the day trying to figure out okay what does this mean? What do I do? The doctors really couldn't give me a diagnosis, they couldn't give me a direction. I finally tracked down a doctor at Johns Hopkins where it looked like there might be a match. I went back to the hospital and talked to the doctor and I said I think she has something called nail-patella syndrome and the doctor went in the back, got online, came back and said yes, yes, I think that's what she has. And it's a relief to get a diagnosis even though that's a connective tissue disorder and there are no therapies for people with connective tissue disorders, but at least I had an idea of what was going forward.

So before I go into sort of what I did about that, let me just say that Casey is now 17 and we're finding out whether she gets into her college of choice, so she's doing all right. She does climb stairs. She walks with a cane; of course she's named her cane Bill Withers for Lean on Me, totally handling it. And the other day...Taren I don't think I've ever told you this, but a couple of days ago I walked into her room and I saw that she had put these little...she's done this her whole life, she put little stickies, Post-It notes on her wall listing things she could do. She had a whole bunch of lists and I thought wow, okay, we could all learn something from that, really focusing on what we can do. So it's changed my life of course. I re-focused my company and it continues to change my life, because she's amazing and how she thinks about things. It's just been a journey.

Taren: Well first of all I am so inspired by you and by Casey and I do agree that's a good way to live one's life about accounting for the things that we can do rather than focusing on the negative. And having known you for a number of years your expertise in the rare disease area has just been so inspiring to so many others. So let's talk a little bit about how your experiences lead you to write the book *Uncommon Challenges; Shared Journeys: Stories of Love, Hope and Community by Rare Disease Caregivers*.

Wendy: What I realized...I had actually put together that story, the Caregiving Story, being part of the HBA, the Healthcare Businesswomen's Association, and I gave that actually a much more personal version of it at an annual conference. A lot of people came up to me afterwards and said yeah, but you're different. Your background is in technology. You're an entrepreneur and I'm thinking I'm not different. I'm not really different. Every caregiver will do whatever they can for their children. What wouldn't you do for your child with your time, talent and treasure?

So I thought well instead of just going forward what I'll do is I'll collect other caregiver's stories. In the rare disease space over 80 percent of the diseases are genetic. That means we're talking about caregivers. They're the ones who are doing everything. So I thought well instead of just telling people that I'm going to go find other stories that are like mine. So I went out and I collected 12 other caregiver stories around these amazing people who are doing things for their children. It's really changing the whole ecosystem.

And I just edited those and put them together as a way to show stories next to each other that really you can't look at each rare disease situation as...they're all unique, but there are common threads of grief and how people handle it and being sort of actually failed by the current healthcare system. And then when you read them back to back you can see that and also what a difference the Internet has made in terms of people being able to collaborate and what they're able to do on their own. So putting that book together was phenomenal and it turns out that it is a great way to learn. Lots and lots of people read it and would comment to me that it really...it helped them really understand what was going on.

Taren: I think it's life changing for a lot of people who have had the opportunity to read it and I do encourage those who haven't had exposure to it to find a copy and really be inspired by what caregivers do, as you said, for their children, what wouldn't they do. You were one of the original Dr. Google moms. We'll call you that and you've been in the rare disease space now for more than 20 years. And as Chair of Global Genes you are lending your talent to this organization. What inspires you the most about this unique ecosystem of patients, caregivers and innovators?

Wendy: The thing that inspires me the most is the opportunity for collaboration. There is thing that sort of is happening. It's happening in our whole life, but you really see it in the rare disease space where people are fractured. They come into their own little tribes. The Internet allows small groups of people to create their own associations, so you could have a very small rare disease community and there could be 50 organizations in the U.S. because the Internet allows everybody to look the same. It's hard to tell who's who.

But what inspires me is when those little organizations and doctors and industry and payers find ways to collaborate and they are, because that is the thing that we all have to do. We have to do it in healthcare. We have to do it to save patients and really that's the piece where I think we're ahead and we're really trying to figure out how to work together for the right outcome.

Taren: I had the pleasure of being at last year's Global Genes conference and I have never been to an event where I was so moved and inspired, so kudos to you and the whole Global Genes team for really bringing the innovative stories that are driving disease awareness, rare disease awareness to the forefront. I also want to talk to you a little bit about something you say all the time; that innovation happens on the fringes.

Can you explain what you mean by that and why it's important for the rest of the healthcare industry?

Wendy: This is something I just believe from a long time ago I think. I grew up in a family of scientists and when you think about science it's always like you find the use case. You find something that's a little bit different. You learn about that and then you can apply it to everything else. And that certain happens in rare disease space where you have generally single mutations and I think on the science side they can figure out how something works. For example if an enzyme doesn't work you can find a solution for that and then apply it to a much broader category.

So I think in science it's clear how you look in the margins and when I say the margins I mean like if you think of a bell curve, the cases that are way at the end, those are the ones that are isolated that can help you figure out what's going on with the whole population. But I also think that we're seeing incredible innovation, not just in science, but also in the way that we work as an ecosystem in the rare disease space because what wouldn't parents do for their kids. And so what we're seeing is we're seeing parents who are not being served by the healthcare system, they start their own companies.

Obviously one of the most famous examples is John Crowley with Amius, but there's Brad Margus with Cerevance. There are a couple of them in the Duchenne space. Ethan Perlstein has B Corp where he's doing research that is being funded by patient groups where he gives them a piece of what happens at the end. He calls them PerlQuest, fantastic. If anybody's interested they can go to perlara.com and see what he's doing. It's just amazing. There are parents who are using whatever their talent is. There's a group of patients in Philadelphia who have a development platform where they're tracking the off-label drugs in the rare disease space.

Seventy percent of the drugs are given off-label and they help track those things and they look at how patients are communicating and what they're taking. They're in talks with the FDA so that kind of data can be considered, probably not for drug approval, at least at this point, but they look at it and companies are looking at it for new indications anyway. Just amazing things that are happening and of course even at the other end of the spectrum when you get to actually drug delivery and the process. The company that I sold Siren Interactive to, Eversana, does at-home rare disease Caregiving and they do a consignment model where it's just all about taking care of the patients in their home and coming up with a whole new strategy for how to do it that's much more efficient.

Taren: Over the last couple of years we've noticed that big pharma, traditional big pharma is becoming more ingrained in the rare disease space. Why do you think that is?

Wendy: Well one, because innovation is happening and they can figure out how to do that and then they can get an orphan drug designation where there are financial incentives and then they can take that same therapy and move it to a bigger indication. That's one.

Two is I think the FDA is also demanding innovation in therapy so who's going to bring the 14th cholesterol drug to market and where there's lots of opportunity in the orphan space to do something truly innovative, so I think there's a perception that you can pick something and be more confident that it will be successful. I can see why big pharma is interested in that. And right now I think it's over 40 percent of the whole pipeline, orphan drugs.

Taren: For orphan indications, absolutely. Global Genes just turned 10 and again, the organization will have a big presence at this year's J. P. Morgan conference in San Francisco. Why is it important for this organization to be among these stakeholders?

Wendy: I think it's critical important. It's very exciting for us. We actually take over the whole Union Square right in front of the big hotel where they hold J. P. Morgan. We call it Rare in the Square and companies put up billboards and we provide meeting space and we have patient groups. Again it's a place for collaboration. But why it's important is because that's a huge part of the pipeline for rare disease companies and we want those small companies to really understand that they have to involve patients. The earlier they involve patients groups who understand what's happening the more successful they're going to be and we want them all to be successful because I think it's less than 10 percent of the 7,000 rare diseases have on-label therapy, so we want that to happen.

So Global Genes, our mission is to start with the patient, right? Start with the patient and go ground up. And we also know that less than 50 percent of these 7,000 diseases have an organized patient group. So you can have a group of scientists who come up with this incredible molecule, but they haven't really thought about what does the patient's situation look like and they get farther down the road and then it's a hard thing to catch up. So by Global Genes having that presence with the companies that are going out and searching for funding, that just seems like exactly the place where we need to sort of bring that up and help make that more efficient.

Taren: Fantastic. You recently took on a new role as Chief Patient Officer at Vitrisa Therapeutics. What is your mandate for the company?

Wendy: Well, of course my mandate for the company is to do the best thing for the patient because I truly believe that if you do the right thing for the patient then you're going to do the right thing for the business. So like a lot of other people in my position there are other people. I sort of have my business resume where I've started a couple of companies. I worked in launching orphan drugs and then servicing patients and working on adherence and now working on the clinical side. And then concurrent with that is where I've done sort of the not-for-profit, working on the NordBord, the Healthcare Business Women's Association and Global Genes and several others. So in my role as Chief Patient Officer at Vitrisa, that's my mandate. Bottom line is figuring out what's best for the patient.

Taren: And there aren't that many who have the role as Chief Patient Officer. Why do you think this is now such an important title within the industry?

Wendy: Well I think it's an important title because people are figuring out exactly what I was talking about before, that if you figure out early on how you can...especially in orphan indications, figure out how you can engage the community, what does the community look like. In my space where the Chief Patient Officer with a pre-clinical biotech, I mean people are surprised that there's a Chief Patient Officer, but this is one of the things I do. I look at our platform and I look at all the different potential therapies that our scientists...and I work with them just to say well here's what it looks like for these patients, here's the standard of care, talking to the KOLs and the patients to figure out where are the greatest needs. Where are the places where we're really going to be supported, which is just another piece in the puzzle of figuring out which targets to go after.

And once we figure that out it's putting color or figuring out how to tell that story in a way that's compelling even to raise money. And then once we've raised money it's figuring out then how to turn all those things into the best possible experience for clinical trial recruitment and getting those partnerships together for once you launch the drug and then taking care of the patients because every patient is worth so much once it's gone through. What's exciting to me is figuring out how that all works throughout the whole continuum and I do think that people are figuring out, again especially in the orphan space, how important that is.

Taren: Vitrisa is not necessarily an orphan drug company. Talk to us a little bit about what the technology and the therapeutic focus is.

Wendy: So Vitrisa is an eye disease company and we have a platform for retina diseases and you're right, we have some orphan indications in some bigger indications. We can create molecules using our platform to address different kinds of diseases. You don't use exactly the same strategy of course for an orphan as for bigger disease states, but I think there are a lot of things that translate and still doing the right thing for the patients obviously still translates. So it's actually really exciting to think about working in eye diseases and also for me personally what we're looking at is preventing or helping or limiting blindness in people, which is life-altering and that's the thing that I live with is it's not death, it's very life-altering. No matter whether it's orphan or not orphan, it's a powerful place to be to think about how you can help people.

Taren: You're doing very meaningful work and it's very inspiring. What has surprised you the most about your new role?

Wendy: Well, the thing that was the most surprising to me because we're pre-clinical is most of the people in the company are scientists and I'm not a scientist. I come from technology and all the scientists would just speak to me like I was a scientist, which I

have to understand exactly what's going on so I can re-tell that story. That's what we're doing. So for a while I thought wow, wait, am I going to be able to really grasp this, but then the thing that was surprising is how important is that storytelling of what the problem is.

It's that it's not just the science. The science is incredible. You can't do anything without it, but it's also important to figure out how you define the problem. It was surprising to me that that wasn't just always there and how helpful it is to have people with different skill sets, even in a small team, even in pre-clinical, having that diversity of thought to be able to go no, let's frame the whole thing. It was surprising, but also inspiring to think about that it's sort of affirming that we need all different kinds of thought to have the best outcome.

Taren: Fantastic. I want to go back a little bit. You alluded earlier to the Healthcare Business Women's Association and that you were a Chair of that organization in 2015 and 2015 was a pretty pivotal year for you. You had sold your company. You took on the role of Chair of HBA. Talk a little bit about that experience and the resilience it took to kind of get through a really big year of change.

Wendy: That was completely insane. Yeah I sold the company...It was insane. At the end of 2014 we closed the deal on December 31st and I think I hadn't slept for like two or three days before it sold. In fact, my brother-in-law was helping me because I was supposed to be on vacation and he's a finance guy and he was helping with all the final numbers. As the final deal came through I'm like oh can I take a shower and he's like yes, yes, please!

And then I started and within two weeks I'm just helping launch a company, a really critical company, a first spin off for a biotech incubator, I'm starting with the HBA. We did our first JPM party in San Francisco with the HBA, I'm starting a new role. All you do in that situation is you just focus on the 10 minutes or an hour that's in front of you and then you go to the next one. At least for the first month or two it was just focusing on what was exactly in front of me and then moving to the next thing and you just can't think about anything else. And then over time it got a little more steady and the great thing for me was that I had, at least for the HBA role, I had really figured out the strategies six months ahead, so it was just execution. I didn't have to think quite so hard about everything to do, I just had to do it.

Taren: And as part of that strategy, I know you've been a stalwart champion of the association's goal to move towards gender parity within the healthcare space. And you talked earlier about the need for diversity of thought and diversity of different ways of looking at a problem. So let's talk about your passion around gender parity.

Wendy: Yeah, so when I started with the HBA I was thinking there's this incredible engine. At that time there were 400 different meetings a year. We're all over Europe and

the U.S. We're going through an operational restructuring, so many type A women in there and men, there's men. We like to say that, a few good men that are supportive of having women in high levels, so my whole strategy was what can we do? Why are we here? It can't be just to have meetings. It has to be about making a meaningful impact, so how do we measure impact? Let's just call it like it is and say look, we are out for gender parity. That's what we want, so we're not going to say it's okay to just have 30 percent or whatever.

We just want gender parity, so let's always remember why we're here, why we're taking volunteer time out of our regular day and trying to make a difference for all of our sisters and daughters and frankly men in the whole industry. What is it, 85 percent of the people who make healthcare decisions are women? Why wouldn't they be represented? Why wouldn't you want them represented at every level? We're going through this enormous time of change. Whenever you go through change in rare disease, in anything you want as much diversity of thought as possible to make the right decisions.

Taren: Couldn't agree with you more. So because gender parity remains such a big issue in our space what leadership advice can you share with women who may have C-Suite ambitions?

Wendy: The way that I think about it or the thing that I guess worked for me is becoming an expert. So you can become an expert in something specific and hopefully something that you feel passionate about; if you're in finance, it might even be government, I mean whatever it is that you feel drawn to. And the great thing about that is that then you can go out and ask for...you could do this anyway, but you can specifically ask for sponsorship. And I think that's critically important, but that way you can go, and I've done this, you go and ask, you can ask for a mentorship

and/or sponsorship from men or women who are senior to you who share your passion. That just works really well, because you're really focused on what the end goal, what the impact is and not any of the other sort of stuff, the politics or whatever and so that's incredible helpful. And then people get to know you. I would also suggest volunteering in the same way, for the things that you're passionate about, that you can try things out and this helps people to get to know you and the people who go to the C-Suite are the people who are known and who can fit into a team with this particular expertise.

Taren: And let's talk a little bit about that sponsorship piece. And that's really about finding someone who is your champion, somebody who's willing to put their skin in the game for you. And that's different than finding a mentor. So when you went to go look for your sponsors how did you approach that activity?

Wendy: So I approached that again by looking at the people who I thought were doing an incredibly good job. In my case, because I ran a company, it wasn't the same, but if you worked in a big company you might find someone outside your company to be your

sponsor that will help promote you and I think looking for someone who shares your passion and who you really admire what they're saying and then you just have to go ask them. It's amazing if you just ask people, people want to help you. Most people will help you, especially if you can show that you share a passion with them, they'll definitely help you because you're going to help them.

Taren: Fantastic. You sit on several boards. Why are board positions important for women?

Wendy: If you just think about you want to make an impact and you're just willing to step in and do stuff somehow that's how it worked for me. We need models of more women chair people because it will help other women to become chairs and having a diversity...again having that diversity of thought at the leadership level I think will just help change the industry and change peoples' perception of what leadership looks like and how leadership should work.

Taren: Fantastic. We talked about being a volunteer for the HBA. How do you believe volunteering for the association has helped your career journey?

Wendy: I had this concurrent volunteer path along with my business path and what's great about that is you get to know people in a volunteer situation that share your goals and want to make an impact and you can try things out. At the HBA for example, by being the Chair of an organization all the sort of governments and the issues with growth and changing our corporate structure has been incredibly helpful as I moved to sort of a younger organization. I'm actually the first Chair for Global Genes and it's been incredibly helpful to take the learning that I had from the HBA and be able to apply those to Global Genes to help us professionalize and grow as an organization.

Taren: And as a volunteer for the HBA you recently took part in the association's inaugural executive women's forum and you were generous enough to share your six-word story with a group of C-Suite women. And these stories are based on that Hemingway-inspired storytelling exercise. Can you share your six word stories with us and a little bit about the back story?

Wendy: Yeah so my six-word story, which hopefully makes sense is disparate voices, fiercely passionate, no stopping and the background for my story is just my deep belief in having disparate voices in a time of change. I'm very passionate about that and I think the right thing to do is you just keep going.

Taren: Perfect. On top of everything else you've got going on, you're also an executive advisor for the Chicago Life Sciences Consortium. Talk to us about what that experience is like and what your role is with that organization.

Wendy: Well, the Chicago Life Science Consortium is a group of executives in Chicago. We live in a really big city. We have 33,000 life science professionals, but they're spread out. We have incredible technology and we have incredible world class institutions, but we don't work enough together to make ourselves a bigger center for innovation, so thinking about how we can do a better job of working together and taking advantage of all of the incredible assets we have here in Chicago is really important.

For a while, because I work in rare disease, I spend a lot of my time...I live in Chicago, but I spend a lot of my time in San Francisco or Boston, both of whom have done of course an incredible job of that. And so it just felt important to do something in my own hometown to think about how can we take all the things we can do and make a center in Chicago that works more efficiently and that can make a difference.

Taren: Have you had any recent successes that you can talk to us about?

Wendy: There are actually lots of things that are going on. It's a slow and steady process of making it all work. I think the life science incubator that was started with a collaboration of a bunch of companies in Chicago has been very successful, though particularly successful in health tech. There are several initiatives that are just being started up closer to the pharma companies of incubators for biopharma companies, so they're still in the nascent stages, but I'm really hopeful that will help make a difference, too.

Taren: Wonderful. As one of the leading women in the industry, how do you gauge success for yourself?

Wendy: Yeah, that's a tricky one. It's really hard. Like everything else I think about impact. I think you kind of have to have a belief that if you just truly believe that you're doing the right thing and you just continually do that, you just have to have faith that what you're doing is going to have an impact and that the more people who sort of tell that same story the better it is and the more successful. So I don't know how to say how I measure success except for the fact that as I tell stories or as I go out and speak that I hear a lot of things sort of reflected back to me. I don't know what that means except that maybe I'm on the right track or hopefully I've had a little bit of influence and that's the only way I know how to measure it.

Taren: I would say you've had a great deal of influence, so modesty aside there. Finally what is the one piece of advice you would give to your younger self?

Wendy: I think the biggest thing I would tell my younger self is that everything takes longer than you think, especially change and that you just have to keep going, you have to be persistent. You have to believe in what you're doing and not ever give up, right? And that this is a big ecosystem that we're looking to change and that needs to change to make it better for patients, that everything takes longer than you think.

Taren: That's great advice, because I do think you're correct, that in changing a large ecosystem you have to be persistent, but you have to be patient. Congratulations to all of your success and we look forward to seeing what you're going to be doing in the future.

Wendy: Thank you, Taren.

Taren: And thanks for being part of our podcast live series.

Wendy: Thank you.

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