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In this episode, Taren Grom, Editor-In-Chief of PharmaVOICE magazine meets with Gail Moore, Director, Global Patient Advocacy at Horizon Pharma.

Taren: Gail, welcome to the PharmaVOICE WoW Podcast program. Thanks for joining for us.

Gail: Thanks for having me today, Taren. I'm pleased to be here and hello to all your listeners out there.

Taren: We got to know a little bit about each other during the PharmaVOICE 100 last year, so I'm a little bit familiar with your story, but I'd love to hear you tell your story to our listeners. So, as a patient with a rare disease and a parent to children living with rare diseases, your role as director of Global Patient Advocacy at Horizon Pharma is not nearly just a job; it's a passion and a mission. Tell us about your journey as a caregiver and as a patient.

Gail: Well, all of this started for me about 22 years ago with the birth of my first child, Kinsey. Kinsey was a normal baby. Everything – perfect pregnancy, perfect delivery, five hours start to finish, can't ask for better than that on a first child, and everything was going great until she's about 4 weeks of age and she came down with an infection and we were quickly hospitalized because of her only being 4 weeks old and they found her to have salmonella in her bloodstream.

And of course that started – everybody going how does a 4-week-old baby get an infection like that and they looked at the supplements that we were giving and all of that and they never really found out why and just really thought well maybe you put her in a carrier and then you touched chicken and you touched her and basically saying that it was me as a mom, I didn't do something quite right and that really began like the worst four years of our lives because Kinsey continued to get very strange infections and such and ultimately after much time and also a lot of doctor visits, a lot of near death experiences for her she was diagnosed with a primary immune deficiency and after that, they looked into the rest of our family.

My mother who had been sick my entire life was also diagnosed and myself and then my son who is 18 months younger than Kinsey. It was like I lived in a doctor's office. Kinsey would get something and then my son Garrett would get it and they'd both end up in the hospital.

So, it was really very trying time and prior to having children, I did work in a professional capacity for a hospital, and I knew what was happening to me wasn't normal. I spent time and investigated and we got her the best treatment. Ultimately, I got very engaged with the patient community that was supporting our diagnosis of primary immune deficiencies – Immune Deficiency Foundation – and through that became an advocate and ultimately that led me to my career.

I began being very active in giving back to the community and getting to know the folks that were out there working to help make my life and my children's life better and that opened a lot of doors and ultimately one day I was asked to be the patient's voice inside the industry side of the business. And I've been doing that now for the last – oh, goodness, 12+ years.

Taren: How are your children today?

Gail: My children are great. They both have graduated college. Once they got on treatment, they led very normal lives. I often say to myself where would we be if we didn't have the treatments that were out there for them and my life would be considerably different, but they're doing great. They're both independent, productive citizens who are out in the workforce and living their best life. That's what every parent can hope for. And like I said myself, I'm also a patient now so I still walk that line as a patient as well as an advocate for patients.

Taren: Well, I'm glad to hear about your children. What I'm not happy to hear about is how you were given such a negative feedback, the initial diagnosis that it was somehow your fault. If you could go back and talk to those doctors, what would you say to them? I mean this is not good behavior obviously.

Gail: Well, I look back on the time and I will qualify that with saying the research 20-some years ago in immunology was really just beginning and they really didn't really understand a lot of it. They've come so far, and I've gotten to witness that, which has really been fascinating. They didn't know any better, and it wasn't so much that they pointed to me; they just didn't know why my children were sick. They kept saying 'gosh, I'm glad we have antibiotics because I'm not sure what we'd do for you.'

In the realm of immune deficiencies in particular at that time, everyone knew of like the boy in the bubble which is severe combined immune deficiencies, but they didn't know about all of the other diagnoses that now they've identified since then when I started. They only knew of 80 different diagnoses that fell under that umbrella of primary immune deficiency and now there's over 350 that have been discovered and now are listed diagnoses for patients that have these reoccurring infections.

So, I give them kind of a break on that because you don't know what you don't know and they didn't intend to make me feel bad, but as a mom when you think that what could I have done different, you naturally go there and it was like "Well, that's the only thing we can think of because we really don't understand why your child would have a bacterial infection with salmonella if it wasn't from some sort of" – I brushed that, but I also used supplements for her and it wasn't from any formula. They couldn't find, they tested everything, so they just assumed that that's the next best way that it could have happened. They didn't have an answer. I think now they would look at that completely differently.

Taren: Let's hope so. And as somebody who's actively involved in the rare disease space, that is still an issue where it's so many of these rare diseases are just undiagnosed because the information isn't available. Is education the answer for doctors who just can't figure it out? How do we change that dynamic for parents who get that devastating news that there's something wrong with their child and they just can't figure out what it is?

Gail: I would always lean maybe towards the parents and just say learn everything you can about the condition or what's going on. If they don't have an answer yet, keep coming back, keep looking, become your own best healthcare advocate. There is a need for more education and thankfully science is growing so rapidly it's very hard for everyone to keep up with all of the new discoveries and the things we're learning, so as a parent or as a patient with a rare disease I think it's also on us to be sure that we're as educated as we can be so that we can go back and share that knowledge and at least raise the topic with our physicians and our healthcare team for things that you may have heard about. It may not be applicable to your case, but at least if you're having the dialogue with the physician or with the healthcare team, you're doing everything you can for your child or yourself.

Taren: Wonderful. Please tell us about how you're leading Horizon's Global Patient Advocacy efforts.

Gail: I work with the national and global patient organizations for the medications and the communities we serve, so I am literally the liaison between Horizon and the patient organization. I represent their voice internally. I educate both internal and external stakeholders about these diseases and then I look for opportunities to collaborate to benefit the community in general. So, I think I have the best job in the world because I really get to give back and really represent patient's voices within our company and also in the community itself.

Taren: Looking in the rare disease space, it's filled with stories of inspiration. It's also filled with stories of sadness, but let's talk about some of those more inspirational moments. What are some of your most memorable successes and some of your most memorable moments that you've had with the organizations you've been involved with?

Gail: Oh gosh, after my daughter was diagnosed and our life settled down, we began to have the life that I expected to have once I had children. I wanted to give back and at the time, there wasn't a lot of opportunities for patients with primary immune deficiencies to get together 20 years ago. It changed a lot now thankfully, but I wanted to really bring these families together. So, I started a retreat program with the organization and did everything from raise the funds to pick the menu and got doctors to volunteer their time to come out and bring these families together in a location that was out of the beaten path. I mean literally that's why we called it a retreat. They were camp retreats like facilities and we bring them together.

The patients themselves would either meet other patients if they were adult patients or if they were children they met other children and that was for many of them the very first time they got to be with someone else who was dealing with the same things they were dealing with and those moments are probably the most memorable. Seeing a child come together with another child and yet they know well that they have to have infusions or they have to have treatments once a month or whatever their treatment regimen is, this other human being understands what I'm going through and they created – it was like an instant bond and you could see it in their eyes.

It was what fueled me to continue to do more and more and more. It was seeing that in their eyes and that they develop these friendships and what's really neat now is that a lot of those kids I now seen and grown up because I still am active in that community, they still have those friendships and they still have those contacts and support that they found from 15, 20 years ago meeting at a retreat in a location out in the middle of – in the boondocks as they used to say – and since yet a lot of them have become advocates of their own in the disease state. So it really is memorable to me to see that I've helped folks pass on that torch, get more of a passion as they've grown into their own adulthood and become more engaged in their disease in their condition.

Taren: That's wonderful. Those are great memories and that's a very telling story. Thank you so much for sharing. We talked a little bit before about the need for more education, but what other areas of the healthcare system do you think need to be improved for rare disease patients?

Gail: When I think about this question, the thing that pops up in my head first and foremost is communication. Many of these patients with rare disease that they have numerous physicians and have a large healthcare team and oftentimes they don't communicate together as well as they could and these practitioners have a limited insight into what's really going on with the entire patient picture and I think that can lead to some care assumptions.

Maybe the GP thinks that the infectious disease is taking care of that. The infectious disease doctor thinks well that really falls in the GP's area, so there's that really having a team that's cohesive and working together and communicating is an area I think that

needs improvement. There's likelihood that there are some gaps and then also there's probably some duplications of effort even maybe testing that the patient may not know that they're getting an additional blood test that they had at their other doctors a month beforehand. So, I think communication is key.

And then the second area I believe needs an improvement is in the area of access to treatment and primarily what I mean by that is the pre-certification process that many patients have to go through to receive their medications. It's very cumbersome and it's very involved and it's involved not only for the patient but also for the physician or the healthcare team and oftentimes it delays treatment considerably. So, shortening that time from the time that they're prescribed the treatment I think is really important and getting the patient for treatments they need as quickly as possible without having so many steps and so much paperwork and so many things you have to do to make that happen.

Taren: What role do you see is the future for patient advocate organizations? There are companies like yours who are really doing tremendous work in the drug development space, but you work a lot with those patient advocacy groups. What is their role going to look like in the future?

Gail: I think it's going to be important for patient organizations in general to become more involved in that drug development process as early as possible. There's so much value that they can bring both to the companies that are developing drugs and also to the treatment that ultimately may be developed. Their early voice in the process is critical and it really would expedite that development also make sure those treatments are meaningful for their community. So, I feel strongly that patient organizations need to really start looking at that and exploring how they can get more engaged and more involved earlier on as medications are being developed.

Taren: Is there something that's happening within the space that precludes that from happening more often? Is it just that lack of communication that you talked about?

Gail: I don't think there's anything that's precluding it. I think it's a new area and for many patient organizations I think they have to also determine whether they have the bandwidth to get engaged that way and the resources to make that happen, but I think it's important for them to take a look at that as they strategically plan for their future as an organization and how they could impact that and even how it could possibly those partnerships could be helpful as they grow their organization. So, I don't think there's anything that's precluding it, just that it's new and it's run short of character. It's something they're not familiar with.

Taren: Got you. Well, that's good because that means there's hope for the future that things will just continue to improve.

Gail: I think so and I think companies are hearing that message loud and clear and starting to proactively reach out to these groups and get engaged with them as well.

Taren: Fantastic. We often hear that collaboration is really one of the keys for success for patients in the rare disease space, what is your feeling about that?

Gail: I'm a great believer in collaboration in general in life. I think it's absolutely important in the rare disease space. As the name indicates, these conditions are rare so working together leads to more innovative ideas. It could minimize obstacles or at least identify obstacles so they can be worked with and it provides a bigger, louder voice in the footprint in general. So, as we come together we can do so much more. There's a patient organization and I know I'm not going to quote this correctly, but basically as one we get things done, but as a group many things get done and I think that's key to this. So, I apologize for messing up the quote, but I think you understand what I'm trying to say.

Taren: Definitely get the sentiment, yes. It's the rising tide lifts all boats and the more hands on deck the better, I get it.

Gail: Exactly.

Taren: Awesome. I know that you are very much involved in a lot of volunteer efforts. Talk to us about your work with some of those organizations and what you get out of volunteering.

Gail: Oh goodness. Well, currently I sit on several community boards and a couple in the rare disease area and others just in my own personal home community. Hope I'm providing good guidance and bringing some of my key learning that I've acquired over the last 20 years of life as both a patient and caregiver and as a parent and as now someone who works in the industry side. Whenever possible, I travel quite a bit for work now, but when I'm home I deliver meals to the homebound and I support a lot of animal rescue activities and then I continue and I will always continue to work in our own disease state because it's the right thing to do.

I need to contribute my time to wherever I can, so when you ask what do I get out of it, well there's all the good feelings you get from doing things like that, but more so also there's the aspect of I learned a lot. It keeps me fresh, but more than that it's that watching and knowing that I'm making a difference and even if it's a small difference it's still a difference that hopefully someone else's life is better because of the efforts whether it's in my rare disease or if it's providing education or insight into another community board on things that I've seen that have helped others. I know that I'm making a small difference and I want that to be my legacy that in some way along the way I've made someone's life a little bit easier.

Taren: That's amazing. Thank you. I'd like to switch tacks a little bit and let's talk about some of the lessons you've learned along the way throughout your career that might help other women navigate their own career journeys.

Gail: The first one that comes to mind to me is really that I used to be afraid to be myself and I think it's important to be yourself. I'm often viewed as very quiet and at times I can be misunderstood as not engaged or not interested, whereas I'm very observant. So, I'm taking in all the time what's going on in the room and thinking about how I can benefit the situation or what I might be able to do or bring to the table. I used to be afraid that it could be – that that was going to be misunderstood and now I know that if I'm true to what my passion is and I'm true to what I'm doing and I demonstrate that in what I do, just being myself is not going to keep me from earning the respect or the rewards that I hope to have.

Those will come if I'm just myself and give it time. So, I think that's one of the key things that I've learned is it's okay to be you and you may not be cookie cutter to every other industry professional that you work with or other executive you work with, we're all different for a reason. We all bring our own special talents and that will with time and with passion and if you work with that passion and demonstrate that you'll earn the respect you're looking for within your organization.

Taren: That's excellent advice. What is the one wow moment of your career?

Gail: Okay, a wow moment. My wow moment is well I'm doing what I love doing. I'm able to make a difference and I'm able to make a difference in an area that a lot of people don't have that opportunity to do and so just that I have taken what started out as being a volunteer career – well, not even solid career, it was volunteer because I was at home with small children and over time that's developed into doing something that I love and it's become a career. That's kind of wow to me because I look back and I'm like how did this all happen.

I'm kind of wowed by the fact that it all happened and it has and I'm so fortunate and I'm very thankful and grateful for what I get to do everyday because I know that I'm making a difference. That's pretty wow for me.

Taren: Gail, it's pretty wow for all of us. Thank you so much and thanks for being so open about your story.

Gail: It's important to be open about it. There's things that I've experienced and that maybe one little thing will help somebody out, so I gave you the very short version. I could go into a whole half an hour version of our journey to being diagnosed and such, but it's important to be able to share that information and hopefully it will help somebody else. So, I'm very open to sharing.

Taren: Well, thanks for that and hopefully if our listeners have questions they can reach out to you. So, we encourage them to do so.

Gail: Absolutely.

Taren: You talked a little bit about being yourself and that's one of the lessons you've learned. If you were able to go back and give a piece of advice to your younger self, would it be to be yourself all along or is there another piece of advice you would give to your younger self?

Gail: I think I would add to be brave and take chances. For many years I didn't push my comfort, my boundaries so to speak, but as I matured I've taken some chances. Some ended up very good for me and some not so good, but from each one every time I stepped out of my comfort zone I've learned something and I've learned so much about myself – whether it's something professional or whether it's more something about myself it's really provided a lot of growth for me in so many ways both professionally and personally.

Taren: Wonderful. And I want to thank you so much again for being part of our WoW Podcast series.

Gail: Oh, thank you so much for having me. I'm very honored to be a part of it and I appreciate what you're doing. This is great.

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