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In this episode, Taren Grom, editor-in-chief of PharmaVOICE magazine meets with Kimberly Haugstad, CEO, Global Genes.

Taren: Kimberly, welcome to the PharmaVOICE WoW podcast program.

Kimberly: Well, thank you for having me in. Pleasure to be here.

Taren: I saw you recently at the Annual Global Genes Conference out in San Diego. I thought you did a fabulous job, and I want to say congratulations on your recent appointment as CEO of Global Genes.

Kimberly: Well, thank you so much. It's been a whirlwind, but I am absolutely loving it.

Taren: So let's talk about your whirlwind. You've been in the job just about two months. What has been your biggest aha moment so far?

Kimberly: Ah, the aha moment. You know, I've had the true honor of spending some time with the RARE rock stars. Many of the RARE rock stars as scientists, like Ryan Taft or David Fajgenbaum, but also really those many, many, many patients and families that we had an opportunity to meet at the summit who have found Global Genes to be that community where they can belong to this big collective of RARE. It's really beautiful and inspiring.

But I think maybe beyond that even, an aha moment for me in coming and putting all of this together and visiting and spending time at the summit was that partner realization. This is truly a time for RARE in the world right now. And really that opportunity to partner with everyone – patients, researchers, industry, payers, the governments around the world – RARE is the time. And we can really role model as an organization to bring this true partnership together and direct forward. So huge aha moment about how important those partnerships can be.

Taren: That's excellent. And those partnerships, as you said, really are starting to bear some fruit, if you will. There was a siloed system for quite some time, but I think you might agree or not agree that there has been a huge movement towards dissolving those silos and moving the disparate stakeholders closer together.

Kimberly: Yeah, absolutely. Absolutely. And I think it's non-optional and patients are really at the core of that. I think that the patient community is really instrumental in this movement to

drive us together and drive forward. It's critical and it's an amazing time to be a part of this world.

Taren: So talk to me about how your role as CEO and president of the Hemophilia Federation of America prepared you to lead Global Genes.

Kimberly: Sure. Well, I suppose the obvious, having built a specific disease area of focus, nonprofit, certainly gives me a lot of insight into the challenges, the opportunities that our partner foundations have. Running and expanding a nonprofit certainly that experience comes with this. I grew the organization that I worked with – the 11 years we were there, we grew year over year every single year. So we had a wonderful run.

The time I spent in hemophilia, I had so many opportunities to try and flex new things and always be striving forward. And frankly the staff – I have to take just a second and acknowledge the amazing team that I worked with at the organization at HFA. They made it easy to do what we did.

But I think maybe the true benefit from joining HFA and being a part of hemophilia, when I joined, I was following my heart. I had a very young son at the time with hemophilia, and my passion was really all about kids with bleeding disorders and what was in their future. It was very personal. I didn't really worry if I had questions or something that I might have to ask or want to ask that others might not like, because I needed to know and I wanted to know for our kids.

And so, putting that elephant in the room out on the table and really pushing for true discussion and problem solving so we could address whatever was on the table and truly move forward was just an absolute – and I remember... oh gosh, it was probably almost 10 years ago, really being taken aback at my time there. A very, very senior executive at a biotech company – I won't give his name, but lovely guy – called to bend my ear about something before he proceeded down some path or other. It wasn't him calling me that really struck me; I've had a lot of conversations with him. But in the conversations he made it so clear that he knew I was going to poke holes in his idea and he was calling me ahead of time so he could get them all on the table and address them proactively. And I realized how important it was to be fearless and courageous to truly ask those tough questions. I think going forward with Global Genes, certainly I can bring that to the table, and it was just it was that piece that I learned about just taking that risk and being fearless and willing to put it out there no matter what that change might be.

I loved what was I doing at HFA, but honestly, it's an amazing time in hemophilia and there are so many options and gene therapies even on the horizon. And so within the next year, I really actually even expect gene therapy to be approved in hemophilia. So my original reason for coming into hemophilia he's 17, and he's doing pretty well. I feel like this is the time going

forward where I can really take that gift I was given in the last decade and learn – and I learned and I saw so much and hopefully I can bring that to the broader rare community today.

Taren: That’s wonderful. So let’s talk about what’s in the future for Global Genes. What does your 100-day plan look like?

Kimberly: Whew, we’re well into that now, aren’t we? Yes.

Taren: Day... what are we... day what?

Kimberly: Gosh, it’s close to two months. So it’s amazing and it’s been crazy. So I’ve really been doing a lot of listening and learning. This is the time to really get in and the honeymoon is on right now. The honeymoon will soon be over. There are just so many opportunities. Awareness and education at Global Genes is so incredibly essential and critical to what we need to do to support our families and foundation. And I’m spending a lot of time looking at our partnerships and how we can work and role model that to true collaborative work to get there.

But I think the big key here for Global Genes is really scaling to reach more. There are 400 million people in the world potentially with a rare disease, and 30 million in the United States alone. So there’s just a tremendous opportunity to provide support. So really taking a hard look at how we can really engage in this work called scale and really ramp up.

Taren: What are some of the things you’re looking specifically to do in terms of scaling up?

Kimberly: We’re taking a real look at the work that we’ve done to date and where there is opportunity to really bring things together under common umbrellas or themes. We are taking a really detailed look at a program we have called the Concierge service – RARE Concierge.

RARE Concierge today is an opportunity to reach out to us through our system and speak with someone, potentially get connected with a genetic counselor and really help on a one-on-one basis. We’re taking a lot of look and thoughts and time to spend looking at how we might be able to scale that, build an infrastructure, likely a technical infrastructure in addition to the people infrastructure to be able to make that accessible and available to folks really worldwide at a future point. So that’s a big piece.

We’re also doing a lot of work looking at how we as an organization do partner. We have recently established our research alliance in addition to the corporate alliance and patient alliance that we have, creating that full triangle and putting some effort into how we truly engage across these different spectrums. Again, it all comes back to that partnering and how we can work together and build that infrastructure so we are a united force within RARE to get things done.

Taren: Excellent. You know, obviously because it is rare disease, there are very few patients sometimes in some of those disease states. But what are some of the commonalities that you see running through the rare disease community and how can Global Genes connect and knit those commonalities together to better help patients?

Kimberly: That's an awesome question. So I think the biggest part here is that we're all humans, and no matter what your diagnosis is, you're still getting a diagnosis and learning how to absorb that diagnosis and understand what it's being and its implication might be. Wondering and fearing what's out there, what's next, what's possible for me, all folks with rare walk down that path. And then it's the journey, right?

So the reality is, we're all coming together as humans with rare disease, and it is a tremendous opportunity and honor and privilege for us at Global Genes to be able to help along that path, to address along that journey and along your life span as a newly diagnosed family with a baby in their arms through taking that individual – maybe that baby is going to school now and how do you transition. Maybe that baby is now a teenager and you're transitioning. And maybe in college again as a young adult transitioning, and how are you as a young adult with a rare disease coping and dealing and managing with your situation and forward.

So I think the reality is, again, we're all human and so our responsibility is to help along that whole continuum.

Taren: So what is it that makes Global Genes unique in your perspective?

Kimberly: I would say we have that California edgy, willing to be a little different approach down pat. It's an amazing part of what we do. We're not operating inside the beltway of Washington, DC. We are just really flexible, really open, and it is incredibly beautiful being a little bit different and a little edgy to match that with being incredibly approachable and accessible. And what we do amazingly well is we do welcome people, I guess, into the fold, so to speak. We work really, really hard to do that, and we believe, I think inherently, no one with a rare disease should be alone. So we want to be here and be approachable.

We also really look at wanting to say yes. So it isn't about, 'No, that's not what we do,' or 'we've never done that before,' but as an organization culturally, we're always looking at this opportunity to look at the forward path. It might not always be a yes right now, but I think we're always looking ahead to what's coming next.

In fact, we did the NEXT report. Actually, the irony of our NEXT report which is a report that it's the first of its kind, comprehensive report looking at over 50 different players in the rare disease field. And this NEXT report that we published just this fall really, really takes a look at patients as drivers in this whole process of rare disease. But NEXT in itself, the irony as our organization looks forward is we were doing the NEXT report initially because we were looking back at the first 10 years of Global Genes. But inherently, because of who we are, we couldn't just do a look

back; we had to look at what's coming forward and ended up calling the publication NEXT. So I think it's just inherent and natural in what we do to look to the future.

Taren: So let's talk about the future. What do you think is driving so much interest today in the rare disease community? There are a lot more players than there ever have been before.

Kimberly: Yeah, isn't it wonderful. It's fantastic.

Taren: Yes, it's exciting.

Kimberly: So I think it's emerging of multiple things. Certainly the science is progressing and continues to move forward. We have also an emergence of new technology with gene sequencing and other tools. We are able to look at so much deeper into ourselves from an identification and diagnosis standpoint, it's accessible. And I think there's just tremendous opportunity as a planet as we're a shrinking community in a planet in the sense that we're all connected more and more, there's more opportunity for us to connect as rare disease, even those individual diseases that have 2, 4, 6, 10 or 20 people on the planet, we're now able to find those individuals and really come collectively together, apply the science, apply the technology, and it's, I guess, a bit of a secret sauce in how we're able to really drive forward today.

You're right, there's a ton of interest and we welcome it. It's an amazing opportunity to provide really great opportunities for our families.

Taren: Somebody at the conference said, and I'm paraphrasing here that with the cost of genome sequencing coming down so significantly, that it could potentially be possible to do real-time drug development for rare disease patients. Do you see this as a possibility?

Kimberly: I wouldn't shut anything down as a possibility. Absolutely not. Yeah, we're seeing where sequencing used to take months and months can now be done in a few days. The Rady's Hospital in California actually is doing sequencing at the pediatric level, and it's turning things around incredibly quickly and truly saving lives because of it. So it's a very, very powerful time.

Taren: Kimberly, what is it about the nonprofit sector that excites you? You're now working in two large organizations that really take a different approach to partnerships, etc. So what is it about the nonprofit sector that drew you in?

Kimberly: It's such an interesting question, my immediate reaction is that other than staying compliant to the rules of a 501(c)(3), I don't really spend a lot of time thinking about being a part of a nonprofit. My background originally was corporate and worked in the IT sector. I worked in the investment sector. I had a private consulting practice for a while, and I was a corporate girl all the way.

But frankly, it's just a designation, the nonprofit status. 501(c)(3), a friend always says to me, is just an IRS designation for a visit. And I really agree with that concept. We're running a business here. Our business has a mission and that mission is not to make money. Our mission is truly to serve our patients and families. We're looking to change the world here. We want to improve the lives of everyone impacted by a rare disease. And I think that's a pretty powerful mission to, and in purpose, have as an organization.

So yeah, really don't look at the nonprofit as a nonprofit. It's just a new avenue, a different avenue for business.

Taren: You just talked about your varied career perspective. How has that influenced your leadership style?

Kimberly: Well, I guess I would say I'm an eclectic mix. I'm competitive, certainly. I suppose you'd say I'm a driver. I wouldn't ask anymore from my team however than I'd be willing to do myself. But I always expect stretch. So the good to great concept, always striving for great. I guess I believe very much, and not a guess – I truly do believe in the concepts of servant leadership. So from my style perspective, servant leadership certainly is one thing I believe truly and I love the opportunity to be a part of building a team, supporting fellow employees as they continue to grow. It's just such an honor to watch a team blossom. It's a privilege.

But also on that same front, I'm really committed to driving progress in bringing a team together and working towards a future horizon and vision. So building a team that supports each other during a transformation is just incredibly exciting, and I think that's truly where we're at here at Global Genes today.

So eclectic I suppose is the way I'd really answer your question.

Taren: Excellent. As a CEO, you're in a rarified group. There just aren't that many women CEOs, nonprofit or for profit, let's be honest. So you are really a role model for so many other women. How do you gauge success for yourself? And then, how do you celebrate those successes?

Kimberly: Thank you for the question. I am seeing in the world that I have been in the last 10 years, I have seen a real progress and change with female leaders playing a bigger and bigger part. Maybe not always the CEO yet, but definitely ensuring that senior level of management and I'm really proud of that. It maybe speaks to the fact that I'm not a new kid on the block anymore that when I've seen some individuals who have grown in their career, while I've been in this industry, I feel really good about that and personally celebrate that.

From a gauging success for myself, I don't know that I think... I probably am a terrible role model at this. I just love the team success. So really, really celebrating and appreciating and watching those relationships grow gives me just deep satisfaction in truly seeing that happen.

Yeah, celebrating, for me is the good to great path. So I guess small celebrations and really recognizing a team success is so much important to me than acknowledging maybe my own.

Taren: Very good. If you had to look back, wind up that way back machine, is there a piece of advice you would give to your younger self, something you know now that you wish you knew then?

Kimberly: So piece of advice that I think that I would give myself if I could do it all over again is to be playful but truly take even more risks and push the envelope. Remind myself or just really offer that you only get this time once and make it meaningful.

Taren: Wonderful. Can you identify for me one wow moment of your career? Something that maybe impacted you so significantly that it stays with you or that changed the trajectory of your career.

Kimberly: I would love to share and there are examples floating around in my head right now that I just have to pull one out, and I think – I could talk about getting our materials into the Smithsonian. It was the Hemophilia Federation or some other big achievements. But there's one that was really incredible, and it was a tiny moment in time, and it was an interaction with an individual named Rodney.

Rodney is a person living with hemophilia, and I was at a meeting, a national meeting here in the US and had attended – again, I was presenting earlier in the day and attended a session just that was at the meeting. The session that was presenting was talking about just really taking a moment. It was a self-care kind of session, it was kind of fun to be a part, and it was speaking to writing down on a card who has really impacted you and what that impact was and whatnot. It was very sweet. And I didn't think a lot about it; I think I had another session I was presenting later in the day and moved forward.

Later that evening, a gentleman – this gentleman Rodney, came up to me, and he pulled me aside and it was a very sort of weird conversation in that we hadn't been – we hadn't connected in a while. I had known him for a while, just randomly had had some conversations and he's a beautiful guy. Just a wonderful man, living with a lot of life challenges. In his 50s, had severe hemophilia and all of the comorbidities that go with that, so a lot of disability issues. He hadn't gone to college or further educationally because of financial issues and living the life he was in. However, he was a brilliant man, and I had had conversations with him over the years just about big dreams, green energy and all kinds of crazy things. So lovely guy.

And he walks up to me. I was talking with someone else and he waited patiently and respectfully for that conversation to happen and then he stepped in and he handed me this little piece of paper and he said, 'I just wanted to give you this.' And then he turned and walked away. And I thought, 'Well, that was different, but okay. He's a sweet man. What is this?' I

opened up the note, it was a note – it said something along the lines of ‘Thank you so much. You’ve listened to me, and you’ve cared about who I am.’ And that was it. It was beautiful.

Taren: Beautiful.

Kimberly: I know. It was so beautiful. It drew me in. I literally had to walk away. I think I ran to the ladies’ room for a minute because I needed a moment just to think about this. This is an individual, a beautiful, wonderful, brilliant individual who gave me the gift of those beautiful words. So incredibly powerful.

But I hadn’t done anything. He was still living in poverty. He still had bleeds. Still all of the comorbidity issues that go with that, living in constant pain, struggling. But he felt valued and he felt heard. And I’ve never, ever forgotten that every single person matters, and taking the time and the moments that you spend, while you might not be able to actually do something actionable, there is something you’re doing, and you’re giving someone just that little bit of being heard and a little bit of voice. And I really hope – in Global Genes, it’s that – and really models this already. And part of my desire and interest in coming onboard is to continue to further that with the whole rare disease community.

Taren: That’s an amazing story. I can’t even imagine how moved you were at the time. What a wonderful thing to pay forward and remembering that gentleman’s words.

Thank you so much for joining us for our WoW podcast program, and I want to wish you tremendous success as you go forward in leading Global Genes into its next decade.

Kimberly: Thank you so much. It’s been my pleasure being a part of the podcast, and I can’t wait for what’s coming forward. Thank you.

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