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In this episode, Taren Grom, Editor of PharmaVOICE meets with Stephanie Brown, Senior VP and Business Unit Head, Rare Disease – North America, Ipsen.

Taren: Stephanie, welcome to the WoW podcast program.

Stephanie: Thanks so much, Taren. It's great to be here with you today.

Taren: I'm so looking forward to speaking with you. Stephanie, I understand you are a scientist at heart, yet you are also a marketer. Tell me how these two worlds colliding has led you to your current position?

Stephanie: Well, I think first of all, that's a good way to describe it. And I'm really happy to share with you a little bit about how I got started in this industry. I do lead the commercial rare diseases business now at Ipsen for North America, and if I may I'll just take a moment to introduce the listeners to Ipsen because I think there will be some unfamiliar with us.

We're a global company headquartered in France with over 90 years of history and we specialize in oncology, neuroscience and rare diseases and we have a team of more than 5700 employees worldwide who are passionate and committed to making a difference in these therapeutic areas. And for me, I discovered the world of biology and chemistry way back in high school and I went on to study these sciences in university as well.

I actually practiced as a chartered chemist following graduation in the quality control labs at J&J in Toronto in Canada (so I'm Canadian). I love science and I love that work, but I also started to learn about the business side of the pharma industry during that time. So I put up my hand and I asked to be sent out as a sales rep and they actually took a chance on me and sent me out to Western Canada where I sold hospital diagnostics and lab equipment and really I never looked back. I loved serving my customer. I love the autonomy of managing my own territory. I loved the feeling that I was making a difference in the healthcare system, and that put me on a course to build a career on the commercial side of biopharma industry, and I've been so fortunate to work for amazing organizations and to gain the experiences that I have gained over time.

And I came to Ipsen about two and a half years ago now and I've been building and growing the rare disease business for them since then. So it's been wonderful to be here.

Taren: Wow, that is quite a lot. Thank you so much for giving us the background on Ipsen and the important work that your organization is doing. Given that you have this affinity for rare disease, tell me why this is a particular passion for you.

Stephanie: I've been working in the biopharma space now for about 30 years and as I mentioned just to have wonderful opportunities building my career across several organizations, I spent the first part of my career in Canada and in global roles for Merck, and I discovered the rare disease space in one of my roles as business unit head in Canada. I was setting up a new commercial unit to bring together all of the specialty medicines marketed by Merck in addition to launching the first oncology therapeutics for them. And one of those oncology products was for the treatment of a very rare skin cancer, and that cancer was characterized by kind of red, scaly patches or plaques, sometimes even tumors on the skin along with a very intense itching. And that experience was what immersed me into the world of rare diseases with all of the challenges for patients and caregivers that go along with that world. From difficulties in diagnosis, to the isolation that patients feel – imagine this is a visible cancer – to accessing the right treatments and therapies and I was just essentially hooked since then. And that particular product that Merck had at the time if it was used in appropriate patients was highly impactful. And that's really what still motivates me today to have the opportunity to impact a patient's life in some meaningful way, is just so satisfying.

Taren: What a lovely way to look at the industry, and I love the fact that you got hooked on it. Now, two years you said that you've been working at Ipsen, and in that time you've really been critical in building out the rare disease business unit. Can you share how you approach that responsibility?

Stephanie: Yeah, so maybe just a little background. Under the rare disease pillar at Ipsen, I'm directly responsible for marketing and sales and operations for two medicines for rare growth disorders that we have on the market today, in addition to preparing for the launch of a potential treatment for an ultra rare bone disorder. I'm also responsible for development and oversight of the patient support services that we provide to support patients along their journey. And although we've got this rich history in rare diseases with products for growth disorders, we are deepening our commitment with some recent investments in the acquisition of assets for a disease called fibrodysplasia ossificans progressiva (or FOP), which is an ultra rare bone disorder.

So building a business unit in rare disease, to me, has to start with a deep understanding of the patient and their particular disease or condition. Every disease is different and presents the patient and their families with unique challenges. So it's important to really seek to understand the care pathway. And what we talk about here is the 24 hours of daily life in a patient living with a rare disease. It's not just about building a sales and marketing team, but really to think about the resources that the patient community will need a support and to determine the roles and organizational structures and so on from there.

I think we also have to consider several critical success factors for working in the rare disease space, including things like ensuring early engagement with payers to educate them, to setting up processes so that communication with our stakeholders is clear and coordinated. Because there are so few patients and so few healthcare practitioners in these areas. Partnerships with patient advocacy organizations is critical of course, having medical experts to engage with our

key thought leaders and many more and so on. And once this is all mapped out, the roles then can be defined.

An example in my business unit is that we developed unique roles for education of healthcare providers and patients and their families and caregivers. And in my view, that approach is the approach that puts the patient in focus and the resources then in turn surround the patient. So that's some of the approach that we've taken here at Ipsen.

Taren: Stephanie, just to feed on that, I know that you have a very strong point of view on how companies should focus that are in the rare disease should focus on patient-centricity. Tell me about this. You talked about some patient support services; why is this more critical in the rare disease space than it is maybe in a different therapeutic category?

Stephanie: Yeah, this is really an area of passion for me, and I also have a highly passionate team. We talk about our patient-focused approach all the time to keep it top of mind, and we're proud of some of the initiatives and support programs that we've put in place to support these individuals living with rare diseases. And really, it's about supporting them with services and solutions across the continuum of care from diagnosis all the way through to treatment. We try to do that with a sense of urgency.

I think our listeners today know that the rare disease space is a unique space and that we really get to know patients directly and it's personal. We get to know them by name sometimes. At Ipsen we try to deeply understand what it's like to walk in their shoes. And we also enable them to share their stories with us and others.

So we spend a lot of time mapping the patient care journey. We say as well as I mentioned we're trying to understand those 24 hours in their life as much as we ever can really understand it without having the condition ourselves. We believe that it's true that mutual learning that we can advance our work and inspire our people as well.

I think another key factor is communication and collaboration and that's an effective way to address the challenges of people living with rare diseases. That's why we listen to patients; we listen to their families, to the caregivers, the healthcare providers, really that 360-degree ecosystem around the patient. And we try to integrate all of those insights into our efforts from the early stages of research and development all the way through the commercialization of the medicine.

I also believe that we will develop the best support for these communities by co-creating resources and solutions and not just asking for feedback following development of a solution when we finished it, but truly partnering along the continuum seeking feedback along the way.

And you mentioned patient support services and this is exactly what we're doing here at Ipsen, we're building this capability internally and we are partnering on a regular basis with the advocacy organizations and making sure that we're co-creating the resources that we're going

to be offering so that they are truly meaningful to that particular community. And that's what being patient-centric is all about to me.

Taren: Awesome. And you talked a little bit about that and it includes the families and the caregivers, and does that bucket also include the advocacy groups that some of these patients belong to because of their rare disease?

Stephanie: Oh, absolutely. The patient advocacy organizations are just amazing and there's one in particular that we're working with in partnership closely now called the International FOP Association supporting that ultra rare bone disorder that I mentioned. We communicate with them on a monthly basis. We share what we're doing. They share what their goals are and their aspirations, and we try to partner together on support for those patients. And it's just been amazing how the patient advocacy organizations have pivoted during the pandemic to online support and services for patients and families. So there really wasn't an interruption in their support for these communities, which is so important.

Taren: Wonderful. And Stephanie, in the rare disease space it's often said that the diagnosis isn't made – it takes a long time for diagnosis because it is so rare. What kind of things are you looking at in your world to help narrow that gap between the patient understanding they have a disease and then being diagnosed with the disease? Is there anything that can be done?

Stephanie: Oh yes, absolutely. I think when you look at the rare disease space, there are still so many challenges that we need to tackle together. All stakeholders coming together to tackle these challenges. In my team we're focused on three key areas right now, and even before we tackle diagnosis we need to find the patients. And obviously this is one of the most important challenges that we all face. These patients are geographically dispersed and there aren't many of them. So it's tough for patients and families, for physicians, for other providers and for companies like ours to literally find each other and connect.

And so we've been working hard to leverage digital technologies to enable us to build virtual groups and communities and connect patients to ease that, really that sometimes crippling sense of aloneness that they feel. We have an approach where we meet patients where they are. So if they're on social media, if they're on Facebook, if they're on web portals and we ask them in to opt in to communicate with us and that can lead to important educational and learning opportunities for both us and the company and for patients. And I think right now we're only just tapping the surface of how we're reaching out digitally, but it's certainly important ongoing work for us.

And the second area is all around what you just mentioned about timely and appropriate diagnosis. To me, this is just such a huge educational effort that is required here still. I think about one of our patient ambassadors as she told her story; as a young woman, she saw 36 doctors over eight years before she was diagnosed. She even had three unsuccessful surgeries before she was able to get appropriate treatment for her disease.

I just reviewed a video of three individuals living with FOP, which is that ultra rare bone disorder. One of those patients actually had an amputation of her arm at a young age due to a misdiagnosis of bone cancer. It was not from cancer. It was FOP.

And these stories, we just we cannot hear them easily. We can't forget them ever and the act really of them sharing their stories with us as an expression of trust that they put in us so that we can really learn from them. These are the patients who will help us move research and treatment options forward. So it needs to start with those trusting relationships. And we also need trusting relationships with advocacy groups. We talked about this as well and they definitely play a pivotal role in education of the broader healthcare professional community and they also obviously help patients and families significantly in educating them about their particular condition or disease.

And I think finally, the third area that we try to focus on a lot is access is to therapy and this is just critical. It doesn't matter how many medicines are approved if patients can't access them appropriately. At Ipsen we've invested in patient support programs. So as I mentioned, we're building these patient support programs with the objective to educate the variety of stakeholders involved in the management of these complex conditions, and really to help patients to navigate through the important and complex world of insurance in the United States and that they receive their drugs in a timely manner.

So much more work to be done, many challenges and but we have a lot of passionate people that are engaged to do this.

Taren: Firstly, those stories are heartbreaking, so thank you for sharing them.

Stephanie: Yes.

Taren: And I think it is a testament to those of you who work in that rare disease space because it really is different than any other therapeutic category. And you really have to have such a passion and such a desire to do for these patients because I can imagine that you would be tearful almost everyday when you hear one of these stories. And so it really takes a resolution to really move forward. So kudos to you and thank you for what you do on behalf of patients.

We talk about patient support services and solutions and companies talk about being patient-centric, but this is really at the crux of it where Ipsen is really looking to be a patient-centric organization based on patient needs. Do you bring patients in early or at all to talk through some of those initiatives that you're working on?

Stephanie: Oh yes, we do absolutely and I totally agree. I mean gone are the days when we're saying that patients may be involved or patients may have a voice. They have a big voice now and from our regulators really involving them in advisory groups when drugs are being approved all the way through to advocating for medicines and advocating for treatments. So yes, this is something that I don't think we're 100% there yet, but we're definitely on the path forward. We

bring patients into our team meetings. We bring patients into our offices to learn from them. We bring our advocacy groups in.

At Ipsen, we've had an executive exchange program where we've bringing in our patient advocacy partners to talk with us about their goals and to understand what they're trying to achieve so that we can partner appropriately indefinitely.

I'm remembering bringing in a young woman and her mother to our business meeting last year in 2020 and she told her story. She was suffering with FOP. She had just transitioned into a wheelchair, not able to completely walk on her own. Her story was a story of resilience, of perseverance, of positivity and we just learned so much from patients and their families and need to continue to do that in order to create the solutions that are right for them.

I think one thing that my team and I started to talk about after that – and you talked about it a little bit, we're passionate about what we do in the rare disease world, but we try to have empathy and not sympathy. So we have empathy which drives us to do the best that we can do and to be the best that we can be at our jobs so that we are delivering for these patient communities, but certainly even reviewing that video that I mentioned that I just reviewed this week, it really – you can't ever forget these stories.

Taren: Often through our conversation you have talked about your teams, and obviously you have significant experience in building high performing teams. I'd like to know from you what are some of your keys to success and what are the qualities that you look for when you are putting together a high performing team?

Stephanie: Well, you've hit on a passion of mine because working with my teams and helping them to grow and develop is a part of my job that I truly love and I invest a lot of time in. But I think it starts with ensuring the right people in the right jobs. There is just an abundance of talent out there who are passionate about making a difference and who are passionate about helping others, and I've been fortunate to find many of those individuals over the years and to work with them in the years of my career. But once you have the right person with great values around the patient especially in the rare disease space, then it's really about ensuring that I as the leader have defined the role clearly and that there are very clear expectations for that role as well.

I believe that everyone wants not only to contribute to work that's satisfying, but also to be able to feel proud of their accomplishments. In addition, I think I also focus a lot around the profile of the team or the collective makeup when I'm hiring and that's what I've been doing over the past couple of years here at Ipsen as I've been building the business unit. And I've always believed strongly in ensuring individuals on teams bring those complementary skills, the views, experiences that all together make the team stronger. So I ensure I've got a diversity of background, a diversity of experiences of the ways of thinking, and I think when you do that you can create a team that has a much stronger impact. That's one of the core roles of a leader in my view.

You have to have trust on the team. The team has to rely on one another. They pitch in. They assume positive intent. They collaborate and they can have challenging discussions that result in a better endpoint and they have to be able to have fun and enjoy the work that they're doing and enjoy being with one another. Spending time on developing that great culture is important as well, and then I think the work doesn't stop there. I also emphasize continued development of my people and supporting their career goals and dreams and where they want to go. I think there's nothing more satisfying than to see someone achieve a promotion or to secure that role that they've been after. So it's really an area of the job that I'm highly passionate about.

Taren: That's wonderful. I can hear the passion in your voice around it and for the people who you have working with you and for you. You've achieved quite a bit of success, what advice can you share with other women who may want to reach that executive level? What steps should they take to give them the best advantage of achieving their professional goals?

Stephanie: This is a great question. I think there are many things that can be done, but to me it comes to two key things that will really help that person to excel. When I started my career changing from the lab bench to a job in marketing and sales, I was most often the only woman in a business role. Even to this day, I have to say I'm usually the only female leading the P&L of a business at the company where I'm working. So I think it's critical that women have mentors and sponsors and that they can really help guide and advice and act to help you advance in your career. And I've always had key people in my life who I've been able to rely upon to discuss everything from next steps, opportunities, work issues, problem solving and finding someone who will move beyond mentorship to sponsorship, someone who will actually help you to get in front of opportunities is important and that certainly always made a point to mentor, advise and guide others in the organization. I always learn a lot myself and it is certainly satisfying to see others develop and succeed as well. So that's the first area.

And then the second area, I would also encourage women to take the leap of faith when opportunities present themselves. Just a couple of weeks ago, I was having a career discussion with a prior direct report of mine, and she was hesitating to apply for a role that represented a promotion for her. And the reason she gave me was that she didn't feel she had 100% of the qualifications that were in the job posting, but I knew that she had the capability to learn and I knew she could do it. So I encouraged her to apply.

So sometimes giving others the push they need at those certain times may be required. And my advice really is believe in yourself. Don't wait to have all of the experience you need before applying for a job or role, just go for it, and you will have the capabilities and you will succeed.

Taren: Stephanie, you touched on something that has become really a common theme that so many times women wait so they can check off every box before they put themselves forward. I think your advice is spot on to not wait until you have to have it all before you go for it all. So thank you for reinforcing that, that's awesome. I note that you are a member of Women in Bio and the WBO. Why are these organizations important to you, and talk to me a little bit more about how you're widening the path for other women.

Stephanie: Yeah. I joined these two organizations just in the last couple of years. First and foremost, I think they're wonderful ways to meet new people and widen our networks, and I've always focused on maintaining my network. That's some advice that I would give for women as well, to really keep those connections going and keep building. At times in my career where I've had challenges, I've just had such positive experiences with others who were just very willing to help me. And so that's really an important part of joining these organizations where you can meet new people and build those connections.

Also, they're just a wealth of opportunities to learn and to take courses and continue to develop your leadership skills. I've definitely taken advantage of the courses that have been offered in these organizations and it's really important to me that obviously that I continue to learn and that's one way that I can do that. So I definitely plan to continue my memberships in these types of organizations, and it's just such a positive experience with everyone trying to lift everyone up kind of collectively to move forward. So more to come in the future.

Taren: That's great. I think you're right, that network is so important and it's not network of a card exchange, but it's building that group of individuals who become like your posse that you can rely on, that you can turn to as maybe is a personal board of directors in some cases. So that's wonderful advice as well. You're also a member of the board of directors from Bio. Tell me about this role and what are some of the meta issues that Bio is looking at?

Stephanie: Yes. I'm so excited about this opportunity because I'm at that point in my career where I have gained in-depth of experience across many segments of the bio pharma industry in terms of commercializing medicines, and also I've had this professional goal to give back by partnering to advance common issues and to just help other companies to bring new innovative technologies to market.

So Bio as you know it's our biotech industry association and they advocate to establish that positive policy environment within which we can bring innovative medicines to market.

With Bio, I'm on the board of directors and I represent Ipsen's views on key issues, and one of the key issues is ensuring that we have a regulatory environment that supports the research and development of rare diseases. Of course, this is near and dear to my heart and as we know there are about 7,000 rare diseases known today, but only about 5% have FDA approved specific treatments. But now if you look where we are, we're in this new era of just exciting research and development, so many positive advances in medical science. If we just look at how treatment of cancer has changed and how knowledge about rare diseases has been elevated over the years. So I'm really glad to be part of this forum to gather different points of views, to exchange ideas, develop guiding principles to support the continued investments that we need to make in this area.

I think equally important for Bio is to ensure that communication and transparency is there on these issues for the patient, for the payer, for regulators, to continue to increase understanding of how science has advanced and of course this is part of the mission of Bio as well.

On a personal note, Bio leadership gave me a very warm welcome. I'm just new, but I'm looking forward to participating, and it's certainly nice to see they're focused on diversity, equity and inclusion.

Taren: Wonderful. And thank you for the work that you're doing there as well on behalf of rare disease patients. Finally, tell me about an accomplishment or a wow moment that shaped your career or changed the trajectory of your career.

Stephanie: Yes. This is a great question and as I was reflecting back over my career, I have been so fortunate and had those great opportunities working at world class organizations. I've met wonderful people who have certainly helped me and I've had many more into my career that have shaped who I am as a leader today, but I think for me it comes down to the fact that the most important influence really has been the patient and their families who have inspired me over the years and still motivate me to keep working in this area. I really truly believe that we need to keep that patient at the heart of everything that we do in this industry.

It's critical, constantly learning from patients and how they manage through obstacles just inspires me everyday. I've shared some of the stories with you. I mean even continuing to be touched by the stories of the treatments and misdiagnosis, the long time to diagnoses, it's just all so inspiring to us when we see how patients and their families respond to this adversity, just perseverance, positive attitudes and the ability to adapt to changes in their conditions. It's just absolutely staggering to see this. And I think over my career I've just had a lot of opportunity to ask lots of questions to learn from patients and their families and those stories certainly motivate me to continue to do my job, but not only to continue to do my job, but to do it to the best of my ability and that's why I stay in this industry and I always say that if we can make even some small contribution from an industry perspective then that's extremely rewarding.

Taren: Well, I feel very inspired by you, Stephanie, and I want to thank you again, all the work you're doing on behalf of rare disease patients and for the industry and I want to thank you for spending some time with us today for our WoW podcast program and I look forward to staying in touch and seeing what's next for you.

Stephanie: Thank you so much Taren.

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