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In this episode, Taren Grom, editor-in-chief of PharmaVOICE magazine meets with Lynn O' Connor Vos, President and CEO, Muscular Dystrophy Association.

**Taren:** Welcome to the PharmaVOICE WoW podcast program. I have been following your career for many years and I know that it's been multifaceted, bridging from pediatric nursing, to technology, to leading a global healthcare communications advertising agency, and now, you are President and CEO of the Muscular Dystrophy Association. But, overlying all of your current success is a passion for patient care and advocacy. What stokes this fire for you?

**Lynn:** First of all, thank you for including me in this fabulous podcast. I really appreciate it. That's a great question. I have, I think, a somewhat untraditional background for this current position but as I have just hit my year and a half mark in the position, I realize I'm using most of the tools in my toolbox.

I've had a passion for nonprofit and a passion for giving back to patients since I started my career as an adolescent nurse at Children's Hospital in Philadelphia. I've always been involved with nonprofits for years as a founding board member of the Multiple Myeloma Research Foundation, and a founding board member of the JED Foundation, and so my interest in giving back has been there for years.

Also, what struck me about most of the nonprofits I've been engaged with is they were both very disruptive. Certainly, Kathy Giusti is recognized as pioneering a new way to bring drugs to market for cancer where there is absolutely nothing and nothing available. She herself was highly motivated since she was diagnosed at a very young age.

And then, on the JED Foundation, there was really no – nobody was talking about suicide 14 or 15 years ago. In fact, that was our biggest challenge, is how do you get people to donate and to back our organization when nobody wanted to talk about the stigma of suicide.

Fast forward to this particular juncture, I was ready to try something new. I've been in the healthcare communications business for virtually my entire career, along with pharmaceutical work that I did originally. I thought, why not try to apply all those skills that I learned all those years to a nonprofit, and the Muscular Dystrophy Association was looking for a leader. It's really a very exciting time to join there because for the first time ever, there are drugs that are coming to market to in some cases, cure these diseases, and we have the opportunity to do a complete turnaround and really recognize the opportunity to move to a high-science organization.

**Taren:** Excellent. As you know, you just celebrated your one-year anniversary at the helm of MDA. What surprised you the most during the first year?

**Lynn:** Yeah, good question. There are so many things. You jump into a new position like this and you're peeling the onion every week. I think the biggest surprise was, this is a very big consumer brand really, recognized by the fact that Jerry Lewis put it on the map in the 50s. Although these are a collection of rare diseases, 43 to be exact, and we're an umbrella organization, it had more brand recognition out there than probably expected.

Looking at the organization when I joined a year and a half ago, we were very focused on community, very focused on camp because quite frankly, there wasn't that much more that we could offer as an organization. Very few people knew that one of our biggest supported areas, not only research, but we also have care centers at 150 care centers in the country. My big surprise and what we really went to work on right away, was how do we double down on our mission? How do we make sure everyone in the community know that we're the leading experts and the leading supporter of research, and we're also the most significant player in the care center network and care support for all patients with neuromuscular disease? Just to put a fine point on that, we delivered 90,000 patients as a tier. Right from the get-go, it was quite obvious to me and my senior team that we need to really communicate clearly the value of MDA when it comes to research and care.

**Taren:** Wow. I had no idea. Ninety thousand.

**Lynn:** Yeah. You really need to talk about your impact and the question is of impact, is if you went away, would you be missed? I would say so with 90,000 visits.

**Taren:** I would say so too. You obviously hit the ground running and you had a vision for the organization. Talk to us about some of the important changes and advances that you're overseeing at MDA in addition to elevating the brand.

**Lynn:** One of the main issues and main opportunities that we looked at right from the get-go was, okay, this is an umbrella organization, so we needed to really define what the value proposition of an umbrella organization. We're also the leading organization in neuromuscular disease and we partner and hope to partner even more with all the single-disease organizations in this space. We need to make sure that everyone out there recognizes that we have done a significant amount of research and support in the top 10 diseases. Those would include ALS, that would include Duchenne muscular dystrophy, Becker muscular dystrophy, and SMA.

First of all, it's really looking at, okay, what does the largest organization in the field really need to deliver to the community so that we're paving the way for better research, better care, and ideally someday, more cares? That was really the focus in the first year. That's really the focus overall. We will continue to invest in the care centers. We'll continue to invest in research, and I think the other area that we invested in this year was communications.

As you probably know, back from when you covered me so nicely when I was at Grey Health, I used to say communications is the cure. I would say that it's the cure here as well. We needed to really document the need in the category, so we did a very large neuromuscular report that clearly identified that this is a group of 250,000 people suffer from these diseases and it costs United States about \$46,000,000,000. That really shows you the attention that's needed for the category.

The second thing we did is we surveyed all of our about 3500 patients to find out what they truly needed so that the MDA could be super focused on the areas of need. We don't have unlimited resources, so we need to make sure the resources are applied exactly where they're needed today to help the patient population to find clinical trials and get cares.

**Taren:** You also were involved in collaborating with a technology group this year. Talk to us about how IQVIA has brought value to the organization.

**Lynn:** Sure. Going back to this concept of our most treasured asset being the care center network, it was very clear that we needed to organize a care center network with technology. I threw a cage of what I learned quite frankly from Kathy Giusti when she first started the Multiple Myeloma Research Foundation. It was pretty clear that we weren't going to find cures in multiple myeloma unless we centralized a tissue bank and had more researchers working collaboratively. So similarly, in our space, this is really a very brand new space and there's only three drugs on the market, you can imagine there will be many more if we get ourselves organized around better research protocols, as well as better measurement.

We looked at a relationship with IQVIA to develop a data hub. We call it MOVR which stands for Neuromuscular Research Program, and we are organizing the top 50 care centers starting with the top 25 to work together to enter all of their patient data. Patients will also enter their own data and will do genetic testing, and we'll have all in one location a tremendous amount of data that will give us insights in designing clinical trials better, also helps us find patients faster for clinical trials, and ultimately, help better case sharing among doctors so that we can raise the outcomes in the category.

We started out with a paper-based registry which was about 3000 patients. We then signed on with IQVIA and we intend to look at this as the combination of the care centers and MOVR will be inextricably linked and will develop more of a tech-enabled care system for neuromuscular disease.

**Taren:** That's wonderful, and that's really at the macro level. I also know that we've had some conversations around some of the stuff that happens on the micro level with the MDA community. Can you share some of those great stories that you found in your journey over the past year? Was there not a couple of brothers who did something with their coffee shop?

**Lynn:** Right. We haven't really talked that much about the fundraising side which is equally challenging and very exciting when you're running a nonprofit. What's happened this year is I've just met many, many incredible sponsors, starting with the firefighters. Very few people

know that they do a national program for us and have for the last close to 30 years where they are filling the boot on every street corner for muscular dystrophy. Again, going back to Jerry Lewis, he really made it clear that this is the charity that everyone should rally around.

Lately, or I guess in the last decade if you want to call that lately, there've been some very novel approaches to fundraising and specifically a lot of DIY efforts are really exciting. I'll focus in on one that is just amazing.

There's an incredible coffee shop, coffee company on the West Coast called Dutch Bros. It was started by two brothers and it's a drive-thru coffee, really, ahead of its time. A lot of young people work there, very cool. They lost one of their founders, Dane, to ALS. Ten years ago, they approached the Muscular Dystrophy Association and said, hey, we'd like to give our profits. One day a year, one Friday in May to MDA. It started 10 years ago when they were a lot smaller. Now, they're a lot larger and last year, they raised about \$1,400,000 on one day with a program called "Drink One for Dane". It's just an amazing example of how people can galvanize around a very important cause, multichannel kind of promotion, and really incredible stories at a local level in Oregon and surrounding states, and to deliver those kinds of numbers is spectacular.

**Taren:** All right. I think that's a great example as you said, rallying around a cause at the grassroots level. I would imagine running an organization, overseeing an organization as large as MDA with as many different factions as it has, despite it being an umbrella group would really stretch your leadership skills in a way maybe that they hadn't been before. Can you talk about how you are overseeing this huge organization right now and what leadership skills you're bringing to bear to make sure that everybody is following the vision?

**Lynn:** Sure. I came in as kind of a disrupter. You know me from the past. I really believe in looking at a situation in a horizontal way and saying, okay, now how can we take all the good things, the assets of this organization and the great people that we have and organizing them in a way that they believe that we can be the innovator in the field. When you take a – we refer to this as a 68-year-old startup. We've been around for a really long time. Obviously, many, many systems are in place that work extremely well, and some others had to be changed to really meet today's times. I would say that the leadership skills that I had in the past, some of the ones that work extremely well that I understand how to analyze the situation and get people to back me or back the concept that we need to change. One of the things that we've done in again, a very short period of time, is many people recognize what we talked about earlier, that the most important thing we needed to do is really double down on the mission, make sure that the communication around that was impeccable so we could be able to go out there and fundraise against the mission.

The second area we needed to look at is, what are the highest priorities for the organization? Obviously, growth, very similarly with a full profit organization, we have to maintain our revenue growth. Again, it goes back to relevancy of our mission and relevancy of the communication that we're delivering out there. We also have to look at how do we recognize these incredible sponsors that have been there for years and how do we help them see not just what is in it for MDA, but what's in it for them. That's a win-win that you have to strike on the fundraising side.

The challenge in a nonprofit is it's not just that you can double down on your mission and develop really unique, incredible programs in the research area, in the care area. We also send close to 4000 children a year to camp, but we have to pay for all these. So, from the leadership and experience I've had in the past, this is probably again, really pulling on every experience that ever I've had. We have to run a physically responsible organization, we have to be great at marketing, we have to get out there and present great new thinking and ideas, and we have to wrap our stories in an emotional way that will really communicate and resonate with individuals so that they will give us money. It's very different than selling a product. I've learned that over the last year.

You wrap that all together and I would say it's one of the more challenging leadership goggles that you can take on. You have to transform an organization that needs to change. You have to address the market needs which is pharma, and biotech, and high science, and technology. You have to drive new revenue streams because the current revenue base is strong but not strong enough for the amount of things that we need to fund over the next couple of years. You have to take a brand that had been known for Jerry Lewis and known out there in the field for these wonderful stories and children that need help. We vitalize that brand so it resonates to millennials and young people so that they will do the kind of fundraising that we look for today which is DIY. Young adults climbing Mt. Kilimanjaro for their Dad, Facebook birthday parties, there's just a tremendous number of new ways that people fundraise. One of the things our team looks at that I'm very excited about, I don't know if you remember the telethon, I don't remember it that much, but many people just watched it every single weekend of their lives.

Karen was one of the first people out there that spoke to young people and said, hey, get off the couch and fundraise. I've heard so many funny stories, remarkable stories of individuals who went out and heard what Jerry said, rode in for that Carnival Kit and put on a carnival at home. One of the things that we're thinking about right now is, how do we own that again? How do we make fundraising fun and interesting for the youngest people out there? That's a trend that's happening anyway and something that we can really get in and do more of.

One last point on this is, Jerry Lewis and the MDA really invented some of these fundraising techniques and it's time for us to reinvent again. When you run an agency, if you aren't reinventing yourself every year you are left behind, and I would say it's very similar here in the nonprofit space. The ones that are really going to do exceptionally well on the fundraising side and marketing side have to have an eye on the trends and really make sure that our message and our packaging is relevant to today's world.

**Taren:** Wow. You have a lot going on. It sounds like it's an incredible journey and I want to applaud you for going back to some of the roots that Jerry Lewis established because I think they are important. I do remember the Jerry Lewis telethons. It's a little nostalgic, but it's also, you're bringing a fresh approach to it. That's fantastic.

**Lynn:** We would love someday to reboot the telethon in 2019 and beyond. We just have to figure out what that looks like, but it could be a very exciting idea.

**Taren:** Sure. You obviously are a disrupter and you are certainly a trailblazer, and you were the first back in the day to really think about how technology can change the life sciences. You were one of the cocreators of one of the very first apps out there, Text4Baby. Talk to us what that means to the patient population.

**Lynn:** Text4Baby started out really as a concept where Mira and I got together and thought about how could we change, and by the way its even more critical now, this terrible stat in the United States that maternal death is higher than some of the underprivileged countries out there. We took a simple idea and that was finding the guidelines and putting together a texting program that related to women's pregnancies. Week 1 versus week 30, they have different messages based on where your pregnancy was. With Johnson & Johnson coming in as a founding sponsor, what then happened is it really became one of the biggest public private partnerships because it was such a good idea and it was easy for people to adopt. You had many, many payors and community organizations and hospitals and doctors jumping onboard and making this available to their stakeholders and constituents.

What I learned from that is you can say, the movement. We had a similar movement in eye care at Grey Health. We had something called 'Think About Your Eyes' which was another – again, when you have a core idea and a core need out there, with 'Think About Your Eyes', most people get their car checked more than they get their eyes checked, and we really were driving people with the multichannel program to get out...to remind people that actually your eyes are very important and you need to check them on a regular basis.

So, I look at those two examples in my life and say to myself in the Muscular Dystrophy Association, how can we create another galvanizing program like this? We're working hard to figure that out. There's nothing more exciting than identifying a need, adding technology, and then galvanizing a community to use the technology to improve care. In both cases, we had great outcomes data.

I will say in the muscular dystrophy space, and we're starting to see some really exciting companies jump in to want to work with us like Microsoft, there's not been enough technology invested in this space, believe it or not. These are individuals who are on wheelchairs, who need all kinds of adaptive technology. That's a focus of our team. When you attend our clinical research conference in April in Orlando, you're going to see we're going to have a whole technology suite. I'm inviting companies to join us to bring technology to these individuals to help them improve the quality of their life.

**Taren:** It's exciting. I look forward to it.

**Lynn:** For the first time ever, it's more like the Neuromuscular Convention and it's really going to be about two or three times the size of the conference we had last year.

**Taren:** Excellent. You started off talking about your involvement and your actual affinity for working for nonprofits, aside from the Multiple Myeloma Association and you mentioned JED

Foundation and we'll talk about that in a minute. The other one is the Healthcare Businesswomen's Association, and you've been an active volunteer with that organization for a number of years. In fact, you were named their Woman of the Year in 2005. Can you talk about how the HBA has enriched you and your career?

**Lynn:** Sure. I can't believe it's 2005, it seems like yesterday. The HBA is a fantastic organization. Again, I go back to Gross Townsend Frank Hoffman which was the original agency that Grey was built on, they sold their business to Grey. I remember their original meeting when Jane became Woman of the Year and that was a long time ago. It was a room with about maybe 100 people in it and you contrast that to how big the organization and how exciting that Woman of the Year event is, it's just really a credit to all the founding people of the HBA and there were just some maverick women out there which is really exciting.

For me, it has been an incredibly enriching experience to be part of the community. I look at so many of the Women of the Year who've become personal friends, certainly, mentors. Kathy Giusti being one, Carolyn Buck Luce another, I could go on and mention so many of them. We spend time together. You have to pinch yourself in some respects. There's only a handful of women who really worked throughout their entire career including raising children, were able to stay at the top of their game. We all want to share this message, share how we got there more broadly with every young woman that's out there trying to figure out how to navigate their career. So, I spend a lot of time mentoring and will continue to be a mentor. I just think the HBA and other women's organizations that I'm associated with who believe in giving back and paying forward. That's what we're doing. It's just good to know that you're in such incredible company.

**Taren:** That's wonderful. You just touched on a really important point too, is that part of giving back and that there are so few women sitting in C-Suite positions. The gender parity still remains such an issue for us in the industry. What leadership advice or any kind of advice can you share with women who have C-Suite ambitions?

**Lynn:** First and foremost, you have to have an enormous degree of confidence in yourself. You have to really be an expert at something. If you've got a passion, or you've got a real expertise in an area, go for it. Go deep, really have that experience and advantage to being a content expert of some kind. So, you combine confidence, content expertise, and the ability and willingness to give your time and your effort to people to help lead. One of the things that I think distinguishes some of the most successful people I've seen, I call it lateral thinking or horizontal thinking. These are individuals who can look at a situation, quickly assess, bring in multiple data points and come up with ideas, and then package that in a way where you can drive some consensus among a team to get them to move forward. The leadership, it doesn't come naturally to everybody but it's certainly something that you can develop. It comes because you have the confidence and the ability to really talk about something you really know about and you can really lead people to the kind of changes they need to be successful.

**Taren:** That ties so well into what your personal brand is. I know you've said it before publicly that you can't park up front unless you drive me there. Explore that a little bit with us and why that is such an important part of your ethos.

**Lynn:** It's a funny thing. It's so funny. My Mom was so much more dominant in my family than my Dad but that was something I just recalled him saying. He died very young, but I recalled him saying that. It's nothing ventured, nothing gained. It's this idea that of course we can do it, of course we can try that, of course there'll be a spot up front. That means to me that he was always trying things.

Some people are much more of a 'measure twice cut once'. I'm more of a person that likes to cut first, and it worked pretty well for me. I think that action is better than inaction. I think decision making needs to happen quickly. I certainly wouldn't be reckless about it. If you see an opportunity out there or you're looking for an opportunity, more times than not, a couple of times a goal or whatever you want to say for any of these borrowed interest comments or statements, you probably will be more successful. I look for people who believe in that, who believe in the fact that we've got to move. We've got to find some new territory where we can be successful, and we've got to do that really well.

Again, I go back to this idea that, in any business, nonprofit or for profit, you have to constantly be reinventing yourself and making sure, pressure testing your strategy. Is it current? Do people buy it? Are the trends behind you? That's what makes a really good leader. I credit my Dad with this concept, and I say it all the time. Let's try it, why not? Let's see if there's a ticket to that show. Nothing ventured, nothing gained. More times than not, if you go forward you find it.

**Taren:** Excellent. It's great advice. A couple of times during our conversation, we've referenced the JED Foundation which is a nonprofit that exists to protect emotional health and prevent suicide for our nation's teens and young adults. You sit on the board of the JED Foundation. Why is this cause important to you?

**Lynn:** I come from a family where there are some mental health issues. I've always been very sensitive to the need to really side with people who are addicts and help them rather than stigmatize them. When Phil Satow lost his son Jed to suicide, he was one of my very good friends and he was also the head of marketing at Forest and he was a great mentor to me. I just started working with Phil and helping him to say what can we do, Jed just died, what can we do? We started right off the bat, creating a website, ULifeline, that actually was put on college campuses to help individuals to assess whether they were depressed, or whether their roommates were depressed, and help them actually find information that didn't exist on campuses about mental health.

I've been in the ground level. It's been just the most amazing opportunity to see how you can again, identify a need and develop a foundation that's capped to address it. John MacPhee is currently running the JED Foundation. He's an amazing guy. I also worked with him at Forest and he's taken the foundation to the next level.

What resonates for me is these kids needs help. We've developed programs that actually get colleges to take a check and look at how they're addressing mental health and put safety nets in place. It's called the JED Campus Program. We're really seeing tremendous progress. This is 14 years ago when you said, hey, I'm on the board of the JED Foundation and we are on the planet to prevent suicide, and the people used to back out of the room, no one wanted to talk about suicide. I'm really happy to say that today given all the situations in the world in mental health and addiction and what JED has done along with several other organizations, many people can now relate. They know people in their family. They know friends who have been hit with this and they want to help us.

**Taren:** Thanks to you all for all the great work you're doing. For those listening who want more information, they can find it on the JED Foundation website which is [jedfoundation.org](http://jedfoundation.org). It's really important work that you all are doing, so thank you.

**Lynn:** Thank you.

**Taren:** On to a more light subject – how do you gauge success for yourself and how you celebrate those successes?

**Lynn:** You just constantly look for the next success. I can't say that I ponder my own success. I look at others who are so much more successful than I am, and I keep raising the bar on myself. I would say that I would celebrate my success at MDA when I feel that the job is done. We're not done yet. We've been working on the brand, we have launched MOVR, we're looking for much more support with MOVR, we need to hit many milestones with MOVR so that we know that the job is done, or at least we have enough data on patients that we can help to raise the bar in terms of outcomes.

On the fundraising side, we just have a huge list to make our brand as relevant as possible and go back to where we were. The crazy thing about MDA and going way back in the 50s I guess it is, there were just two brands, two fundraising brands out there, UNICEF and MDA. My job's not done until we get MDA in that top 10 in terms of awareness out there. Leaders and people who are looking to be successful just are constantly raising the bar in themselves and that's why they keep hitting new heights. I hope I'm able to do this in this new career that I've picked, nonprofit.

**Taren:** You know, it's so funny Lynn, is that I ask this question on a lot of women and it seems to be one of the toughest questions I ask. It's a hard thing to define.

**Lynn:** Yeah.

**Taren:** I think it's hard for women to self-reflect on what that success means because they are always trying to raise the bar and get to that next thing. Thank you for your answer.

Finally, what's the one piece of advice you would give to your younger self if you could go back in time?

**Lynn:** I'm going to reflect on again another wonderful friend and colleague who I met through HBA and is a Woman of the Year, Carolyn Buck Luce. We were just having a drink the other night talking about this. One of the things that she talked about for years is owning the decades and defining, and I think she's even writing a book, to have a plan for every decade. I would say if I had any advice to my younger self, I should have done that, because now these decades go by quickly. You think about having stayed in the healthcare communications business for over 20 years, I look back now and say, sure I met a lot of milestones there and had a lot of fun and did a lot of great things, but if you really divided your life in 10-year increments, you might make some goals by decade that could then ladder up to where you are today.

Again, hindsight 2020, I think conceptually now it's not too late. I think everyone out there should really think about decades because when you're raising children, you're head down on a job, decades can go by very quickly and you need to maximize the 30s, maximize the 40s, and particularly the 50s because that's when your kids are in college and you have more time for yourself and you really need to define what is that next gig that I'm going to do? Where should I apply all my talents and time so that I'm fulfilled enough that I'm giving back to society? That's my advice. Take it a decade at a time.

**Taren:** That's wonderful advice and I think its advice that we should all look to take up. I will now start to think about my decades as well. Thank you so much. I appreciate it.

For our listeners, we just want you to know that the 2019 MDA Clinical and Scientific Conference will be held April 13<sup>th</sup> to 17<sup>th</sup>, 2019 at the Hyatt Regency in Orlando. So, make your plans, go see what MDA has up and I want to wish you continued great success, Lynn. Congratulations on a great first year.

**Lynn:** Thank you so much and thank you for including me in this wonderful project.

**Taren:** It's our pleasure.

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