

January 6, 2021

Welcome to WoW – the Woman of the Week podcast. This episode was made possible by a generous sponsorship from ConnectiveRx. For more information, visit connectiverx.com.

In this episode, Taren Grom, Editor-in-Chief of PharmaVOICE magazine meets with Anne Quinn Young, Chief Marketing and Development Officer, Multiple Myeloma Research Foundation.

Taren: Anne, welcome to the WoW podcast program.

Anne: Thank you so much for having me. It is such an honor to be in the company of such incredibly accomplished and inspiring leaders and honestly, congratulations on launching such a successful podcast.

Taren: Well, thank you so much and I'm so happy to reconnect with you after your PharmaVOICE 100 back in 2018. So it's been a little bit. So I'm really happy to have a chance to catch up with you.

Anne: Me as well.

Taren: I can't believe when I looked at this number I thought huh, I've known you for quite some time and I can't believe that it's almost 20 years since you've been with the Multiple Myeloma Research Foundation. I would love if you could share some of the highlights that you've experienced during this time because you've seen some remarkable developments.

Anne: Absolutely. And let me also congratulate and recognize you because PharmaVOICE has been around even longer and it's been amazing to watch PharmaVOICE grow over the last 20 years. So congratulations on that as well.

Taren: Well, thank you.

Anne: So back in 2002, which seems in some ways like forever ago and in other ways like yesterday. The MMRF was a relatively small new organization that had a pretty unique mission at the time. We were focused on accelerating new treatments and a cure for a disease that was pretty uncommon, had very little NIH funding and really very, very little general awareness. There had been no new treatments in over 30 years and most patients lived for about three years after their diagnosis.

At the time when our founder Kathy Giusti who was a patient – an atypical patient, most myeloma patients are males in their 60s and 70s; she was a female who was just 37 years old, most people at that time starting foundations spoke about advocacy and support and education, and so starting a research foundation, again, was highly unusual. But Kathy's background as a

pharmaceutical executive and as a patient who was trying to extend her life merely to see her one and half year old see kindergarten, it was the natural thing to do.

So when I think back in 2002, we had raised about \$10 million, which at the time was pretty big. About 90% of foundations didn't even raise a million. But now fast forward 18 years, we've raised half a billion dollars to stimulate myeloma research. I joined simply to work with Kathy because as I mentioned, she was an anomaly in the nonprofit world back then and I knew it was a once in a lifetime chance. And it was an exciting time because within a year of my joining, the very first drug was approved in more than 30 years and that was Velcade. And I remember so clearly we were at the launch meeting at Millennium (which is now Takeda) when the approval came through from the FDA. And imagine an entire company it's their first oncology drug coming to market. We brought myeloma patients to be there to help the leadership team help the reps understand what an experience would be, and everyone was in tears. It was so exciting. I remember speaking to Matt Harper from Kathy's hotel room; it was just a historic moment.

And then what's happened in the last 18 years we've had 12 more drugs approved. So you had nothing in 30 years and now 13. Patients are living three times as long. I know we'll talk a little bit more about this, but we've had a series of firsts as an organization as well. We built the very first multicenter tissue bank so that scientists could better understand the disease. We used those samples to sequence a genome for the first time. We built a clinical network that started out as four centers; it's now 24. We've launched 80 phase 1 and phase 2 clinical trials. We launched the CoMMpass which is a longitudinal study that's now the largest genomic dataset of any cancer that led to the first platform study in multiple myeloma. And then our most recent and arguably our most exciting and revolutionary initiative, the CureCloud.

Taren: Wow. I have chills to all of that. First, half a billion dollars, 13 drugs and how many patients you all have impacted and extended lives for, it's just immeasurable. I can't even imagine how gratifying it is to go to work everyday. Just incredible.

Anne: It really is.

Taren: And what you all are doing is hard and so that is even – it's even more impressive. The dedication because there's so much sadness too because you can't save everybody, but just doing all that you all can do for patients is just remarkable. Can I just backtrack a question? How did you and Kathy meet? I know you joined MMRF from the start, but how did you all connect?

Anne: Well, it's funny, it seems very antiquated right now, but it was an ad in *The New York Times*. The newspaper, an ad and it was funny because my background was healthcare communications. I worked in a number of large PR agencies and then I got my Masters in public health and worked in healthcare consulting. The healthcare consulting was really interesting and that's how I got to know oncology, but it was not personally fulfilling. I missed the days in PR when I was working side by side with patients building disease awareness campaigns, helping

educate them about the latest developments. So when an opportunity like this came along I couldn't say no.

The two other funny things happened at the time. One, one of my former colleagues and a mentor was working in corporate communications at Millennium, and she was so excited about Velcade and about this disease that has seen so little innovation that I knew about myeloma and Velcade from her. And then unfortunately someone I went to grad school with, who was only into her early mid-30s, was diagnosed as I was going through the interview process. So there was a funny confluence of factors that came together and there I landed.

Taren: Wow, talk about serendipity, right at the right place at the right time and for those in the audience who are too young to know that yes, people did get jobs by answering ads back in the day.

Anne: Back in the day.

Taren: That's an amazing – like just what a great connection there, and it was meant to be as they say. I'd love to talk about what the future is and then we'll talk about your role. You mentioned the CureCloud. Tell me what that is and how MMRF is empowering patients through CureCloud.

Anne: Sure. So CureCloud is at the heart of it, is a research study, and it was launched to answer questions that we hear from patients everyday. Right now with 13 new treatments – and you can imagine the number of combinations because lines of therapy are given in three or now four-drug combination. So there's so many different options and really no defined pathways based on data to say okay, you're this person, this patient with this subtype, you should be given this combination and this sequence. We don't have that. So we constantly hear these questions from patients, what's the right treatment for me, in what order.

There's a pre-myeloma condition called smoldering that really hasn't been deeply studied. So we hear from smoldering patients all the time 'what's my chance of progressing to myeloma? Should I be treated? Should I wait to be treated?' And then with this huge onslaught of new treatments in the immunotherapy realm, when do you use those? Do you use those at diagnosis? Do you wait until patients have relapsed? So we hear all these questions from patients and we had built which is still the largest genomic dataset of any cancer, so that was really to drive scientific hypotheses. So we learned amazing things like new targets for drug development. We learned how to define high risk. We learned what the different subtypes are.

But they weren't answering the questions that we were hearing from patients. And CoMMpass was 1100 patients, it was 76 sites worldwide and it cost \$40 million. It was a uniform patient population. All patients started the study and we tracked them longitudinally from the diagnosis. So we don't have – and a lot of patients given the disease is still incurable, passed away after a few lines of treatment. So we don't have a big enough or a diverse group of patients, but we weren't about to invest \$80 million, \$100 million in another research study the

same way, so thankfully technology allowed us to launch a research study that went direct to patient.

The other thing that we wanted to do besides making this super easy for patients to join – and any patient, it doesn't matter where you're treated, we also wanted to give something back to patients. So CureCloud looked like is if you're a patient you have active multiple myeloma. From your home computer, iPads, phones, you can sign up. You sign a consent. You sign a medical waiver that grants access to your EMR. So you're not filling out lots and lots of different forms. You're giving one permission. Then we send a phlebotomist to your home to collect a blood sample. Multiple myeloma resides in the bone marrow, but there's new technology now that you can learn some of the same genomic information from a blood sample.

So instead of having to go to the cancer center, especially at a time like this, have an invasive bone marrow biopsy means you get blood sample collected from your home. Then we pull all that data together to build a huge dataset to answer those questions that I mentioned and for the patients to enroll, we sequence their blood sample and then we send them and their doctor a report back of what we found through genomic sequencing.

The genomic sequencing for myeloma right now is only available at big academic centers. This means that we are opening up this cutting edge technology to any patient anywhere and they don't even need to leave their home. And then we're not just giving the results back to the doctor, which is what's typically done; patients can have it in their hands. So if their doctor chooses to ignore the report, doesn't want to discuss the clinical trials that are listed there, that patient can just take the report and go see another doctor.

Taren: It's amazing. How did you all come up with this? I mean obviously it took a lot of great minds thinking hard about a problem that needed to be solved. That's so cool. What is the patient response?

Anne: It's been amazing. The patient response was amazing and the doctor – and the physician response has been amazing.

So we launched in July. We had been scheduled to launch in May, but everything as you can imagine was shut down. The Broad Institute is our sequencing partner and they had shifted all operations to COVID testing. So when we launched in July with very little marketing, we had over 100 people sign up within the first day, and we have over 350 fully enrolled in the study now, again, with very little marketing because things have been a little bit delayed due to COVID. One complexity that we didn't see initially was the fact that we couldn't have – we have a chief medical officer and we had assumed that he could sign off on all of the sequencing tests.

But what happens is there's these old laws in the books in about a third of the states that for whatever reason that would constitute practicing medicine across state lines. So we needed to put in place a process whereby the patient's physician needed to sign off on the form. And we were a little bit worried would that cause a delay in patients getting into the study, especially during a time like this, and it really hasn't.

So we've had such tremendous enthusiasm from patients. Right before COVID really hit, I presented with one of our board members the concept at an ACCC meeting and described what we were endeavoring to do and got a standing ovation from the community oncologists in the room. Because they were practicing – they were seeing cancer patients in rural settings, in places where patients had very low socioeconomic status and the fact that we were making this easy for patients, giving them access to this kind of technology, giving them and the doctors access to data, they were thrilled. And for free, and for free mind you.

Taren: Right, and for free.

Anne: Yeah.

Taren: And that's the thing too. So when we look at this patient populations that are so removed from academic centers, their continuum of care just – I don't want to say deteriorates, but it lessens because they just don't have the same kind of access. So this is so great.

Anne: Yeah. We fought even through the CoMMpass study that I mentioned earlier, one of the analyses that we did was to look at black versus white patients and how they were treated and what their outcomes were. Remember, this is a little bit old. It was enrolled between 2011 and 2015, but we found that back then black patients were much less likely to be treated with a triplet upfront, which was becoming the standard of care. So not surprisingly their outcomes were worse. So we've seen firsthand through our own data that there are inequalities that we've all heard about and we feel very strongly about democratizing access and democratizing care.

Taren: It's the only way. It's what needs to happen. So kudos to you all again. A minute ago, you talked about the number of medicines that have to be used in combination and because we just don't know the direct path of the disease – and that's another area of focus for you all is looking at that dynamic of precision medicine. So talk to me about what you all are doing in that area.

Anne: Myeloma is, like many cancers, a heterogeneous disease. But what's tricky about myeloma versus, say, a breast cancer is that it's pretty uncommon. So you need to have a critical mass of data, of patient data, to start to make sense of it, and that's really where CoMMpass grew out of. So what we have done through CoMMpass is define subtypes and then what we did was we launched the first arm trial – arm clinical trial in multiple myeloma called MyDRUG. So patients are screened for genomic alterations and then depending on what their specific alteration is, they're put in that specific arm. So unlike other clinical trials where you're comparing head to head each arm, these are tailored arms based on patients mutations. And what's really exciting is all of these arms have treatments that are FDA-approved for other cancers, which means that if there are positive results, the patients outside of the study could potentially get access to a brand new option off label.

And we're continuing to build on that. We've added arms where we're continually looking at the research to find out to see what are some new targets that are highly expressed in myeloma patients and are there treatments. So with a platform trial design it's very flexible to open and close arms as the research evolves.

Taren: Amazing, amazing stuff that you all are doing. And specifically you can talk to the whole broad spectrum of what the organization is doing and that's really specific to your role which is overseeing the strategy and execution of the organization's marketing communications, patient engagement, all of that. Tell me what a typical day looks like for you, if you have such a thing as a typical day. And not only that, you're in charge of fundraising too. My goodness.

Anne: Yeah. It's exciting and I think that forget about the rewards of working at an organization where I've seen firsthand the progress that the field has made together with the needs that are still there in terms of patients are still relapsing and are still dying even if they're living longer. It's really that mix of – on any one day I could be talking to a million dollar donor. I could be running an educational program for patients. I could be talking with partners to figure out okay, we have these, we're building this dataset, we know we need to answer these questions, who has the right machine learning or AI platform to figure out how to answer these questions.

So it really is a mix of all these really interesting things that I think are helpful in terms of keeping me most helpful to the organization and most helpful to the patients we serve because it is – because there's a lot going on and it is really, really complicated.

Taren: It's complicated. You've got a lot of balls in the air. There's moving chess pieces around the board. I am exhausted just from like one day with you. But given all of that, you all hold such a strong vision for the organization and its mission. I want you to look in your crystal ball, what do you see in the next 20 years? You've made such great progress in the past 20 years, what do you see the next 20 years holding for you all?

Anne: That's actually really easy. I see subsets of patients being cured. When I say being cured, I don't mean you're on treatment forever. I mean patients who can go off treatment and live a full high quality life. There are segments of patients who are living 15, 20+ years and it's important to learn from them and this is where immunotherapy comes in too because we know it's not just about genomics. We know the immune system is playing a powerful role, and how do we look at these extraordinary responders and understand what's going on in their immune systems. A lot of them, and Kathy Giusti included, have had stem cell transplants from others, whether it's a relative or a matched unrelated donor.

So there's something about getting a new immune system to allow you to fight off the myeloma. So I have no doubt between treatment advances that have been made and the pace at which research is running that there will be a segment of patients who are cured.

Taren: You've just made my cup runneth over. What optimism. That's the best news I've heard in so long I can't even begin to tell you. That is fantastic. So hope to all who may need it and oh that's just – that's great. I don't want to gush too much, but that is awesome. I want to switch

tacks just a little bit. I mean obviously I'm so inspired by all that you are doing and you were recognized as one of our most inspirational individuals in the life sciences industry back in 2018. Tell me about your leadership persona. How is it that you keep your teams revved up? How do you keep them operating at such a high level?

Anne: I think of myself as a player coach in that I'm working alongside of them in many instances, but at the same time really working with them to keep them motivated, to push them to their potential. I lead by example, and I do say it's really conscious. It's just in my nature to work as hard as I possibly can and knowing that, look, this is a – the mission we have is not an easy one. The work we're doing is complicated. Patients lives are at stake. I don't demand people who work with me to necessarily work the hours that I do or at the pace I do, but I do find that those who are attracted to the organization have a certain passion, have a certain work ethic, have a certain determination, and we end up inspiring and pushing each other. But again, I think they see how hard I'm working and I really – I'm so grateful for those who come to the organization.

We typically don't get people out of nonprofit. These are folks coming from, you know, in my area you have agency people, you have pharma people, and they're choosing to come over to the nonprofit side and work super hard. And the payoff is simply seeing the impact on patients lives. But it's also important, I think, to have a certain amount of recognition and gratitude for their efforts so that they stay motivated too and feel like they really are making a contribution.

Taren: Absolutely. With MMRF growing so much over the last 20 years, you all really are in a national spotlight now. Is that added pressure to what you're doing, or does it just kind of help lift the boat?

Anne: It definitely helps lift the boat because I think two things: One, we – the MMRF tends to attract type A competitive people who like to be first, who like to be best. So it serves our population well because it means we launched the first tissue bank or the first to sequence a genome, and there's a pride for us and a certain fulfillment in doing that. But what we're also very happy to do is share all of these models with everyone else. It's incredibly gratifying to see other organizations, these small organizations achieve so much more, so much faster than we did because we were really breaking new ground and also didn't have technology on our side.

We are very happy to rise to the pressure because we're doing this for our patients. Kathy has really – she maintains her position as chief mission officer at the MMRF, but her work right now is really to bring the best business models in precision medicine across all cancers and really across all diseases. So we really are looking to make an even bigger impact.

Taren: It's amazing, and you are creating models that are being emulated and so much – as you said earlier, so much is just given away. You're sharing it with a generous heart to the industry so that others can learn which is remarkable in this day and age, let's just be frank about that. So again, additional kudos to you all for being so unselfish because you could very easily take that and keep it proprietary and make money off of it. But that's not who you all are. So that's

fantastic too. The next couple of questions are a little bit of a lay up, but let's get there. Who is it that you turn to or look to for inspiration?

Anne: Well, it probably won't be a surprise, but I would say Kathy Giusti first and foremost.

Taren: Me too!

Anne: Seriously and for those listening, she's not only the founder and chief mission officer, my mentor, but also a PharmaVOICE Red Jacket winner, I think in the first class of recipients. She's one of the very first WoW podcasts. I don't think I fully appreciated when I joined the MMRF and working for Kathy and that's the number one reason I joined. I thought of her as the business leader and the opportunity to work with someone like her in a nonprofit setting, but I didn't really think as much about her, the patient. And when I think back now about what she was – what she had taken on, in the back of our mind thinking that she wasn't going to live very long is just incredible.

And then for her to still be at it today and believe me, she works just as hard or harder than anyone else in the entire organization, and as I mentioned earlier for a much bigger cause. Myeloma will always be our mission and her first focus, but she's really setting out to help every patient.

And then along the way, I've been so blessed to meet so many inspiring patient and caregivers who are dealing with the diagnosis, with treatments that can have really not easy to manage side effects and they show perseverance. They show courage. They show strength. They just are optimists and then so grateful for the work we do. It's so, so inspiring. I've lost, unfortunately, so many patients that I really cared about, but they together with the ones who are still living, honestly inspire me everyday.

Taren: I've talked to Kathy a number of times and I have to say as much as you say how inspiring she is to you and to me as well, she turns the tables and says she's so inspired by you and the team that are working on finding these cures and moving the mission forward. So she pays it right back to you all. She thinks this is just – it's what she was put on this planet to do, but she gives so much of the credit back to you and your teams. So what a nice energy you all have. So again, this is a bit of a lay up, but there's got to be so many rewards working for the MMRF, what's the top one for you?

Anne: I would come back to CureCloud. CureCloud, what's really amazing about it is it's the first, I say, initiative in the organization that literally took the entire organization working together to make it happen. Our chief data officer to build the platform, our chief medical officer to write the protocol, our chief scientific officer to make sure that we had the right blood biopsy technology and sequencing, and then me and my team make sure are we creating the most frictionless, easy, engaging experience we can, particularly in times like this when we're all living on Amazon and we can track every single package and there's complete transparency. We looked at models like that when we were putting together the interface for CureCloud. We weren't thinking about oh let this look like a traditional registry of research studies. We wanted

this to be like a true consumer experience. So it hasn't always been easy because we all come at this with very different and very strong opinions, but what came together was incredible.

And then the piece that I really personally pushed for from the very beginning was giving something back to patients because that's one of the things that really sets this apart. If you look at other research studies, patients are contributing their data, but they're not getting anything back. So it took a lot of hurdles, but we created a patient-friendly report – again, a similar report goes to the doctors, but a report in language patients could understand that very clearly outlined potential clinical trials for them, that for many of these patients could open up brand new options that they didn't know existed.

Taren: Anne, I hope the rest of the industry follows that lead because that is one of the missing pieces. You hear it all the time is that patients who participate in clinical trials and they really are donating and giving of themselves and sacrificing, but they don't ever get that return, and that's really been a big gap. Because this is our WoW Woman of the Week podcast, we ask this of all our interviews; tell me about an accomplishment or a wow moment that shaped or changed the trajectory of your career.

Anne: So I would have to go back to just joining the MMRF simply because I had a goal for my working in PR and healthcare communications to work at an organization like this but way much later in my career after I had spent time being properly trained in more of a corporate environment. But that serendipity that we talked about before between a *New York Times* ad, to a grad school colleague being diagnosed, to a friend and mentor really being so excited about what was happening, that completely changed the direction of where I was headed or at least accelerated it.

And then along the way I would say there have been smaller moments, that just I would say kept inspiring me to make sure that we always kept patients' best interest and what our mission was in terms of curing every patient. There can be so many distractions as you can imagine, and our goals are not always aligned with everyone else in the ecosystem, so it's really important for us always to find that common ground. But at the end of the day, we need to stay true to our mission. We need to stay true to our brand. And so thankfully I think there are a lot of wow moments that come along that, again, I need to make sure that I'm always staying true to that.

Taren: Well, wow, wow, wow for you and congratulations to you, to the entire MMRF team, to Kathy for such incredible work that you're doing on behalf of patients and really changing the face of the industry and how it looks at patient care and patients themselves. I want to wish you the sincerest best going forward in all of your pursuits. It was great pleasure to speak with you, and thank you so much for sharing so much about what you're doing and how you're helping patients.

Anne: Well, thank you so much for this opportunity. It's been fun and again, we're so grateful for anything opportunity to spread the word because we still have a lot of work to do, but it's exciting as having an impact and again, really, really grateful for this opportunity.



PharmaVOICE Podcast Series

Thank you for listening to this episode of WoW – the Woman of the Week podcast. And thanks to ConnectiveRx for making this episode possible. For more information, visit connectiverx.com. And don't forget to check out our other episodes of WoW at pharmavoice.com/wow.