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In this episode, Taren Grom, editor-in-chief of PharmaVOICE magazine, meets with Kathy Giusti, founder and chief mission officer at the Multiple Myeloma Research Foundation and faculty co-chair of HBS Kraft Precision Medicine Accelerator at Harvard Business School.

Taren: We'd like to welcome Kathy Giusti, a PharmaVOICE Red Jacket Honoree, to this week's PharmaVOICE WoW podcast program. Kathy, welcome.

Kathy: Thanks so much for having me.

Taren: It is our pleasure. Kathy, your story is well known to so many, but for those of our listeners who haven't had the opportunity to hear your inspirational journey, would you please share how you came to found the Multiple Myeloma Research Foundation? I can't believe it's almost 20 years ago now. And then after that, talk about the genesis of the Multiple Myeloma Research Consortium. So let's start with MMRF.

Kathy: Sure. I know 20 years has passed by very quickly. I started with an interest in healthcare because my father was a physician and my mom was a nurse, so it's not surprising that I was a premed major enrolled in medical school. But along the way, my father actually said to me, he thought that was a bad idea for me to go into medicine. I was impatient and he wanted me to try business. So I actually went over and started in sales at Merck at the time and then moved into their headquarters in marketing, and I really did love the business side of science so I ended up staying there and then going on to Harvard Business School to get my MBA. And then did a stint which has actually served me well lately at the Gillette Company in consumer marketing, and finally landed at several pharmaceuticals outside of Chicago where I worked on new product launches and was involved in the worldwide franchise for arthritis for the organization. And it was at that time that I actually was diagnosed with multiple myeloma at the age of 37, and back then multiple myeloma was truly a death sentence so I was told I would have three years to live at best.

And so that's why I started the Multiple Myeloma Research Foundation was my daughter was 1 at the time and my son hadn't been born yet and I was hoping that I could buy

enough time that she might remember me, even if I bought a few years she might remember me; and that's how the organization started.

Taren: I can imagine what you went through when you learned of that diagnosis and then to have the strength to then find a way to literally help yourself as well as others. So what was it like starting up the MMRF? What were some of the challenges, obstacles, and the tremendous opportunities you found?

Kathy: I think the biggest switch for me was I had a major job at a pharmaceutical company and I loved it, I really loved it, and I had a lot of people working with me and I was surrounded by tons of people. But now I was switching to an entrepreneur, running and starting a non-profit – I had never worked in the non-profit sector in my life. And so now I'm at a computer in my home trying to build a company from nothing and I've lost my sounding board and my teams and everything else around me, but I will say that the path I had taken along the way, moving from science to business school and going from sales to marketing to worldwide – all of those things prepared me really well to be an entrepreneur. And in some ways I'm kind of glad I took that space on because I think at the end of March we've really shown that the non-profit sector can be extraordinary and you get a lot of amazing work done.

Taren: That's tremendous. Why did you start the consortium? How does that fit into the puzzle?

Kathy: Well what happened along the way, and I think this is the training I had as a business person through my work at Harvard Business School and other places, was I always knew that you can't just say what you're going to do – you have to have a plan and you have to write it, you have to organize it, and you have to have your milestones around it so I've always been incredibly disciplined in that way. I started by writing the first plan in myeloma saying 'what is the greatest challenge that we're facing in this disease right now.' And that challenge was we didn't understand the basic science of the disease and everybody had their small little tissue banks but we didn't have any critical mass in this uncommon tumor type.

So what I did was the business solution for that was to say well we need to create a collaborative model – a model where the academic centers...and back then I could count them on one or two hands. They were focused in the field of myeloma, could be sharing their tissue, sharing their ideas. So that was why I developed a clinical network that focused on banking tissue centrally as well as conducting phase 1 and 2 trials and attracting pharmaceutical companies to come into the field and I do think that has been

the success of the MMRF. We've never strayed from that idea of studying the landscape of what's going on in our disease and then identifying the business solution around it.

So as we moved even further, looking at our business plans we realized "Okay, we don't know enough about the subtypes of our disease" so we moved forward to do the first genomic sequencing of a myeloma tumor. Then we said 'okay, it's great that we know a lot about one-off tissue samples and sequencing in myeloma but we really need the sequential, the longitudinal data combined with clinical data,' and that encouraged us to then launch our CoMMpass study. And that's how we've reached the point of knowing there's 12 subtypes in myeloma, we need to pursue cures for each and every one of them and all of that became our model for precision medicine. So I'm a strong believer in studying the landscape, looking at the space, seeing the challenge we're trying to solve for, writing the plan with the best partners out there, and driving forward.

Taren: It's an amazing accomplishment and you truly broke new ground with that CoMMpass study. How did you overcome some of the challenges of getting pharma companies to really lower their barriers to collaborate freely?

Kathy: Well it has been interesting. We have found that if you bring the pharma companies together and they're part of the ecosystem in which you're trying to solve the problem, they can be extraordinarily helpful. So when we were developing the CoMMpass study, we were conducting that with our academic centers, and together we were following over 1,000 patients sequencing their genomes, collecting their clinical data, and then working with our pharmaceutical partners who were part of a pre-competitive consortium in the model. So they paid for half of the CoMMpass study, the rest came in through philanthropy, but we were constantly feeding back to them what we were seeing in subtypes, in targets, information like that. And the joy of that was you want the pharma companies to see this kind of information because they're the ones that are developing their pipeline; and in myeloma which is a very heterogeneous disease, we need a multitude of drugs.

What I have found to be most fascinating is our plan now is not only on the genomic side but also looking at the precision of immunotherapy. So again, just last year, we wrote an entire business plan around immunotherapy data models, venture models, and we've been driving that forward; and just recently we had a two-day meeting here at the MMRF. And again all of these people were part of the plan; we don't write them by ourselves, we bring the whole ecosystem to write the plan, but we brought everybody together and said now it's time to operationalize this beautiful plan. And we brought in our top pharma partners, we brought in our top academic centers, the MMRF team, and together we sat down and prioritized what did we need to do together in the immune space so that we

could say how do you take immune data? How do you share it? How do you harmonize it? How do we make sure that we're prioritizing the best therapies and combination approaches in myeloma?

I have to tell you, you had competitors sitting at the same table with each other, it was a really collaborative group and that's what gives me amazing pause when I look at the models. If you're the convener and everybody sees where you're headed, people are people; they want to find cures and they will work together. You just have to get that plan out there, pick the people that will collaborate and keep everybody driving, hitting those specific milestones that are so important to our patients.

Taren: I think it's terribly exciting and important the work that you're doing; and for this work, I know that you were recognized in 2017 with the Precision Medicine World Conference Pioneer Award. Talk to me about what that meant to you personally and what it means to moving that precision medicine model forward.

Kathy: I think it meant a lot to me personally because it validates our mission as a team. So in myeloma, I remember when I was first diagnosed. I could go to an American Society of Hematology meeting and myeloma wasn't anywhere to be found. In today's world, myeloma has seen such unbelievable progress and it's a tribute to everybody in this ecosystem that has been working tirelessly together. So when you look at myeloma, we have come from no drugs to 10 drugs approved, from not understanding the biology of our disease and knowing there's 12 subtypes of the disease, and from a very dismal three years to our patients living 9-10 years and yet none of us are complacent. As a team, we all are inspired by our progress but always looking for the next thing that we want to solve.

So I think the awards give awareness to the hard work of the entire myeloma community and also allow people to understand that the model is transferable. Other people can look at this model and learn from it and hopefully make equally as much progress in their cancer or their disease.

Taren: Again you have been recognized by a number of organizations and received a number of industry accolades including being named number 19 of Fortune's World's 50 Greatest Leaders and one of Time magazine's 100 Most Influential People in the world, and is one of 34 leaders who are changing healthcare. That's got to be a tremendous responsibility. How do you celebrate those successes, and I know you say it's a team-based approach, but you have to feel a lot of responsibility as well – talk to me about that.

Kathy: I do think when you when you lead organizations like this, I think the responsibility is to make sure you teach others how to do what you've learned or you keep learning from other people as well. But I think for me, I'd love to tell you that I celebrate all the moments I am truly grateful and humbled by each and every one of them, but my job every day is working with patients. And I always say to people that the patients that are doing really, really well are out thankfully living their lives and hopefully celebrating amazing and wonderful milestones, but it's the ones that are in trouble that we'll call they're out of options. They're struggling. They don't know where to turn. They can't find a trial.

A lot of these issues have still stayed the same over years, and because of that I still feel the urgency every day in here because I'm close to these patients and I want to see the progress. It's not even just the myeloma patients because I think people understand that I care about all cancers. And just last weekend I was working with a young woman, she's 24 years old and diagnosed with stage IV ovarian cancer, and I'm scouring everything trying to find any way to help her and that's the responsibility I feel is I felt she's 24, I was 37 when I was diagnosed and I want so much better for these patients and that's the responsibility I really feel every day.

Taren: I can't believe that where you are sitting and with all that's on your plate that you take the time to answer individual emails and to dig down deep and be very tactical with these patients that you run into. I think it's an amazing thing that you do. I'm blown away by that.

Kathy: Oh it's joyful. I do find in any way that you can be helpful and I think it keeps you close to the patient. Otherwise, if you looked at the myeloma stats and just said we're doing great and we've tripled lifespan, you might have one attitude, but when you're talking to patients that have relapsed, they don't know whether to do a CAR-T trial, they're confused, and we know data will give them the answers, it inspires you to do better every day. And I think the patients are really helpful at keeping all of us at the MMRF in a 24/7 mode working as tirelessly as we can.

Taren: You just touched upon some of the milestones that you all have achieved over the last 20 years. What are some of the nearer-term milestones that you're looking at say in the next few years or 10 years?

Kathy: Yeah, they're next on our list. So number one would be this intense focus on immunotherapy, but what I always say is doing it right. Immunotherapy, there's so many possibilities out there and understanding which are right for the specific cancer type is really important. I think that ties very much back to understanding data standards,

putting data together in a way that it can be harmonized and sharing that data. Otherwise, we're not going to make the progress we need.

The second space for us is that myeloma looks like a crowded field. We've had a number of drug approvals; we have potentially more coming this year. And so a pharma company or biotech may look at the space and say 'it's crowded and I've copied out these other drugs. Do I want to come?' So what we built because our disease, as I said earlier, is so heterogeneous is a separate LLC that will become our venture fund. And the reason we're highly focused on that is because if we have a fund where we have a team just on the business development side scouring every company and looking for every opportunity and they know we're out here, not only will they get the funding from us but they'll also get access to all the things that the MMRF has to offer from our tissue, our data, our expertise, and our clinical network. That's what's going to drive immune therapies and targeted therapies much faster.

And then the third area we're highly focused on is saying there are care pathways. Like we can look at our data and say if you're this type of patient, you probably should move down this type of treatment, and yet it's hard to get that data in the hands of the patient and the community oncologist so we're really building out beautiful data visualization opportunities where that data does get placed in the hands of the patient and the community oncologist who so desperately needs it. So those are our three major initiatives over the next few years. They're powerful in there and they're daunting but...

Taren: It's exciting.

Kathy: ...I have no doubt we'll do it because we have great partners to do it with.

Taren: I have no doubt you'll do it either. It's exciting stuff and I wish you all the best and continued success. Tremendous. Just to switch gears a little bit here, I'd like to talk about your role as the faculty co-chair at the Harvard Business School of the Kraft Precision Medicine Accelerator. What kind of work are you doing there and what's the accelerator doing? I know this is exciting to you.

Kathy: I love this. So I actually spent half time as the chief mission officer and founder of the Multiple Myeloma Research Foundation and then the other half time up at Harvard Business School working on the Kraft Accelerator. The Kraft Accelerator came about at Harvard because Robert and Jonathan Kraft... Robert had lost his wife, Myra, to ovarian cancer. They had sequenced her genome at the Broad Institute but they couldn't find a drug fast enough for her and she did pass away. Robert and Jonathan were wise enough to know if they gave a significant endowment to the business school, that they could get a

team that would focus on the business of science. And the dean of the business school of course thought that this was a great idea because you want business schools solving healthcare issues.

Dean Nohria called me and asked if I would be willing to come up and run this initiative with my co-chair, Richard Hamermash, who's been on the faculty at Harvard for a number of years. Together, we bring together the best of the best in precision medicine onto the Harvard Business School campus and we really ask them to identify the challenges in precision medicine but we keep work teams together that solve for those challenges.

We focus on four areas up at the Kraft Accelerator. One is direct a patient where we bring in amazing direct-to-consumer Harvard Business School grads from Uber or Rent the Runway and we actually have them teach our healthcare organizations how to drive patient engagement and retention as you move toward registries. Our second area is what we call data and analytics such as how do you make sure that once data is being provided that it can be harmonized and analyzed in the most appropriate way by asking the right questions. The third is as you do that and identify new targets and care pathways in the space, how are you building that back out to clinical trials, more innovative trial designs such as master protocols. And then as you do all of those factors, it really allows venture firms and philanthropists to come into the space and help to commercialize the drugs faster so that you have access for all of the patients involved.

So the joy for me is that up at the Kraft Accelerator we've been working across all cancers and we've started to work across diseases that are passionate about precision medicine – it can be muscular dystrophy, it can be Alzheimer's. And what I'm finding is the models are definitely transferable across cancer and they're definitely transferable across diseases, so the power of this endowment and the support of the business school using the faculty, the students, their dissemination machine at Harvard – all of those things have served us really, really well, the Accelerator, to make a huge difference.

Taren: Wow, that's amazing stuff. And congratulations again for really bringing healthcare to the forefront and continuing to be an innovator and an entrepreneur and now as an educator. You are such a role model to so many, who do you look to for inspiration?

Kathy: It's funny. As I said earlier, my daughter was 1 when I was diagnosed and my son wasn't born. I think now as the mother of a 24 year old and a 21 year old, I see the capabilities of this next generation and I love their energy. I love what they're able to do and I really love to be inspired by them.

Just recently, up on the Harvard Business School campus, we had maybe about 50 students from Lafayette College where my son goes and we invited them all up so that they could understand the business of science as well. So 60 students from freshman to seniors all heard different presentations. We did all kinds of programs with people from a PhD from Count Me In, an engineer that had been at G&S, Patients Like Me, consultants at Pricewaterhouse, and venture firms. It was so rewarding for me because I thought their questions were right on the money and I'm always hoping that mentoring and sharing ideas like that with the students will allow them to find their way faster, allow them to find their love in science and technology, because we're absolutely counting on the next generation to execute on the dreams that we all have today.

Taren: Amazing. You talked about mentoring, and I know that several people in the industry think of you as a mentor. Why do you think it's important to be a mentor to the next generation?

Kathy: The longer you're in the space, the more wisdom you have to share; and if you can teach anybody else what you've learned along the way and save them that time and energy and help them to see that we've all had failures, we've all had successes, just keep learning from them – it is a gift. And I think for many of us who really do want women coming into science and technology, because even when I look around the room I want everybody to come in, but I always see that it is fewer women. I want them to know there are really fun places to work in science and technology and you may have a PhD or you may have an MD, it doesn't mean you have to take a certain path; there are many paths you can take in this field and all of them highly need it at this point.

Taren: Absolutely, and I think you touched on an interesting point that it doesn't have to be the traditional pharma model because the healthcare ecosystem is evolving so quickly and it's expanding, and the umbrella is becoming even bigger that there are multiple paths for women to take.

Kathy: Absolutely.

Taren: Tell me about an accomplishment or a wild moment that shaped your career.

Kathy: Well I think I probably have a couple of those. I would say the first one was when I went right to college pre-med major and assumed I was going to go to medical school. So when my father actually said to me "I don't think you should do this," I was shocked. And when he said "I think you should do business and here's why," I was shocked. So that was a moment where I shifted completely from science over to business

and that did change a lot of what I was doing and then moving on to the Harvard Business School space.

I would say obviously the second point was my diagnosis because of course I loved the pharmaceutical industry, I love everything I was doing there, and I definitely would have stayed if I had not gotten sick. So that diagnosis led me over to the non-profit sector.

I would say the third one was at the same time that my mom was fighting melanoma, my sister was fighting breast cancer, and my dad had died of kidney cancer was when I got the call from the dean of the business school and the Kraft asking me if I would be willing to come up and work across all diseases in precision medicine. I'll never forget that moment of thinking the stars are aligned and I can't think of anything I'd rather do and how I could have a greater impact than going out there and working across everybody. But I'm not sure if that call hadn't come, I might be doing something completely different at this point. I'm glad I took that risk and headed up to the school.

Taren: You are just so optimistic and forward thinking which is an incredible thing given your family history and the medical tragedies that you've had to endure. How does it work for you? I mean I think a lot of people would just be devastated by the news that you've had to deal with.

Kathy: I think for me, I feel like I've just been incredibly fortunate that I have moved in my career and moved through so many opportunities with my family that I don't really look back and feel...there were challenges, of course, but I don't look back and think that it has not been an amazing life. I think it's been an amazing ride and I've been incredibly, incredibly blessed. And I've worked with some of the most amazing people across the country throughout the world in terms of finding cures. So what feels better than waking up every day and coming into your office and saying "I'm curing cancer" or "I hope I can help somebody else figure out how to cure Alzheimer's."

Taren: You have the correct right attitude and I hope that those who listen to the program do take inspiration for what you've been able to accomplish and continue to accomplish. I can't believe this is almost 20 years ago as well that you were named Woman of the Year by the Healthcare Business Women's Association. How does that recognition kind of impact your trajectory?

Kathy: That award put me on the map at a time when I desperately needed it. I mean I can look back and say the Healthcare Business Woman Association completely got me to where I am today and I will never forget the fact that Barbara Blasso and Lynn Ross nominated me for that award having worked with me when I was at Searle, but also

having watched me get the diagnosis and then move over to the non-profit sector. The HBA took a huge risk in giving the award to someone who was just literally starting her career in the non-profit space but everybody believed in me there, and the fact that everybody did believe in me I think gave me just tremendous confidence. And then there was just amazing exposure, and now all of a sudden everybody knew what happened in my life and what I was trying to do. In all honesty, that entire room rallied around me as I gave the speech.

I would say I'm forever indebted, and I feel like I've met some of the most amazing women at HBA moving from Barbara and Lynn, but Meryl Zausner also won the award and she's on the MMRF board as we speak, and she's extraordinary. So, talk about mentoring and sharing and everybody giving back. This is what you want it to look like in the world of healthcare, where we all really, really want to help each other.

And what comes around goes around. Even for Lynn and me, she's now running the Muscular Dystrophy Association and we're working together up at HBA because she has a great data model of the myeloma group, has a great data model others do, and we need to both teach other groups what we've learned in the data space because it is so challenging and we would never want everybody to struggle as much as we have, but these bonds that you created at HBA they're very long-lasting and just so appreciated.

Taren: I remember being in that room when you gave your speech and I was inspired then as I am today. So finally, if you had to wrap it all back up and if there was one piece of advice that you could give to your younger self, what would it be?

Kathy: I think it would be to truly believe that things happen for a reason. Even the greatest challenges in your life will always make you so much stronger and so much better. And I can say that now because I've kept a personal journal since the day I was diagnosed so I've written a journal for every year that I never expected to live. And I always wrote it for my children, Nicole and David. But just recently, I went back and I read every journal, over 20 journals, and I can say that what I learned from reading that was the diagnosis I had and the fear that I had it allowed me to take so much more risks in my life and allowed me to dare to be first. I had to because I only thought I was going to live three years. so if I was going to make a move I had to be decisive, I had to go, I had to be quick, and I couldn't worry that I was going to get it wrong; if I got it wrong I have to pivot. The successes I've seen today are probably attributable to that.

I think the other thing I learned by going back and reading those journals was I savored every moment with my children and that's really, really hard to do. So you kind of have to look at it and say if you only have three years and you think every time I was getting a

test result back I might only have another year or another year or another year, you live in that year. And that you look back 20 years later and you're like "Oh my gosh, that was incredible." I tried not to miss a single game or a cheer competition or something that was really important to them despite a tough job and battling an illness. But I think the bottom line is I went back and I read those journals and, yes, I would have changed things day to day but overall there's not a lot I would have changed because the challenges that were handed to me made me stronger.

Taren: I can't thank you enough for sharing what it's like to live the best life possible and I feel like you have done that and you're continuing to do that. So thank you for sharing your very personal journey with us; and as I said before, I continue to be inspired by you.

Kathy: Thank you so much. I appreciate it.

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