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In this episode, Taren Grom, Editor of PharmaVOICE Magazine, meets with Catherine Ivy, Founder and Board President of the Ben and Catherine Ivy Foundation.

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

Catherine: Thank you. It's wonderful to be here.

Taren: We're delighted to have you. Catherine, your story around founding the foundation is very personal. Would you mind sharing your story with our audience?

Catherine: Oh, sure. Well, it was in 2005, I was living in Palo Alto, California and very happily married and life was moving along, and my husband and I were actually hiking on vacation, and his thumb went numb. We assumed it was no big deal, get it checked out when we get home. We were flying home, it happened again, but at that time, he felt like his tongue was losing movement, like he couldn't control it. It was an odd sensation. So we came home, and they thought it was probably a pinched nerve. There was an MRI opening in six weeks, but there actually was a cancellation the next day. So we took it just to get it done with and it ended up being a brain tumor. My husband could have been the poster boy for Whole Foods, very dedicated to his health. Three days after finding out it was a brain tumor, he had surgery and the surgeon walks out and said it was glioblastoma, which is advanced brain cancer. It's the fastest growing deadly cancer there is. About 20,000 people get it in the US a year, adults.

Ben had the surgery, and then he took the medication and six weeks from that day of surgery – six weeks after that, he just overnight could not walk, eat, or write. He basically became paralyzed. And because of the pressure in his brain from the tumor, even though it was removed, it was coming back and there was brain swelling. He actually gained some of his movement back, but his quality of life was not good and he passed away four months after surgery. So it was out of nowhere, very fast, and a lot of suffering.

A very painful situation. I didn't even know how to spell glioblastoma. My sister who's a nurse, who helped me with that, but I worked in business and I read headlines and thought they're making great strides in cancer. And they are, but there's many types of

cancer. There's basically been one drug for brain cancer in the last 30 years, and it adds about a month to your life. So this diagnosis became part of our lives very quickly.

Taren: Very quickly, I think are the optimal words. Within six months, you had gone through diagnosis, treatment, surgery, and then your husband passed away.

Catherine: It was actually four months.

Taren: Four months – oh, wow.

Catherine: For the people diagnosed with brain cancer, advanced stage IV, 98 percent of people survive 16 months. That's the average. Ben was on the shorter side of that, but his quality of life was so compromised that in the big picture it was a blessing that he didn't have to continue on like that. Now we are at the end of 2019 and there are more options now (thank goodness). The life expectancy prediction has not changed, unfortunately, and that's what I'm working very hard on trying to change, but there are more treatment options that can help people.

Taren: It's an incredible story. During that time, that four months, did you ever think that you would be able to catch your breath again, just from one thing to the next thing to the next thing?

Catherine: It was a very surreal experience for me. With this just highly aggressive cancer and it affects a person's brain and Ben was so sick. I remember, first, the amount of stress of waking up and you don't know if your husband's going to be alive in the evening. That was extremely difficult. I went through a period of time, especially at the end, it's like this is the hardest day of my life, and then the next day would be harder. But somehow I survived it, and I didn't think I was going to, but when your worst nightmare happens and there's nothing you can do to stop it, it really rocked everything in my life. It's been 14 years, and now I focus on how lucky I was to have such a great partner, but it was just too short. But I'm just so grateful that he was part of my life for 11 years.

Taren: I will say that's looking at it from a glass half full now in perspective. So let's talk about where this horrific event has led you. You said that there are more options available and you are working with the endowed Ivy Brain Tumor Center at the Barrow Neurological Institute. Talk to me about the work that the institute is doing to address brain cancer.

Catherine: Ben and I had decided years before that if anything happened to him we wanted to do a foundation. And so when he was sick it became very clear the purpose of that foundation. So almost immediately we created a nonprofit with the intent to try and

contribute to find a cure to brain cancer. So I've been doing this 14 years. We are not an enormous foundation, but we are the largest private funder of brain cancer in the United States and actually the world.

Our foundation is funded all over the United States and other countries, and we've been doing it a while. I have funded every type of science where it's vaccine or stem cell. And with great hardworking, very smart people, nothing has changed. And this year, actually this fall, we will have invested over 100 million dollars and there hasn't been a change. Now if someone put 100 million dollars into an investment and had a zero rate of return, there would be some concerns. And I saw this was happening. We had the best and the brightest, it was so frustrating, and in 2012, I was like well maybe I just can't figure this out. This is not working. I'm so frustrated. I was getting very discouraged. I actually went to Jordan and worked in a Syrian refugee camp as a volunteer, and that really reignited my energy of, I do have a choice to try and influence something, and I'm going to go for it. And then I came back, and this presentation from Barrow was sent to my office. Barrow actually is in my backyard, which is what really helps, but they do more brain surgery than anyone in United States. And that brain tumor tissue is the golden egg of research.

So in 2013, we started something called a phase 0 clinical trial. It's something that has never been done in brain cancer and basically the day before a tumor is removed, a patient is given a micro dose of a drug that matches their tumor. And so the next day during surgery, the surgeon can determine if the medicine got through the blood-brain barrier and if it hit the cancer target. And if so, you continue on that drug cocktail. And if it didn't work, you've lost nothing. Because right now with brain cancer, there's some new options I had mentioned. There's vaccine, there's immunotherapy. You can wear an electric field cap. But none of those have really shown progress. But when you choose one of those therapies, you're guessing. You have no idea if it'll work. And then you wait two, three, or four months to see is this immunotherapy working. Well if it's not, that tumor's growing and if you have an average of 16 months to live, four months is a huge deal. So with this phase 0, you choose the best thing that matches your tumor genetically and you've lost nothing, but you could have gained great information.

So we started this real slowly in 2013. It's worked really well, and about a year and a half ago we decided we're going to really scale this. We've invested a substantial amount of money, and we've been very thrilled with the results. It's going to take some time, but we will see patterns of which drug cocktails are working based on matching these tumors. Eventually patterns will emerge. I'm still funding other places, but the majority focus is on this Ivy Brain Tumor Center, which does only phase 0 clinical trials and they're the only one in the US at this point doing it for brain tumor.

Taren: The science is fascinating. Why do you think that your institute, your involvement is the only one doing this type of research? Is it because it's so experimental? Or is it so expensive? Where and why is your organization the only one – or the largest one – doing any kind of brain research at this point?

Catherine: Well, there are two things – economics. In order for this to make sense economically you need volume, and Barrow has the volume of 1300 brain tumor surgeries a year. So in economies of scale, that makes a big difference. And then the other event that's happened is the genetic sequencing has become more affordable and more precise that by taking a patient's tumor sample and sequencing, it's become so fast and cheap that, okay, so this is what this tumor looks like, we can match the drugs. So it's been those two main things.

Taren: And how many phase 0 patients have you had so far?

Catherine: Just over 200 and we started a year ago June.

Taren: Do you have any metrics to support the science?

Catherine: We do. With some of the drug companies some of that is still confidential. So that would be a question that we'd have to ask Dr. Sanai or the people at the center. But we have published based on one of the clinical trials we have published, and there has been media attention for that, but there's a lot more in the pipeline.

The thing is, is it's so fast and it's still extremely high quality, but we need answers fast. I'm so tired of waiting. These patients need it fast. And this process answers that. It's been interesting because at least four other institutions have said 'well, we thought about doing that 15 years ago, but went in a different direction.'

The other thing that plays into this is our foundation committed 50 million dollars to the center. It's by far the largest grant we've done. But the thing that I requested and they were so accommodating, which was unusual, is they don't take any intellectual property, take the money off the table and we're only going to focus on a cure.

Taren: Wow. That is unusual.

Catherine: It is highly unusual in this country. And so what that brings is, for phase 0 clinical trial you can try any drug, you can try any immunotherapy. You can try anything. We don't care. We just want a cure. Those contracts for intellectual property can take years, so to the credit of Dr. Sanai, he was like, 'fine, set that aside. This is about the patient and we need to get this train moving.'

I was looking internationally because no one will give up intellectual property, not many institutions at least in the US. So I thought I was going to have to go to a foreign country. So all the stars aligned on this, so it's been really exciting, and I am finally very encouraged for the future of patients with brain tumors and brain cancer.

Taren: Wow, that's amazing. And we'll keep our fingers crossed and continue to watch what happens at the institute. Because you're right, if this provides benefits beyond 14 months of average life, the results could be remarkable. And really, it is exciting stuff, so congratulations.

Catherine: Thank you. Finally, it feels really good that things are going in the right direction. And so I hope it stays on that track, but I'm encouraged. It's nice when you know your money is really causing change and positive change.

Taren: Absolutely.

Catherine: Very grateful.

Taren: Starting a foundation couldn't have been easy. What are some of the barriers that you had to overcome to really get it up and running and how do you raise awareness around the foundation and the work that you're doing?

Catherine: We're a little unique and that we don't raise funds. My husband had a real estate company and I sold that and I used the funds from that. So I have a finite budget, which also motivates me to get this done. So we do not fundraise, which is unusual. I'm grateful because then we can be fast, and we can be aggressive and kind of fill in what the NIH cannot do. I'm learning all the time with the foundation and I went in cold and have had a very steep learning curve. I've made all the mistakes, but after 14 years, I feel more comfortable. I was a financial planner previously. I did that for over 20 years, so my mindset is saving money. It has had to shift to give it away, but I run very lean. And there's nothing wrong with conferences and bringing people together. It's a family foundation. It's my style. This money is for research. It's not for a bunch of airline tickets and hotels. I just want to be very focused on changing the research. And when I first started the foundation, a lot of people very passionately would say, 'oh, if you give us a lot of money, we'll find a cure and you cannot buy a cure.' It just doesn't work that way. And so like any business, time reveals who walks their talk and you learn more and become more fluent in the science. I've learned a lot, and I'm continuing to learn as I go.

Taren: Do you ever think you'll get to a point where you would start to do some fundraising? You did say that you had finite, the well is only so deep, but the research is so promising. So do you ever envision a time where the foundation be not family and you would go out to generate additional funds?

Catherine: I'm not at that point yet, one day at a time, but not in the near future. It's very to me, and maybe I don't know how other foundations, so I think it's extremely difficult to give away money productively. It's really easy to give away money, but I'm very milestone and accountability driven. And it takes time to do really get into detail so that science can be productive. And the IRS mandates that I give away 5 percent a year. So that's always a tough balance because I've got to get the money out the door, but that I wish they would do that on a five-year average, so that if I have this great project, but it's going to take extra six months, that would be so helpful, but it is what it is, but at the foreseeable future, no, I don't. I'm really focused on the next 10 years. We'll be fine and going down this path that we started. I feel we're moving towards first base. I want to go for the home run.

Taren: That's excellent. Well, it's very inspiring what you're doing. You said there was a learning curve for you. So tell me about how serving on the board of a number of other related associations helped you. You served as a member of the Mayo Clinic, Arizona Leadership Council. You are a board member of the Translational Genomics Research Institute, and the Philanthropy Workshop, and you started on a number of other boards. So how does that help you guide the foundation and how does that help you develop the skills you need to run the organization?

Catherine: A lot of those organizations have great leaders. So the two things I get from being on boards, and I don't like to be on too many boards because I have no time, but watching their leadership, I learned so much learning from others and I really benefit from that. So watching what they're doing, learning from their mistakes, learning from their successes.

And then the other thing that really helps me being on other foundations is, I can get a little on the trees, and when I take a step back on these boards, it forces me to look at the forest, a bigger picture. And that really helps me with my own foundation because I get so deep in the details. I have to take a step back and being on those boards, when I contribute to their perspective, I have to look from the forest. And so it helps me then translate that to my own foundation.

Taren: You take a very unique approach. You mentioned earlier about taking a journey into Syria and volunteering to give yourself some perspective, and then you use your time on these boards to give yourself perspective. I don't know that everyone does that. What is it about your make up that makes you take those steps back and really think about what your mission is to go forward?

Catherine: Well, my husband worked for 30 years to create this nest egg for the foundation. He worked so hard that I feel that it's my fiduciary responsibility to be really

smart about the money and make the most of it. And so those strategies really helped me do my job better and so that's why I do them, then work so hard. And this is the most aggressive deadly cancer, and it affects people of all ages. When you get diagnosed and there's like, well, there's not really anything and people die so quickly, this has to change, and I think it can. With staying focused and persistent, something has to shift. I do things to support myself because I don't want to burn out either, which can easily happen.

Taren: Sure, it could very easily happen.

Catherine: Yeah. And so those activities helped me. I've tried different things, and that's what works.

Taren: And it's unusual. Not everybody would take that approach. So, again, I think what you're doing is amazing, and it's inspiring. Drug discovery, drug development, especially with disease that is so catastrophic and so fast moving, can be very defeating. And you could really lose, as you say, you could lose perspective, but you could also become very depressed about the fact that there hasn't been significant strides since you started this. So I feel that you're encouraged by what's going on at the Barrow Institute and finding Dr. Sanai's... Did I pronounce his name correctly?

Catherine: Yeah.

Taren: How did you two connect? How did that relationship develop?

Catherine: Ten plus years ago, I heard about his work and how talented he was. And so I asked to meet him. And he was reorganizing a tissue bank, and then we stayed in touch and he shared his ideas. He's lost two relatives – close relatives – to glioblastoma and he knows, but Nader is unusual and it's hard to articulate. He's obviously very gifted, as they all are intellectually, but he's got his priorities straight and he just makes it happen. His communication, he's able to take complex things and communicate very clearly. And so I think he's going to make a change. I just do. Some things you cannot describe.

Taren: Right. Well that brings me to my final question. This is our WoW podcast. Is there anything that you can identify from your journey over the last 14 plus years that you could categorize as a wow moment as part of this life journey that you're on now?

Catherine: People are not surviving this disease. And so I've got death in my life a lot, which is not fun because I've got a big heart and I get attached to people. It's just awful to watch. I was at an unrelated to brain cancer conference in Seattle, and I've had this happen two or three times. And somehow some gentleman found out I was there. I wasn't speaking or anything, and he walks up to me with his wife and he was emotional

and said, “the clinical trial that you funded just saved my life,” and then explained how he was able to see one of his kids get married. That’s very moving.

I’ve had a mother write me a letter how her son is still alive because of actually a phase 0 clinical trial done a few years ago. I had a woman who flew into... where was I? I was at the Mayo Clinic in Rochester, and she flew in from Chicago to bring me flowers because her life had been extended from a clinical trial we did. Those things really fill me up.

But the big wow in the last few years is when I was in Syria in a refugee camp when you see 80,000 people have zero control, zero freedom of choice. And no, I can’t control brain cancer, whether I can cure that or not, but I can control me trying. And so that was a major okay, I’ve got to keep going, and I’m not going to give up.

Taren: And as the science progresses, I hope you’ll stay in touch with me so that we can report out on the positive impact you’re having on the lives of so, so many people. It’s amazing work you’re doing and thank you so much for being part of our program.

Catherine: Well, thank you for your time. I appreciate it.

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