

Speaker 1:

Welcome to the Eye on the Cure podcast, the podcast about winning the fight against retinal disease from the Foundation Fighting Blindness.

Ben Shaberman:

Welcome everyone to another installment of the Eye on the Cure podcast. I am Ben Shaberman with the Foundation Fighting Blindness, and I'm delighted today to have with us Dr. Bonnie Swenor. She has a Master's in Public Health and a PhD, and she is the Director of the Johns Hopkins Disability Health Research Center, and an Associate Professor of Ophthalmology at the Wilmer Eye Institute. So before we get started in learning more about the important work that Dr. Swenor is doing, I wanted to ask Dr. Swenor more about how she got to this place, because this work was not her original aspiration coming out of school when she was early in her career. And Dr. Swenor, can you tell us more about that story, those moments?

Dr. Bonnie Swenor:

Yeah. First of all, thank you so much for having me on this podcast. I really appreciate it. So you are correct. I am in a position that I never imagined I would be in my career. I am an unlikely academic in some regards. I started my career with a strong interest in science in undergrad and began working in basic science and then transitioned to public health trying to have a greater impact after college. I was working in DC in a science consulting firm, largely working in cancer and nutrition research. And so this is in 2005, so a number of years ago. And I one day was on my way to work running late admittedly, and was walking up, probably running up the metro steps because I was late, and about halfway up those metro steps, I had a very sudden change in my vision, in my right eye.

It was a sunny day in January, and I at first really just thought it was the sun streaming down that elevator bank of steps, but that after image of the sun, which is what I thought it was, just wasn't going away and wasn't going away. I got to my office and realized maybe there was something wrong. So we had in my office building on the first floor an optometrist actually office. I went down and just asked if that optometrist could take a look.

And in the back of my eye he saw something that caused alarm, and I could hear his voice change as soon as he looked into my eye and told me I needed to see a retina specialist right away. I had no idea at that time in my life really about anything in ophthalmology. But subsequently I was diagnosed with something called myopic macular degeneration. And since that day, since that point, I've been losing more and more vision every year after that first instance. I had a pretty rapid decline in vision over that next about year and a half, and began losing vision in both of my eyes. So obviously had a huge impact.

Ben Shaberman:

So this all came about without any warning or any history. You don't really have a history of this in your family?

Dr. Bonnie Swenor:

No.

Ben Shaberman:

And myopic degeneration isn't really a genetic condition?

Dr. Bonnie Swenor:

Correct, Yeah.

Ben Shaberman:

Can you give us a little overview of what myopic degeneration is?

Dr. Bonnie Swenor:

Yeah, yeah. So myopic macular degeneration occurs in people that are high myopes. So people that are nearsighted that need glasses to see in the distance doesn't always happen, but can happen. And so when you're a myope, in that case, your eyeball actually elongates. And as your eyeball elongates, what happens is it can cause stress or thin the back layers of your eye, the retina. And in that process, some of the cells in the retina can die as they're thin and stretched, and there can even be cracks in the back of those layers of the eyeball. And those things, the cell death, the cracks in the back of the eye lead to vision loss and sometimes sudden vision loss depending on the location. And so that day that I just described, I had no idea this was going on in my eyeballs. That's really what had happened and was the beginning of this journey for me.

Ben Shaberman:

So it's a pretty incredible story because things happened so suddenly and without warning. What was that like for you emotionally? I mean, you must have been extraordinarily afraid.

Dr. Bonnie Swenor:

Yeah, I absolutely was. I think at first I didn't understand, right? At first when I received a diagnosis and heard those words, I had never heard before, I didn't know what it meant, quite honestly. I didn't know my vision loss was permanent at first. I didn't really get that information from that initial appointment. And I remember thinking, when is this going to get better, right? And seeing my retina specialist and asking that question. And I remember my retina specialist looking at me. And again, I think as a person whose vision was changing, being clued into people's voices more, his voice changed. And he said, "Bonnie, your vision isn't going to come back." And I had no idea. And I remember just being devastated and I had to stop driving over that period of time. I stopped working. I went on disability leave for my job because I was having a very hard time keeping up.

Reading is a challenge, recognizing people's faces and features is a challenge. I was very depressed and I've discussed in public spaces before. I contemplated if life was still worth living. And it was a very, very hard time on where I am today in a very different space. I think about that often and I think about why I felt that way. I do this work, which we're going to talk about in a minute, and I sort of really have thought over the past 15 years of what caused me to feel so hopeless, right, which is really how I was feeling. And I think a lot of it was because I didn't know anyone else like me. I thought I had to let go of my aspirations to be a scientist, to be a researcher, which is what I really wanted out of my career that was so important to me.

And I sort of bought into the stereotypes of what life with vision loss was going to be like. That was creating this response. It's not actually the loss of vision that has that emotional response. It's sort of that societal norm that you can no longer do, right? It's that grieving that you go through because you think you have lost opportunity. And things are different. I don't want to put complete rose colored glasses on. I still have lots of daily challenges, but my quality of life is very high.

Ben Shaberman:

So was there a moment or a key situation that kind of helped you turn the corner to start looking forward and getting beyond this really challenging emotional state you were in?

Dr. Bonnie Swenor:

Yeah, that's a good question. It certainly was in bits and pieces and took a long time. It wasn't all at once, per se. A lot of it was gaining confidence in myself and in my work. But I spent a long time hiding my vision loss. Clearly I went to grad school. So at the time when I didn't indicate that I had this initial vision loss, I had just applied to graduate school programs and I put that all on hold. So when I eventually did go back, I spent a lot of effort hiding my vision loss. Was worried people wouldn't want to work with me or would think I wasn't capable. But after I completed my graduate training, only a very small group of very trusted mentors knew. But I was running one of my first studies that I was running as a researcher, and I had a participant that had some questions about the study and asked to meet with me, the person running the study.

And so I sat down with this individual and we had a conversation and I tried to, as best as possible, relate to what this person was asking about. And I disclosed my own vision loss and I felt instantly very awkward and uncomfortable in doing so. I felt maybe that was inappropriate or I shouldn't have shared, there should be some barrier there. And this person sensed that immediately and called me out quite honestly and said, "Why are you apologizing for saying that? Why would you not share that?" And I said, "That's just not something I normally talk about. I'm sorry. I hope I didn't make you feel uncomfortable." And this person said, "Dr. Swenor, if you can't talk about your vision loss, if you are not okay with it as a researcher at the Wilmer Institute, how the heck can I be?"

And I think about that moment a lot, in a lot of ways really was so important. I needed to hear that. I needed to experience that because that person was completely right. I think that moment was one of the key moments in shifting my perspective around this work. I've spent so long up until that point thinking that if I just threw myself into the research, I could make good change for people like me. But I realized I was not really doing all I could by hiding who I was. And I needed to change that.

Ben Shaberman:

Right. And that took years.

Dr. Bonnie Swenor:

Years.

Ben Shaberman:

From the moment you had-

Dr. Bonnie Swenor:

Years.

Ben Shaberman:

... the vision loss experience to the moment you could actually come out and be honest about it with other people.

Dr. Bonnie Swenor:

Right.

Ben Shaberman:

So here you are today. So this all began in 2005.

Dr. Bonnie Swenor:

Yeah.

Ben Shaberman:

We're obviously in 2021 now. And you are, as I said earlier, the Director of the Johns Hopkins Disability Health Research Center. So what does that research center do?

Dr. Bonnie Swenor:

Yeah. So that center is all about changing the paradigm of disability. So not unrelated to that scenario I just described. I don't want anyone to ever have to feel that sense of shame or hiding around who they are because of a disability, because of vision loss. And I have thought for many years around how do we change that? How do we change society? And I think there's an important role to play as a researcher using data to do that. So our tagline is, "changing the paradigm from living with a disability to thriving with a disability." The majority of public health and clinical research disability is at the end of the equation. It's something we're preventing, we're treating, we're curing. And certainly there's important reasons to do that work, but unless we are equally investing in maximizing health equity and inclusion of people like me that already have a disability, that already have vision impairment, we are leaving a lot of people out.

What is that message we're sending, right? We're sending that people like me aren't as valuable, shouldn't have as equal chance at life. And so our center is trying to change that. Disability is at the beginning of the equation not the end. So that is a multi-pronged approach that includes innovative strategies to collect data, using data to change policy, to change the narrative in the ways people view people like me, people with disabilities, and to include people with disabilities including vision loss in all stages of our research, in ways that really haven't been done before.

Ben Shaberman:

That's wonderful work. Wonderful work. Very cool. It just occurred to me, this is totally serendipitous, but we're interviewing you on July 27th.

Dr. Bonnie Swenor:

Yeah.

Ben Shaberman:

2021. And it was yesterday, 31 years ago that the American Disabilities Act. Do I have that? Yeah, the Americans With Disabilities Act was enacted. So this is very timely. We didn't plan it this way, folks. It just kind of happened. So, that's very cool. Are there certain elements of your research that have been particularly enlightening? Has there been a recent project that you've learned something that you think is really worth... Well, I shouldn't say really worth talking about, but newsworthy and impactful?

Dr. Bonnie Swenor:

Yeah. So I mean a great question. I think it's hard to ignore COVID 19, right, at this time. So my center during the pandemic launched a COVID 19 dashboard for people with disabilities. And so I'll talk about that for a second. So what that dashboard did is it collected data and information around how people with disabilities were being prioritized in the vaccine rollout and comparing across states and territories. We not only did that, but we quickly learned early in that process that we needed to make that information accessible. So in compiling that data, that information, we realized that many of the websites from state agencies were providing that information in inaccessible format. So as someone who lives this life with vision impairment, that's a barrier, that's a problem. So our dashboard focused on accessibility of that information to share it out. We then created a second dashboard around tracking the accessibility of the vaccine information and registration websites across states, another barrier that we realized and not unrelated to that first realization.

And so we worked with a group called WebAIM to create a score of accessibility, and we rank states. We updated that dashboard every week. That project is now over. But that was really an important project, and I am very proud of it. We had great partners, the Center for Dignity and Healthcare for People with Disabilities. And we were funded by AAPD, the American Association for People with Disabilities. And that work taught me some really important lessons. It taught me number one of how infrequently critical information, particularly in this moment, is accessible to all members of our population. And I think probably for the audience on this podcast, they already know that. We need to do better. Our dashboard, we did see that that needle move. We saw states respond, states start to invest in the accessibility. It's an important moment. You just referred to that ADA anniversary, there has been a greater focus on the disability community, on accessibility. I'm really grateful. I am more hopeful than ever before about that. And so that's been a really, I think, important project for our center.

Ben Shaberman:

And that's great that the research you're doing is having an impact. Obviously good research is good research, but when you can make a difference and cause change, that's really, really critical. So for our listeners, many of whom have vision loss from genetic retinal diseases or maybe other causes, and you having gone through the journey you've gone through personally and now as the director of this research organization, the Disability Health Research Center, is there any particular advice you would give our listeners out there for advocating for themselves, other than of course, they need to learn how to do it? Any special tips or experiences?

Dr. Bonnie Swenor:

Yeah, I think this is a really great question, and honestly, one, I do get a lot. I think one of the most important things is finding your community. We all need that. I think the pandemic has elevated the need for that, but for people with this unique experience that is critical. I've often said no one hands you a guidebook of how to lose your vision. Our retina specialists, our ophthalmologists, even low vision rehabilitation specialists are so critical and important, but having someone in your community that has this lived experience, you can bounce ideas off of who you can talk to, who I'm a mom with two small kids, how do I not lose my kids at the playground? How do I dose Tylenol in the middle of the night for a feverish child? Those kinds of things are so important, and having someone in your community to talk to relate to in a meaningful way is a game changer.

So I think that's important. That can be hard to find. And we are working on strategies to change that, and I hope others are as well. I also think that, and I alluded to this in my own story, there is societal views of people who are blind, people with vision impairment, disability in general, that are not positive.

It is hard to not internalize that. It is hard to not consume that and truncate your own expectations. But I hope that people with this lived experience ignore that. And that is part of having this community, right? I am working very hard to try and change that societal perception that's not independent. There's a huge force of people behind that, but know that that is not reality. That is an antiquated view that we've got to change. People with vision loss, vision impairment are valuable, are important contributors, and can honestly achieve whatever they want to achieve.

Ben Shaberman:

Well, very well said. And you yourself are a great example of taking that challenge and having it fuel your career really, and ultimately doing great work for all people with disabilities, not just visual impairment, but yeah, people have to find a way forward, and I'm sure everybody's journey is unique to some extent, but your work and you're overcoming that sudden vision loss back in 2005 is quite inspirational. So thank you for sharing that. For our listeners, if you have any questions about the podcast, as always, you can send an email to [podcast@fightingblindness.org](mailto:podcast@fightingblindness.org). Dr. Swenor, thank you so much for telling your very inspirational story and perhaps more important, thank you for the great work you're doing in disabilities research, and it's great that it's having such an impact. Any final thoughts or comments before we say goodbye to our listeners?

Dr. Bonnie Swenor:

Thank you. Thank you so much for having me on the show, and thanks so much to your audience.

Ben Shaberman:

Okay. Well thank you Dr. Swenor. And thank you to all our listeners for joining another installment of Eye On The Cure. Stay tuned and come back for the next episode. Thank you.

Speaker 1:

This has been Eye on the Cure. To help us win the fight, please donate at [foundationfightingblindness.org](http://foundationfightingblindness.org).