

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 the Eye on the Cure podcast. I am your host, Ben Shaberman with the Foundation Fighting Blindness. And I am delighted today to have a truly inspirational guest join us. And many of you may already know of her because she is a well-known personality in many circles, especially the foundation's vision loss world. And with me is Rebecca Alexander, affected by Usher syndrome Type 3A, which causes combined hearing and vision loss. Rebecca is a psychotherapist, author, fitness instructor, disability rights advocate, and an incredible athlete. And she's won many awards and honors, including the foundation's Hope and Spirit Award. Welcome to Eye on The Cure, Rebecca.

Rebecca Alexander:

Hi, Ben. Thanks for having me.

Ben Shaberman:

Well, it's my pleasure. And I want to add, Rebecca, that you're a wonderfully inspirational speaker. I know you've been a keynote for some of our meetings and obviously a number of other meetings, and you really captivate the crowd. And we could spend a lot of time, the next 30 to 40 minutes or so talking about your many achievements, and that would be fun. But for this audience, I'd like to discuss your journey, your journey with Usher Syndrome, and what you've learned about the condition and living with this difficult condition.

So first, can you just tell us where you're at right now, what life is like right now, where you live, work, if you have any significant others or people in your life? I think you mentioned to me earlier, you have a dog. Tell me where you're at.

Rebecca Alexander:

Yeah. So I am in New York City. I was born and raised in the San Francisco Bay Area, and I moved to New York City in my early 20s to attend graduate school. It was no coincidence that I moved here. I was always fascinated by the bright lights and big city. But I was also at a time in my life where I knew that driving was not something I was going to be able to do for long term. And this was before ride-sharing, no Uber or Lyft existed. And so I wanted to be in a place where I knew I would be in sort of the same boat as everybody else. And in New York City, people use the bus, the subway, taxis, they walk to get around. And so, I really felt like this would be a good place for me to have longevity and also to have the accessibility that I would need in terms of my disability, as it progressed.

So I've been in New York for, oh man, about 22 years. And I guess that officially makes me a New Yorker. So I am cochlear implanted on both sides. I'm very fortunate that my hearing loss was very mild when I was a child, that in fact, we were told that it was likely because of frequent ear infections that I had what was described as a cookie bite of hearing loss in one of my ears, which was my right ear. And so at the age of 12 when I had difficulty seeing the blackboard at school, my dad took me to an optometrist. There was something in the back of my eye that he couldn't really identify because his equipment wasn't sophisticated enough. So we went to UCSF, we went to Stanford, and they both confirmed a diagnosis with retinitis pigmentosa.

So, my initial diagnosis was RP. We didn't know yet at the time that I had Usher Syndrome. And it wasn't until I was at the University of Michigan as a sophomore, I was about 19 or so, that I had a significant dip in my hearing. And I experienced very loud ringing, tinnitus, in my ears. And I think there was maybe some idea that my mom may have known or dad may have had some idea that maybe it wasn't just RP, but I certainly didn't know for sure. And that was my first official diagnosis.

But to go back to your question, which is, where am I now? I have a very busy life, thriving psychotherapy practice, and I teach fitness classes. And just completed my yoga and meditation teacher training for adaptive and accessible trauma-informed yoga. And I couldn't tell you for sure exactly what my degrees of vision are now, but I would say it's somewhere probably less than 10 degrees.

And just to remind people, I think that this audience knows very well, but people will often say you have certain percent of vision loss. And we don't actually look at vision loss in terms of percentage, we look at it in terms of degrees. So if a normally cited person has 180 degrees, I can describe mine as somewhere less than 10. And hopefully that gives people an idea. I have this very small sliver of vision on my outermost periphery. Which some people with RP or Usher Syndrome experience as donut vision where you can see inside the donut and outside the donut. But there is a area within your field of vision that you don't see, which makes up that donut.

Ben Shaberman:

Exactly. Thanks for explaining your visual experience because I think your visual experience is not uncommon, but everybody's visual experience is a little different. So again, thanks for clarifying that. So you were diagnosed at a relatively early age. And how would you say that that shaped your relationship with your family and then moving forward, in your career?

Rebecca Alexander:

Yeah, that's a good question. And I'll tell you that I was very fortunate to have very supportive parents. But I will also tell you that at the time that I was diagnosed with RP, my parents had recently separated and were getting divorced. And so, there was a confluence of dealing with this diagnosis. At the age of 12 when you can, for all intents and purposes, see, I struggled at night, as most people when they're first diagnosed, experience. I struggled with tripping over the dogs, over the dishwasher, if it were open.

I was contending with this diagnosis of learning that, okay, when I went into a movie theater or if I was navigating at night, I would need to grab someone's arm. It wasn't like, "Rebecca, you're going to be blind by the time you're an adult." I think there was a lot of, what I would describe as developmentally appropriate information that was shared with me. That this is what I have difficulty doing, seeing at night, seeing below me, that there are parts of my vision that are not as strong as other parts of my vision, and that my day vision was more reliable than my night vision.

And so, I think that having that support from my family was crucial for me. My parents became very actively involved in the Foundation Fighting Blindness. In fact, my mom was the Western Regional Director for the FFB in California for over 20 years. And my dad was on the board, and they really tried to be as involved as they could be to understand what life might look like for me, to connect with other people, to find a sense of community. And I'm so grateful to them for doing that, because it really did give me exposure at an early age, at a time when maybe I didn't want to have that exposure. But it certainly created this level of comfort for me in being able to be around people who had vision loss.

So I attended an FFB conference for the very first time. It happened to be held in San Francisco, where I lived across the Bay Bridge. And so we attended that. And that was where I met two of my dearest friends to this day, Dave Wesley and Craig Stein. And we still are on a group text. And we met as

teenagers there. And what was far more meaningful to me than any of the other aspects of this conference was just connecting with other teens who lived with what I lived with. And to be able to share similar experiences and laugh about it and really feel like I wasn't alone, was just crucial.

So I think that early on in terms of my education, the education system's much different now than it even was when I was growing up. And so, we didn't have IEPs the way that we do now. One of the biggest issues I think that I faced was, at the time that my parents were getting divorced and I was also going through this diagnosis, there were some teachers who were less than sort of accommodating or understanding. They said that I was a dreamer, that I had my head in the clouds. I think it's likely that maybe I didn't hear in some classes.

And I had a twin brother who's not affected by Usher Syndrome, but who was incredibly smart and incredible athlete. And so, I think maybe there was some piece of feeling like he was the smarter one or he was the more gifted and capable one, in terms of academics and sports. And so I think that actually having these messages early on from certain teachers, not from my parents, but from certain teachers questioning what type of student I was or who I would become or my intelligence, was what propelled me. At some point, my mom realized that I needed to get some extra help with, let's say it was math. And I transferred to a new high school and I found that a lot of the material was somewhat of a repeat of the material I'd done the year before.

And I finally found that I really could strive and thrive academically, and I really found a greater level of confidence in myself. And something happened in that moment where it was like, "Oh, right. I have control of my trajectory. Or I'm the one who can determine who I will be, how intelligent I am, and that these teachers who had undermined me...", it was sort of an FU to them to show them what I'm capable of and not be defined.

Ben Shaberman:

That sounds like such an important moment in your life, an important transition. I can only imagine that when you first started getting that messaging from teachers, that must have been really difficult emotionally.

Rebecca Alexander:

Yeah. There's a time that I can remember, and my mom remembers this time too, that my fourth grade teacher, we had what was assembly, and it was in, I think the rotunda. And we would go in there and it was always dark. And they would have it dark when all the classrooms would file in there because they wanted kids to keep it down so that then we could start. But because it was dark, I would grab my teacher's hand, or I think there was even a kindergartner that I'd befriended who would guide me into the rotunda. Because the fourth grade and the fifth grade and the sixth grade would connect with younger students, just partnerships.

But I remember this teacher told my mom that I was needy, that I was clingy, and she essentially criticized me to my mom. And so there were two things happening, A, I couldn't see, and B, my parents were getting divorced. And that lack of empathy and compassion to this day is something that I will never forget, and I think is so crucial when we are working with young people and particularly young people who are living with vision or hearing loss.

Ben Shaberman:

Wow, that's a really inspiring and challenging moment. And I guess going through that, do you think experiences like that led you on the path to become a psychotherapist? Because you're really trying to help people now through their emotional challenges, whatever the cause.

Rebecca Alexander:

Well, I think that when you're treated that way as a young person, you look to adults to be the ones who make you feel validated. Or if there are certain ways that they treat you, it makes you feel lesser than or incapable of or capable of, whatever it may be. Because we look to our teachers, we look to adults, we look to older people to really be our leaders, our guides, the ones to cheer us on, and to be our coaches. And so I think that that really sort of reinforced this feeling of insecurity in me.

And over the years as I started to do more orientation, mobility training, O&M training, I would find that I was learning all of these physical life hacks or tools that I could use, like flashlights when I went to summer camp. At the time, it wasn't as much technology, but devices that could be used to improve my quality of hearing. If I was on the phone, there was a certain little piece that you could put over the actual head piece where you listened to the phone that would amplify the sound of the call.

So all of the physical aspects, those were things that I could learn. But there was always this emotional piece or this piece that was intangible that was never really addressed. And that I only found in the times that I spent with people who also lived with the condition that I had. When I would attend conferences, there was a sense of connection and emotional understanding that was unlike anything I'd ever experienced, and certainly I couldn't gain from learning some of the orientation mobility skills that I needed to.

And so, that made me become more and more curious about, yes, I understand the physical implications. And with FFB and all the research being done, we are constantly bombarded with, they're working on this very promising treatment and there's so much hope, and I am the cure and everything. But that to me, was just one, almost minor part. And I know it's not minor, but a small piece of what it is like to live with a condition that causes you to lose two of your most vital senses.

Ben Shaberman:

Right. And I think you're making an important statement about the journey and also the role of the foundation. Yeah, we're funding research, we're creating hope, but there's the here and now of getting through life with progressive vision loss and hearing loss. And there's the emotional side and the connection, and that's just as important as anything else.

And can you talk about how your, for lack of a better way to put it, emotional state may have ebbed and flowed through your life? You talked about when you were young and how the teachers were not supporting you at all, or not as much as you needed. You kind of found your way through that. You came up with some life hacks. But I imagine that your emotional journey has had its ups and downs.

Rebecca Alexander:

Right. So all of our emotional journeys are very much impacted by the people who raise us, who we're surrounded by, who we sort of develop these belief systems about ourselves based on how we're treated. And I think this is crucial not just for people who live with a retinal degenerative condition, but also for the caretakers, for the parents, for the siblings, for the loved ones, for the spouses, for the significant others, whatever. Because it is very much a part of how we experience ourselves in life, based on how we're received and treated.

One of the things that I've found in my practice, and I am so relieved that we are finally having these mental health conversations. And unfortunately in my mind, I think it's COVID that really brought mental health to the forefront. That all of a sudden people are like, "Oh yeah, we're all really struggling with our mental health." And so I am certainly not by any means happy that COVID came to all of us and has caused the type of destruction for so many of us that it has. But I'm very relieved that it brought about the significance and the utmost importance of taking care of your mental health.

I would say that my emotional health and wellbeing really sort of has evolved. I think that when we live very much in this medical model, it's very difficult to be in this place of being very hopeful and optimistic and putting a lot of effort and time and energy and fundraising into funding treatments and looking for ways of stopping further progression. I've always struggled with the word, cure, because I think that because I'm now, well, 44 tomorrow, but since I was 12, I was told in 10 years there would be treatment.

And here I am at 44 and I'm still living without treatment. Which is something that I think there's been a carelessness with which people have communicated, particularly to our community, that there's going to be treatment in 10 years. And for those of us who live with this, that really is less a physical issue and more the psychological and the emotional implications of receiving information like that, and then having to live with it.

So in terms of the here and now, I think that I have been through all of the emotions that anybody can imagine you go through when you live with a condition like this. I think the only difference is that because mental health has been so interesting and curious, to me, I've seen myself almost as my own, I don't want to say, lab rat, but on the one hand been totally affected emotionally by having a condition like this. And on the other hand, I'm so curious about the emotions that come up for me in living with a condition like this. How much grief and loss is involved, and how much we don't necessarily discuss the grief and loss that's involved. Because it's not like we're dealing with the death of a loved one, but there is tremendous loss and grief involved.

One thing that is crucial for us to remember is that it's okay to be looking for treatment and very hopeful and optimistic. But I also think that when we live based on that medical model, we live with this underlying assumption or idea that there's something wrong with us, that we need to be fixed. That until there's treatment, our lives will not be meaningful or fulfilling or that we have to rely on others. And we all have to rely on others. Communities and the most thriving communities are ones that are based on interdependence, not just dependence, that we are all interdependent on each other.

Ben Shaberman:

Those are all great points. And first of all, happy birthday. I know our listeners, this is just audio, but for 44, you look awesome. You're-

Rebecca Alexander:

Thanks.

Ben Shaberman:

... obviously taking care of yourself. But I think part of what you're saying, and it is so important, there are different ways to deal with the grief and the loss and the emotional challenges. It's not like there's a magic bullet or one thing you can do. Thinking about the future treatments and cures or whatever you want to call them, that can provide some hope. But clearly, as you've said, that's not everything.

As you've gone through life, coming up with hacks to adapt to your vision loss and hearing loss, that's really important. And you mentioned that you need to have people in your life that can give you support and help take care of maybe difficult situations. So I think what I hear you saying, is to deal with the grief and the loss and the emotional challenges, you have to approach it with different tools and different resources.

Rebecca Alexander:

I think that many of us who live with, again, retinal degenerative conditions, there's a few things that happens, one of which is, that we may have the people in our lives. The people who are closest to us are generally the ones who wrestle with it the most with us, and that we wrestle with the most, because we so badly don't want to have or need help. We don't want anybody to need to help us. And we absolutely want people to be mind readers. Because when we have to ask someone for help or when we have to tell them what we need, it means that we are admitting or we are saying out loud that I am incapable. When in fact, we're not incapable, we just need support in being able to do whatever the activity is or whatever... if we need to get from one place to another, it's something that we need someone to help us maintain our autonomy in doing.

And so I think that oftentimes when we fight with each other as family members, as loved ones, what we're not talking about is the frustration, is the sense of loss. It is the grief, is all of the sadness because we're so afraid to talk about that stuff. It's so much easier to sort of battle. It gives us a sense of this superficial sense of somehow being in control. When in reality, we are not in control. And the only thing that sort of really happens for us is this real sense of frustration with ourselves, with our loved ones. And it also keeps us from developing that emotional connection with the people who really do want to help us most.

So I think it's important to remember that when you are struggling through it, whether as a loved one or someone living with it, asking yourself, "Okay, so what's really going on here? What am I really feeling?" Because anger and frustration is one of the first things that sort of comes to the surface, when dealing with grief and loss.

Ben Shaberman:

Right. And as I'm listening to you, I'm thinking how universal your message is, that you have to obviously communicate with your loved ones, let them know what's going on. And that applies to anyone, regardless of their abilities and limitations. And as I'm thinking about it, that must have prepared you so well to be a psychotherapist. Because in a way, you had to learn how to navigate the world by reaching out to people and advocating for yourself and expressing yourself. And I presume that's somewhat of the message you deliver in psychotherapy, at least part of the message.

Rebecca Alexander:

Mm-hmm. Whenever parents of children have been diagnosed with a retinal degenerative condition, come to me and say, "How can I help my child?", the first thing I tell parents, first and foremost, is that they should seek counseling or therapy. Because what happens is, we have our own feelings and emotions and fears and anxiety and all of the things that come up for you, understandably, when you have a child who's been given diagnosis that you're trying to wrap your head around.

The difficulty is that when we don't address it and our own feelings, we don't take care of ourselves, so to speak, we project our anxieties, our fears, our beliefs onto our child. And that in turn, develops in the

child. And children don't know that they're incapable, they learn it. And they learn it based on how they're treated and the tools that they're given, or the tools that they're not given.

So I always think that first and foremost, when you want to support your child, that you need to get that support for yourself of what are the fears, what are the belief systems? And yes, you can absolutely be a champion for raising money to find treatment. But you also need to be in the here now and provide your child, no matter what happens, with all of the tools to be as independent and self-advocating as possible. Self-advocacy, I simply cannot impress upon people enough how important teaching self-advocacy skills is to everyone, but certainly to children. And that's how confidence is built, it's how needs are met, it's how success is achieved, all of those things.

Ben Shaberman:

Those are great points and messages, and not only for the parents and young kids, but for people at any age. So I want to shift gears a little bit and talk about your memoir, *Not Fade Away*. And I have a quote here from Meredith Vieira, the TV personality, former host of *The Today Show* and *The View*. And about your book, Rebecca, she said, "Her eyes and ears may be declining, but Rebecca's sense of self is sharply focused and profoundly tuned. By sharing her life, she has enriched mine and will yours too. I love this woman." That's such wonderful quote, a sweet quote. So tell us, what inspired you to write the book? Was there a certain event or moment where you thought, "I want to share my story."?

Rebecca Alexander:

So I have an older brother who is a White House correspondent and host of *The Today Show* on the weekends. And we were really trying to raise awareness for this condition. This is in like 2008. And there was not a lot of awareness. This was before social media was what it is now. And I realized that the only way we're going to get awareness out there is if somebody comes out and says, "Hey, I have this. This is what it looks like." And I wanted to be able to start getting the word out so that people could come together, and that there would be a greater sense of community and belonging. Because it can be incredibly isolating to have a diagnosis like this.

When you go to a doctor's office, they tell you all the news that is not going to make you feel good. But they don't give you necessarily the resources that you need to connect with other people and find a sense of belonging. So a literary agent saw that interview, read the article from *New York Magazine*, and reached out and said, "Hey, I think you should write a book." And we met up and I said, "What does it..." I must have been 28 at the time. And I said, "What does anybody want to hear from a 28-year-old? Like a memoir?" How vain do you have to be to write a memoir at 28? And so I said, "I really appreciate it, I think that's sort of a silly idea."

And some years later, we had a spin-a-thon. I taught spin for many, many years. And we had a spin-a-thon, and it happened to be written up in the *New York Times*' style section. And the same literary agent approached me, I think this was in like 2011. And he said, "Now, would you consider writing a book?" And what I realized from that last initial meeting until then, was that I found that reading memoirs was particularly meaningful to me in reading about people's lives. That no matter how different our circumstances were, there was this very deep-seated common ground that was the human condition.

And so I found so much that I could empathize with, that I could learn from in reading other people's memoirs. And so I figured that there weren't other books about people who were living with Usher syndrome out there, and that it would potentially be meaningful to others. And it was incredibly cathartic to write this book, to put all of these experiences into one place for myself. So, I found it to be very therapeutic.

Ben Shaberman:

That's great. And I know COVID has had an impact on this, but there's a movie, a potential movie in the works.

Rebecca Alexander:

Yeah.

Ben Shaberman:

Right?

Rebecca Alexander:

Yeah. Yeah, that's been an interesting experience itself too. It's been, I mean, gosh, now almost eight years in the making or so. And it's gone through many iterations, and it's continuing to evolve. And now I have a larger role in terms of consulting, so we'll see. Let's see what happens.

Ben Shaberman:

Okay. Okay. I know when it comes to things like books and movies and Hollywood, it's sort of a circuitous, ever-changing path. So, we'll be patient and see what happens. And hopefully that'll keep moving forward and come out in the not too distant future. So, I want to get back to another question or comment that I requested. And maybe I totally got this wrong, but do you in fact have a dog or did I...

Rebecca Alexander:

No, I definitely have a dog.

Ben Shaberman:

Oh, okay.

Rebecca Alexander:

And Ben, she is... So not only do I have a dog, people often ask me, "Well, are you religious, having a condition like this?"

Ben Shaberman:

Right.

Rebecca Alexander:

And sure, I was raised as a reformed Jew in Berkeley, California, for whatever that's worth. But what I will tell you is that if you spell God backwards, it spells dog. And that is how I would define my religion. There is nothing that makes me happier than dogs. My life is filled and full because of dogs. So yes, I have a dog. And I spend every morning in Central Park for off leash hours with my dog, and all of my dog friends and their dogs. So yes, I have a dog.

Ben Shaberman:

That's great. What kind of dog? Is it a mutt or a certain breed?

Rebecca Alexander:

She's a, what we call, a designer mutt. She's a mini Bernedoodle. Everything's a doodle, poodle, caboodle. And I had a mini Goldendoodle. I have a lot of people in my life who are allergic to dogs, so in order to be mindful of that. I grew up with golden retrievers and Bernese Mountain Dogs. So yeah, her name is Violet and she is a miniature pony. Yeah, there is nothing in my mind that is better than dogs.

Ben Shaberman:

Well, that's great.

Rebecca Alexander:

Yeah.

Ben Shaberman:

That's great. That's a nice moment to kind of wind down with. Rebecca, thanks so much for talking about your journey specifically. There's so much in your life that's happening and has happened. I appreciate your focusing on the emotional side and the adaptations that you've needed to make, I should say adaptations. And I think that's so meaningful, again, for many of our listeners who are dealing with progressive vision loss. But for those of us, regardless of our challenges, you really give some important information and messages that we can all take with us. So, thank you. And enjoy your birthday. Any big plans tomorrow?

Rebecca Alexander:

So it's supposed to be four degrees tomorrow, I think, a whopping four degrees, and we are going and doing bumper cars. As sort of a side note, I used to love driving and I brag about the fact that I was a great driver. And so my friends always say, "We should go to the racetrack.", and whatever. And so they decided to take me to do bumper cars. There's about maybe 12 of us going to do bumper cars in four degree weather, on the ice, in Bryant Park. And then we're going to grab a bite. So, we are going to freeze our tails off.

But I think the last thing that I wanted to share with everyone is that two things that are so important is, having a sense of humor is vital to living with a condition, when you have vision or hearing loss. And I have so many ridiculous stories and funny things that have happened. Because if you don't have a sense of humor, it's hard to get through life, period.

But more than that, I want people to know that when you experience times of loss or difficulty, it's okay to completely break down and cry. And you have to, because it's only in being able to allow yourself to experience those emotions that you can then continue to move forward. I hope that people will take that away and certainly know that they're not alone, that we are all in this together. No matter how far apart we may live from each other, we're all doing it.

Ben Shaberman:

Right. Thank you for sharing that and enjoy your bumper car excursion. It sounds like a lot of fun. And that's an important message as well. You got to have some fun and do some crazy things. So, enjoy your birthday. And again, Rebecca, thank you for taking time out of your busy practice to talk with us. I think what you've had to say, I know it's been therapeutic for me, and I'm sure it'll be therapeutic in many different ways for our listeners. And to our listeners, thanks as always, for tuning in. And we look forward to having a new episode in a couple of weeks.

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Speaker 1:

This has been Eye On the Cure. To help us win the fight, please donate at foundationfightingblindness.org.