Announcer:

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'm your host, Ben Shaberman, and really glad you could join us.

When I got the background on the story of my guest for this episode, I was very intrigued. And then, after talking to him, I was really inspired. And, as many of you know, we at the foundation celebrate and tell the stories of people with retinal diseases and vision loss who do remarkable things. We tell the stories of artists, athletes, musicians and, honestly, their courage and resilience are always inspiring. But my guest for this episode, his name is Brendan Creemer, he is truly taking on his retinal disease in a bold way. He is dedicating his education and career to finding a cure.

So Brendan, welcome to Eye on the Cure. It's great to have you with us.

Brendan Creemer:

Hi everyone. Thank you for having me. Nice to meet you. Looking forward to talking.

Ben Shaberman:

Well, we're looking forward to the conversation. And just a little background on Brendan for our listeners. Brendan is 24 years old. He grew up in Palo Alto, California. He has Usher syndrome Type 1F, which causes profound deafness at birth and progressive vision loss from retinitis pigmentosa. And it also causes balance issues due to some vestibular challenges.

And Brendan, you are one smart dude when it comes to science and facts. So please don't hesitate to correct me during our conversation if I say something you think needs a little help, okay?

Brendan Creemer:

Absolutely.

Ben Shaberman:

Okay.

And just so people know, Usher syndrome causes vision loss and hearing loss. It affects about 4 to 500,000 people globally, and that translates to somewhere in the neighborhood of 25,000 people in the US. And Usher 1F is a relatively rare form of Usher syndrome. And I also want our audience to know that the Foundation Fighting Blindness is collaborating with the Usher 1F Collaborative on a natural history study called RUSH 1F to better understand Ush 1F disease progression and also designs for future clinical trials of Ush 1F therapies.

Okay, Brendan, let's get started. I'd like you to tell us a bit about your diagnostic journey. You were born with profound hearing loss, is that correct?

Brendan Creemer:

Yes.

Ben Shaberman:

Okay.

And so, what actually led from that situation to the Usher syndrome diagnosis?

Brendan Creemer:

So I was very little and I had just gotten my first cochlear implant and it was working fine when my parents noticed I had some vestibular delays trouble with walking and standing up, and they were concerned. They thought that that was somehow linked to my deafness. And so, they took me in and there the doctors figured out that it could possibly be Usher syndrome, which causes both deafness, and balance issues, and also vision loss. And so, they ran an ERG and electroretinogram or whatever it's called on me when I was young. And from there they were able to detect the early signs of vision loss. And so, that's how I was diagnosed.

Ben Shaberman:

Right.

How old were you when they came up with the Usher syndrome diagnosis?

Brendan Creemer:

22 months. And I was way too young to learn about it then. My parents didn't tell me until much later in life.

Ben Shaberman:

Okay.

Let's talk about that a little bit. What was it like as a kid to have hearing loss and then, get the Usher syndrome diagnosis? How did you react?

Brendan Creemer:

So I didn't mind the hearing loss at all. In fact, as a typical kid would with any type of technology, I found cochlear implants to be kind of cool. But when I got the diagnosis, I was 10 years old when my parents decided to tell me. And back then it didn't really matter because it seemed so far off and I was just a kid living in the moment. It didn't matter too much to me back then but of course, as we will get to in a little bit, it did matter to me as the years went on.

Ben Shaberman:

Right.

And how do you feel your parents dealt with your situation and the diagnosis? How did they react?

Brendan Creemer:

Oh, they were pretty devastated in the beginning and started scrambling for whatever resources and information they could find.

And the thing is, a lot of organizations like the Usher 1F Collaborative didn't exist back then, and you wouldn't even know what subtype I had, and there wasn't as much information back then when I was first diagnosed. And so, they were just really scared, really nervous in the beginning. They didn't know what was going to be coming of me, what sort of research was out there. And so, they just started looking for whatever they could find to help me grow.

Ben Shaberman:

Well, that's a natural reaction. A lot of parents react similarly when somebody is diagnosed with a retinal disease, or a similar condition.

When were mutations in Ush 1F identified?

Brendan Creemer:

I'm not quite sure on the exact date, but I'm pretty sure it was in the late 2000s. I know some other folks with Usher syndrome had their mutations identified in 2006 and 2007. I got the subtype diagnosis in 2009 when I was 10, when they first told me when they were able to do a blood test. And so, it wasn't for about 7, 8 years after I was first diagnosed.

Ben Shaberman:

Sure.

So growing up with Usher syndrome, you had the hearing loss, but the cochlear implants, I get the impression, have served you well. And in terms of the vision loss, how was your vision as you were going through elementary school, and middle school, and into your later school years?

Brendan Creemer:

Well, as I think some other individuals with Usher syndrome might be able to relate, they didn't know they were diagnosed until people told them. That is the amount of peripheral vision I was losing was not enough for me to really notice it. And it was really slow to the point where even now I can still only really notice it if I look hard enough if I think about it. And so, even as I lost some peripheral vision, I grew smarter as I grew older. And over the years I was learning how to get around, and my brain just figured out how to adapt using central vision, and work with that as I got older.

Ben Shaberman:

Right.

But you mentioned this earlier in our conversation, there was a moment though when the diagnosis really hit home for you. Do you remember that and how it felt? Was there a trigger?

Brendan Creemer:

Yeah, so it was when I was 14 and the Usher 1F Collaborative was just being launched and the [inaudible 00:07:31] who were in charge of it had put together a website with everyone's profile. And my mom uploaded a profile of me to the website, with my permission. And I was looking at the story that she put up there and it gave such a bleak outcome of my future. And I was like, "What is this? This is not right. This is horrible. This is just too much."

And the other thing is I was having plenty of issues in school with being over accommodated for my disabilities in classes. And I realized that none of this would've happened had I not had Usher syndrome in the first place, had I not had that mutation in my genes. And so, that's when I realized that Usher syndrome was the number one problem in my life, and all other problems were not relevant to this anymore.

And so that's kind of the moment when it hit home for me. And I should also add on, as I got older, I became more conscious of my status in society as an individual with a vision impairment. And I've realized this whole time, I've never been comfortable with label of visually impaired as in the same way

that a trans person might not be comfortable with cis pronouns. Like we are who we choose to be and we should not let society define who we are. And so I was like, "Why do other people have to decide that I have this? Why does my body have to decide that I am this kind of person? The only person who decides who or what I am is me."

Ben Shaberman:

That's a really mature and reflective perspective on who you are. I applaud you for that.

So as you went through school, how was school in your, let's say, elementary school years and middle school years? Did you do relatively well?

Brendan Creemer:

I did. There were some subjects that I liked and some subjects that I didn't like. And I'd say most of the time I was actually over accommodated more than under. I know some people can't relate to that. In fact, I could relate to the opposite, but I felt like the number of aides that were coming around me was a little too overwhelming in some instances. And other times it was obviously helpful but, at some point, it was just too much. And I didn't like being alienated from the other kids by having these disabilities.

Ben Shaberman:

Right. That's a really tough thing at that age to be a kid or an adolescent and be labeled as different from everybody else. I can imagine that was pretty challenging.

But there was a pivotal moment when you really got pulled into the science, just biology in general. And can you tell us about that?

Brendan Creemer:

Yes, absolutely. So science has always been my favorite subject in school, even since elementary school. But it was in high school when it sort of hit home to me in the same way that my Usher syndrome diagnosis did. So around the same time that my story got posted to the website, and I had the revelation about how bad it would be, I was taking biology in my first year of high school. And we had just gotten to our unit on biotechnology, and I was absolutely wowed by all of the new stuff that I was learning about how scientists could edit DNA using modern technologies to create new species of organisms. And, to be honest, do stuff that up until that point, I literally thought was the work of science fiction and no more.

And so I was honestly impressed and, as I said, this was happening around the same time as I had the revelation about my condition and I decided that I would do whatever it took to find the cure for my condition. And so, I elaborate on the science a little bit more, I was intrigued by what scientists were doing like creating new species like glowing mice or whatever. And I was like, "If scientists can create mice that glow green, can scientists change genes in retinal cells so blindness can be reversed?"

And it turns out that research was indeed going on. It had been going on for some time. There was an organization of researchers working to cure not only blindness, but Usher syndrome. And that was when I realized that this had to be the career for me. I wanted to do whatever it takes to find this cure and I still will. And I could combine my passion for science, which I've always loved, I always wanted to do something science related growing up, and I could combine that with my personal struggle to not only help find the cure for this condition for myself and others, but also choose a solid career path as well.

And I mean, this is something where I could have just given up, I could have realized that I was going to have to live with this, but to quote a certain Martian astronaut, I was going to science the bleep out of this.

Ben Shaberman:

That's a great quote. And I really applaud you for finding this path forward because doing the science and the research is not necessarily the easiest path forward, but you've really found your personal mission, if you want to call it that.

So you went through high school and tell us about what happened next, about college. Where did you go and what did you study in college?

Brendan Creemer:

I went to Lewis & Clark College in Portland, Oregon. And I studied first biology and then I switched it to biochemistry when I realized the curriculum would be more appropriate for my goals into joining biomedical research.

Ben Shaberman:

Right.

And so, when you graduated Lewis & Clark, what was your degree in?

Brendan Creemer:

Biochemistry and molecular biology.

Ben Shaberman:

Okay, that's pretty impressive.

And then when you finished Lewis & Clark, which wasn't all that long ago, you landed a really cool internship in nearby Oregon Health & Science University. Can you tell us about that?

Brendan Creemer:

Yes. So just to clarify, that internship actually happened during my time at Lewis & Clark, not afterward. It was the summer between my sophomore and junior years there. But still, I was looking for internships in the field of biomedical research, hopefully, something related to vision restoration, which was obviously my end goal. And during college, I was receiving some services from the Oregon Commission for the Blind, and they got in touch with at first KCI Institute because they figured that would be a good spot to try to get me an internship at based on my career goals. And, through them, they found out about this lab at OHSU run by Dr. Martha Neuringer and Dr. Trevor McGill, where they're doing research into a number of retinal diseases including age-related macular degeneration, retinitis pigmentosa, and more recently Usher syndrome.

And when the PIs of that lab heard about my interest in application, they knew they had to take me on. And what's cool about that is they were initially not planning on taking any interns that summer. In the past several decades, they've had some sort of intern in their lab every summer for the past 10, 20 years. But that summer, they decided they weren't going to take on anybody because they just had a lot of work going on, and it was a lot to manage. But when they heard about me, they were like, "No, this is something we cannot pass up." And they had to bring me in because of my motivation. Out of all the

interns they had, I was the only one who really understood the significance of what they were doing in this research to restore retinal vision loss.

And when I was there, I assisted with this one project where they were trying to assess how well a drug could lower the immune response to stem cell therapeutics that were in development elsewhere. And so, the work I did was mostly obtaining tissue samples from animals models that the lab prepared for me that I used chemicals to stain, and then look at them under the microscope to compare the prevalence of certain immune system cells in animals that had been treated with the drug compared to a control.

Ben Shaberman:

That's really, really cool work.

And you mentioned Martha Neuringer and Trevor McGill. To many people in our audience, both patients and families and the professionals, they know those names. Those are researchers that are well-connected to the Foundation Fighting Blindness. We've funded them. I think we're currently funding Dr. Neuringer for, in fact, some Usher syndrome research. So you really connected to our family.

And so you graduated from Lewis & Clark. How long ago was that?

Brendan Creemer:

Two years ago.

Ben Shaberman:

Two years ago.

And tell us what your plan became after you got your bachelor of science.

Brendan Creemer:

After I graduated, I started working in a lab at the National Institute of Health as a post-Baccalaureate fellow, just to take some time in between to figure out what I wanted to do in the long run where I, ultimately, decided I wanted to get a PhD in biomedical sciences because then I could have a voice that guides the direction of research.

It doesn't necessarily mean principal investigator, in fact, less than a small percentage of people who get PhDs become principal investigators. That's the current statistic. But I knew that that was a degree I still wanted to get. And so, I applied and got accepted to the University of Iowa, which is where I am right now. I'm in my first week of graduate school here in their biomedical sciences program. And my end goal after graduation is to have this voice be with a team of lead researchers to guide the research towards finding the cure or help bring it to market by being involved in industry. But one way or another, I want to be up there helping guide the flow of research.

Ben Shaberman:

That's awesome. And you are well on your way at a relatively young age.

So are you working in the lab yet at University of Iowa?

Brendan Creemer:

No and yes. So, the way the first year works is you rotate in three different labs to try to get a feel for what life is like before you start doing a thesis. And so, this has only been my first week. So yes, I am

working in a lab, but I'm just starting a rotation, and it's a lab that does research into molecular mechanisms in retinal cells. So kind of adjacent, but still a good first step into the field.

Ben Shaberman:

Most definitely. And University of Iowa is another academic research center that we're very well acquainted with and does great work in the inherited retinal disease space. So we're very excited that you're finding connections in homes with these really important research centers.

So just one other question about your work and moving forward. Obviously, you're working on your master's, I presume you're interested in getting a PhD. Is there a certain kind of research you feel fairly committed to? Or are you in a more exploratory mode to see what path you might take professionally?

Brendan Creemer:

It's really funny you asked that because the answer is oddly enough yes to both of those. So I'm committed to this field of retinal research, that's the area I want to go into. But there's so many different research tools you can use to explore the retina that it's still a bit of an exploratory path that all of the labs that I'm rotating in, or planning to rotate in this year are from different sub-programs of the biomedical sciences program.

Right now, I'm in a biophysics lab and later on in the winter and spring, I hope to rotate in labs that specialize more in cell and developmental biology, or pharmacology and other areas. And so, even though I'm heavily focused on this broad significance of retinal research, there's so many different techniques, and avenues you can use to approach it that even now it's still a bit of an exploratory process.

Ben Shaberman:

Right.

And we at the foundation, our science department, we fund a lot of different types of science and research because we're going to not only need cell therapies, we're going to need genetic therapies, small molecules. So I'm sure whatever path you take, you can really make a difference and benefit the field. So I'm just so excited that you've taken this challenging situation of having Usher syndrome and you're really turning it into an important mission to not only help yourself, but potentially many, many other people.

And so before we conclude this episode, we have a special guest to join Brendan, and me, and I just want to get a couple comments from this guest. And the guest is Stacey Ashland, who is Brendan's mom. And I just wanted Stacey, to get your thoughts and perspectives on what it's been like to have this superstar son of yours, and how he's taken on the challenges of Usher syndrome.

Stacey Ashland:

Yeah, thank you so much.

As Brendan mentioned, when he was super young, we were absolutely terrified. It was an unknown territory to find anybody that knew anything about Usher syndrome for a long time. So we were mostly, when he was young, focused on the cochlear implants and hearing,

And learning to walk and talk. But pretty early on, we knew that he was really, really bright. He just had an amazing capacity to learn things. So, as time went on, it became clear that he had bypassed us in his knowledge of things, a lot of subjects, including science. So it's been an exciting journey.

But he's been on this path for a while. I think Brendan, you said you were 14 when it kind of hit home to you what you were dealing with. And he did a couple of summer programs during high school. One was at University of Iowa in the summer with Bud Tucker's lab. And then undergrad, like Brendan talked about, was a little bit of a journey figuring out biochem/molecular bio was the major to have. And then, landing the fellowship at NIH for two years was amazing. And now starting the PhD program, it's all just like, some people are like, "Wow, wow, he's so amazing." And it's like, "Yeah, we know." We've always known he had a lot going for him for sure. And it's great people are kind of blown away when they hear his story.

Ben Shaberman:

Well, that's just it. I was blown away when I learned about Brendan.

And I mean, Brendan, you're 24, right?

Brendan Creemer:

Yeah.

Ben Shaberman:

So you're still a young guy, and I'm very excited to see in the next few years, decade, whatever, where you go and the impact you make in the fight against these retinal conditions. So thank you for what you're doing. And Stacey, thank you for being a supportive mom and having such an amazing kid. It's wonderful to have you both on Eye on the Cure.

Brendan Creemer:

Thank you so much for having me, it means a lot.

Ben Shaberman:

Well, it's my honor and privilege to have you. And like I said, I'm very excited to see where you go in your academic and professional career in the not too distant future. So thank you both for joining the podcast, and taking a little time out of your day to talk with me. And listeners, thank you, as always, for joining Eye on the Cure, and we look forward to having you back for the next episode.

Announcer:

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