

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 this episode of the Eye On The Cure podcast. I am Ben Shaberman, your host and Senior Director of Scientific Outreach at the Foundation Fighting Blindness. And I'm really excited today to have a special guest. I say he's special because he's actually an actor on television, on Netflix. His name is Ben Mehl, and that's also why he's special because his name is Ben. But really he's special because he's on the Netflix show, *You*, which is based on the novel, *You*. And it premiered in September of 2018. And the story, I don't want to give away too much because people just need to watch it and follow the flow, but it follows this guy named Joe Goldberg. He's a library manager, he's a stalker and a serial killer, and he falls in love and has a family. And that's how the show goes.

And it's in its third season. And there will be a season four. And I've watched a couple episodes. And it really pulls you in. It's a little creepy because you have this normal guy who's a stalker and a serial killer, but it's kind of fun in its creepiness. And Ben, our guest today, plays a completely blind character. He's a librarian at the library. His character's name is Dante. And in real life, the reason we have Ben on this episode is Ben has Stargardt disease.

So welcome to this episode of Eye on the Cure, Ben. It's great to have you.

Ben Mehl:

Hi, thanks for having me. It's great to be here.

Ben Shaberman:

So it's interesting that you were able to leverage your retinal disease, your vision loss to play a blind character. Did you ever imagine in your wildest dreams that something good would come out of [inaudible 00:02:25]?

Ben Mehl:

It's so refreshing to get that question because yeah, that's exactly what it feels like. Yeah, in acting, you're always looking for what your advantage is, what your edge is that makes you right for the character. And they were specifically looking for somebody who was either totally blind or had low vision to play this part. So for once in my life, it was a real advantage, it gave me that edge. I was what they were looking for.

Ben Shaberman:

That's very cool. Now, like so many people with Stargardt disease, you have central vision loss because Stargardt disease is a form of macular degeneration. It affects the macula where you get your central vision. But you still have a lot of peripheral vision, which is pretty typical of many people with Stargardt disease. So you're not completely blind as your character is. Was it challenging to make that leap from being partially sighted to playing a character where you're completely blind?

Ben Mehl:

Yeah, it was, and I took it very seriously. I talked with a lot of people and I did a lot of research and I trained with an orientation and mobility specialist to learn how to use a cane and to understand better what it really means to have no vision. Because as you said, I do have all of my peripheral vision intact. It was just very important to me to accurately represent that. On the one hand I felt like, yay, I'm glad that they picked me, that it was important to them to find somebody who was partially sighted to play the role. But I was still within the community in terms of the amount of sight that I have. I'm kind of like a privileged member of the community.

What I did was I observed people. I went to a place in Manhattan that is housing specifically for blind people. And I would just watch people come and go, and observe how people had poise and skill and confidence in moving through the world with no vision and using a cane. And so that's what I wanted to bring to the character.

And what I came to realize was Dante, my character, has been blind for a number of years, and has had the time to learn those skills and to adapt, and to develop that confidence and independence. And so the fact that I have the vision that I have actually helped me play the character more accurately because I could use that as a kind of cheat. So I didn't have the experience that Dante had to be able to learn how to move through the world without sight, but I did have the vision that I do have to help me cheat and not pretend that I'm fumbling around, but actually do things as skillfully as I think Dante would be able to.

Ben Shaberman:

That's great. It's great that your experience informs the character so well. But you do have to play a relatively poised, to use your words, blind person, which sounds a little challenging.

Now, which came first for you, acting or the diagnosis of Stargardt disease, the vision loss?

Ben Mehl:

It was acting. Since fifth grade, I've been acting. It's always been a passion of mine. I went to an art school. And then in high school I was a drama major. And then when I went to university, I double majored in drama and astrophysics. They were both just passions of mine, totally separate passions, but both passions.

I was actually doing a musical, *Reefer Madness*, the musical, and I started to notice this spot in front of my vision. And I had kind of noticed that in my math and science classes, especially, strange things were happening. I had missed numbers and I didn't understand why I wasn't seeing them clearly. And I kept going to the optometrist and adjusting my prescription. And it took some time before getting the diagnosis of Stargardt disease.

Yes, so acting definitely came first. And with the diagnosis, it really gave me a crisis of not knowing what this would mean for my life and how I would move forward with this. And I can talk about... Yeah.

Ben Shaberman:

I presume you must be a pretty passionate actor because you decided to stick with it despite the vision loss.

Ben Mehl:

Well, I did. I won't sugar coat it because I know I'm talking to a population of people that can understand what that diagnosis can be like, or at least some people. It threw me for a loop. I just didn't know what it meant for my life or how to adapt yet because it takes time to adapt. And after about a year and a half

to two years, it was about a year and a half after the diagnosis, I remember I just had this big weeping evening, and I remember being in my mom's arms and letting it all out. And I think it was really the moment where I fully accepted what had happened and the loss of it. And it was then that I was ready to move forward and say okay, I'm not going to let this stop me from pursuing the things that I want to do in my life. And I'm going to take the bull by the horns and learn what it means to be an actor with Stargardt's, and see what that road can take me.

And from there, I decided to audition for conservatories in New York. I got into Julliard and to NYU, and I ended up going to NYU. And I've been pursuing my career ever since then. This opportunity with Netflix has been the biggest moment in my career for me. My mom unfortunately passed away a few years ago. I wish that she was here to see this because she was so supportive of me through all of that. But, yeah.

Ben Shaberman:

Well, thanks for sharing that story about your mom, and that "epiphany" or emotional moment you had with her. That's really beautiful and I'm sure she would be so proud of your success now. And you're successful in other parts of your life, if I can use that word. You have kids, right?

Ben Mehl:

I do. I have twin daughters. They're identical twins. They're four years old. They're in school right now.

Ben Shaberman:

And are you married as well?

Ben Mehl:

I am, yeah.

Ben Shaberman:

Cool.

Ben Mehl:

And we actually met when we were in high school, so she knew me before my diagnosis. And when I got the diagnosis, she stayed by my side even through all of that uncertainty and what it would mean for her future. That meant everything to me. I'll never forget that.

Ben Shaberman:

Yeah, that's pretty courageous to stay with somebody who wants to be an actor. I mean, that's-

Ben Mehl:

That's true.

Ben Shaberman:

And on top of that, they're losing their vision. So I'm impressed. So please personally give her my kudos for hanging in there and giving you-

Ben Mehl:

She definitely deserves it. I will.

Ben Shaberman:

Giving you that opportunity. And so when you're recording the episodes and doing the work, how does your interaction with the crew and other actors? Are they accommodative? Do they appreciate what you're going through? Are there challenges?

Ben Mehl:

Yeah. I'm someone who loves to talk about it. Because it's an invisible thing, no one would know unless I talk about it. I love having the opportunity to talk about it with people so that they can understand what I'm experiencing every moment. And I did have great conversations, especially with the other castmates, letting them know. They were really interested. Penn Badgley, who plays the main character, most of my scenes are with him. And Tati Gabrielle, who is the librarian, and becomes the love interest in the third season. They were just so interested in all of the stories I had about what it's like living with Stargardt's, about the hallucinations that I have in my blind spot sometimes.

There was a funny moment, and I don't know if I'm going to remember exactly, but there was someone on the crew, I was looking at them and there was something that I needed to see. And he made some comment, some kind of joke, like, "Are you blind?" Or something like that. He obviously had no idea. He was kind of clueless. He didn't realize that the actor playing this blind person was also visually impaired. And he quickly was told, I don't know who told him, somebody told him. And he came and very sincerely apologized to me, which meant a lot. He was so uncomfortable and felt so bad. But the apology was just very sincere and I really appreciated it.

Ben Shaberman:

That's nice. He had a learning moment and you were kind about it.

One thing that strikes me about your situation, obviously you have this retinal disease that's causing vision loss, that could progress, and working in the business you work in, how many seasons of You are you in? I know you're in the third season, right?

Ben Mehl:

That's right. So I'm just in one season so far.

Ben Shaberman:

So far. So you have this uncertainty moving forward. Will you get cast again? And you couple that with your uncertainty about your vision. Is that a hard space to be in? I don't mean to raise your fears here, but...

Ben Mehl:

Now that you put it that way, yeah, that makes a lot of sense. But no, it's true. It's funny, as you say that... I'm also a teacher. What I do most of the time is I teach acting. And the thing that I work on the most with my students is going into a place, going into the unknown, going into that place where you are uncertain, and you make discoveries there. It can be a very interesting place to explore from and a very compelling place.

Yeah, it can also be scary, but that's also kind of been the barometer for when I know I should do something is if it scares me. Then I kind of know, yeah, I should probably do that. So yeah, life is scary.

Ben Shaberman:

Yeah, I mean it's scary for all of us, especially in these times with the pandemic and everything. But we all have these issues. You kind of have them, as they say, in spades. But I think for me, it's inspirational because you're succeeding, you're doing what you want to do, and you're, in many respects, living in the moment and doing it successfully. So I congratulate you. Besides getting into the next season of You, do you have other aspirations? Are there other acting gigs that you would really love to get or you'd like to pursue?

Ben Mehl:

Absolutely. Most of my career, I've been doing theater. That's my first love and I want to continue to do theater. It's a tricky time. Theater has gone through a tricky time. But yes, I mean, as an actor, I'm auditioning, and that's how it goes. I don't know what will come next, but a short film that I just did is being turned into a series. So that's exciting. Again, into the unknown.

Ben Shaberman:

Can you talk about that or do you have to...

Ben Mehl:

No, that's not something I can talk about yet. It's also in an uncertain place.

Ben Shaberman:

But that's something cool we can look forward to. And speaking of that, do you have a website where your new fans from the Foundation Fighting Blindness can follow you?

Ben Mehl:

I joined Instagram with this show, so you can follow me @benmehl. My last name is M-E-H-L. And that's the best way to keep up with me at this point.

Ben Shaberman:

Okay, very cool. And just to close things out, for so many people out there who are part of our community, our family, are there any words of advice or encouragement that you might give to somebody who's sort of on the same path, trying to come to grips with their vision loss, and maybe a little undecided what to do with their lives and their careers?

Ben Mehl:

Yeah, I think the most important thing is to follow your joy. The uncertainty that comes with this is just a fact, but it doesn't have to define everything else. There are so many discoveries to be made with vision loss. There's still there so much. I think in the beginning, the only thing you can focus on is the loss, but that makes you forget everything else that's still there and that is still to be discovered.

I think of my mom. She would see everything in her life as a challenge, and she faced so many medical challenges throughout her life. And it's a challenge. And that can be a really positive thing. Challenges are great. So stay positive.

Ben Shaberman:

I like the words you use, follow your joy. Pretty simple, but great words of wisdom. And Ben, congratulations on your success in You. Your success in you, I like that. And again, give us that Instagram account again so people can follow you

Ben Mehl:

@benmehl.

Ben Shaberman:

@benmehl.

Ben Mehl:

B-E-N, M-E-H-L.

Ben Shaberman:

Okay. And we'll look forward to seeing more from you. And it's been an honor and a privilege to chat with you and have this open and honest discussion.

Ben Mehl:

Thanks, Ben. And thank you for all of the work that you're doing. I know it means a lot to all of us, and thank you.

Ben Shaberman:

Well, thank you. And it's our supporters and members of our community that help drive the research, so we all do it together. I want to remind our listeners, if you have a question, you can email it to podcast@fightingblindness.org. Again, that's podcast@fightingblindness.org.

Ben, I will let you get back to your day. Thank you again for your interview, your excellent words of wisdom, and we're hoping to see you move forward in your career and do amazing things. You're an amazing person.

Ben Mehl:

Thank you so much, Ben.

Ben Shaberman:

Thank you.

Speaker 1:

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

