

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'm your host, Ben Shaberman with the Foundation Fighting Blindness, and I'm very pleased and excited today to have a very unique guest with me for this episode. Joining me is Steven McCoy, whose personal journey, along with his list of projects and accomplishments, is really remarkable. As we go through our conversation, you're going to get to hear a lot about those. But perhaps most notable about Steven is that he is the first Black deaf-blind journalist. Steven has Usher syndrome. That's what causes his vision loss and hearing loss. Steven, it's great to have you on the podcast. Welcome.

Steven McCoy:

Hey, thank you so much. That was a great introduction. Thank you.

Ben Shaberman:

I could spend 10 minutes just talking about [inaudible 00:01:19]. Just your current projects alone, that list is mind-blowing. But if it's okay, what I'd like to do is start off chronologically and talk about your childhood because you grew up in a single parent home, was just you and your mom, and you were in Newark, New Jersey. You were fairly young when you were diagnosed with hearing loss. Can you just reflect on those early days and tell us what that was like, how it affected you as a kid.

Steven McCoy:

Yes, absolutely. It was not easy, I would say. In the home it was great because I had the support of my mother, who eventually, I did have my little brother 10 years later. He and I are 10 years apart. But just growing up, being a child who is differently abled, who was suffering from hearing loss, it was hard to keep a natural [inaudible 00:02:28] of communication, if you don't know what people may be saying. I knew that I was different from everyone else. I knew that me wearing hair aids caused division because a lot of kids, they wouldn't just play with me like anyone else. Instead, they would just stare. They had questions and questions that I wasn't quite understanding to answer myself because I'm just a kid. It's like, "Well, yeah, I don't want to wear these because people won't play with me like they play with the other kids." That was how I was. It wasn't easy, but I'm very glad that I did have the strong support of my mother and my family members. My home life was a lot more fun than the outside life.

Ben Shaberman:

That is great that you had a good, strong family support system. But if we can, let's talk about your school experience because that, as they say, was a two-edged sword. On one hand you had some challenges because of your hearing loss, but on the other hand, you're a pretty smart guy and had some real success. Can you talk more about that?

Steven McCoy:

Yes. School was very cool. I managed to... If we're talking about me as a child in elementary and middle school, there was a lot of bullying that happened because of my hearing impairment. Those were visible things that you can see, you can see my hearing aids. And I had the hearing aids at the time that goes

around the ear so you can see it from the outside. And wasn't only my peers that I was bullied by, it was also select of teachers who were a part of the bullying and a part of that ongoing, painful time. It was just really hard, especially just growing up. For me, I not only knew that my peers were the way that they were, but also knowing that if adults are treating me this way, of course it had an effect with me growing up.

But it wasn't all the teachers, I had some amazing teachers. I even remember a teacher telling me... Because when my voice was being mocked, they would mock my voice. And I remember my teacher, Ms. Jenkins, she told me, "Your voice is very powerful and you're going to use it and make a difference one day." And this is just ironic, that I always knew I wanted to use my voice because even just growing up, there had been men in the urban area that I came from that had abused me, that has punched me in my chest, punched me in my throat, and telling me to speak with more bass in my voice. Because if you were a soft-spoken little boy, they associated that with femininity and that just wasn't the way to be coming from an urban environment because...

And from them, think in their mind, they were doing the right thing to toughen you up. But I always say, "Listen, I have as much bass in my voice and there's bass in what I do every single day. And because of what I do every single day, you can't tell me that I'm not tough." It's not easy to go out into the bigger world to truthfully tell your story of how you are different from the world. But actually just me going around the world and speaking to so many different people, if not you that's dealing with the challenge, there's someone that you love that's dealing with the challenge, or there's also someone that you love that may be keeping it a secret from you so that you won't judge them. Or whatever the challenge is. And that's where I was.

Ben Shaberman:

And you do have a lot of bass in your voice. It's a very strong, powerful voice. Now you found some refuge through all that's going on, kids bullying you, adults bullying you, but you found refuge in writing, did you not?

Steven McCoy:

Yes. It's crazy, because of the bullying, I was so nervous to speak. So I went into a time in my life where everything was silent. I did not speak. I did not want to talk in my classes. If I didn't understand something in class, I would not raise my hand because when that was done, the attention was on me and everyone would start laughing at me and those type of things. I just tried to be as invisible as possible. That's how I already felt, but it was important for me not to be at the forefront, that way I can just hurry up. Once 2:30 hits, I know it's almost time for me to go home.

It's crazy because all of those thoughts that built up in my head when I was silent, I put on paper. That was my way of expressing myself. Those thoughts had to go somewhere. And I fell in love with wording and rewording things and coming up with storylines. And actually, it's so funny because again, like I mentioned that my brother came 10 years later, so I was the only child for a while. And I would play with my action figures and I would make storylines out of them, which is... I don't know, when I look back at it was funny because my grandmother used to say, "What are you doing? Why aren't you actually making your action figures fight and stuff? Why are you having them talk like that?" I always say it's her fault, to be honest, because she got me into soap operas very early, Days of our Lives. I watched that through her and I just fell in love with storylines and writing stories and it comes pretty easy to me.

Ben Shaberman:

That's great. Watching soap operas with your grandma. I remember when I was a kid, when I'd get sick or have to stay home from school, I grew up in a single mom household and we'd have [inaudible 00:09:49] a neighbor come over and I'd watch soap operas too. Back then [inaudible 00:09:56] channels and that's all you could watch. Anyway.

So you're going through a pretty challenging time in your early school days with hearing loss. You're finding a way forward. But then comes the RP diagnosis, the diagnosis of progressive vision loss. That must have just crushed you. I don't see how it couldn't have, but tell us about what that experience was like.

Steven McCoy:

I think I went into a state of shock when they told me, when I was diagnosed. Now it's crazy because just the other day, you know how Facebook has those Facebook memories on what you posted years prior? And one of the Facebook posts was in 2009 and I said on my status, on the caption was, "I went to the eye doctor and oh God, they're saying that I'm going to need glasses or contacts." And I'm like, "Huh." Because I do remember at that time, my doctor, my eye doctor, he was informing me that my eyes looked really bad, but we did not even know anything about the RP until years later. And that's because RP is very rare, which I actually find that it's becoming more common with so many different stories that I've been able to read upon or communication that I've had with other people.

But I thought my life was over. I just kept picturing my last days for some reason, I don't know. I went that deep. What the specialist was telling me, she just said, "Yeah, you're going blind." And I even said to her, "Do I come back? Should I make an appointment?" And she was like, "Well, yeah, you can, but we can't change anything." And it felt a little bit heartless, which is why I went to... I changed my specialist and went to... Even for just a second opinion alone. Yeah, it turns out throughout all the tests, I actually do have RP, but this particular specialist, we did a lot of deep tests and things like that, and he was just like, "Steven, you are going to be okay." He gave me a list of vitamins to take to keep my vision at a steady, and he just said, "Get you a flashlight and go live your life."

Even with me being in journalism, I just thought that... I was very, very... I had it all planned out, what I was going to do, and I was going to retire in my journalism career, a career that I worked so hard to remain. It was just very, very tough because I'm going to these red carpet events. I'm not hearing as best. My hearing is decreasing. I'm bumping into things. We got to go into this room now for the media room, then we got to go into the conference room. And all of these different changes. It was just really difficult for me, especially because I was keeping my disability as a secret. I didn't want people to know. Especially in the entertainment business, if something's wrong with you, they'd want nothing to do with you.

It was already cruel considering the fact that I am a black man in media. I was already mistreated with that, but I didn't allow this to stop me. One of the things, I've always had a big imagination. I've always been very inquisitive for what tomorrow will be. But it did get to a point where I did not want tomorrow to come. I just couldn't do it anymore. But throughout a lot of self-evaluation, a lot of communication, even with just my mother, I just realized the only thing that I did not do is just be honest and see how people would react. There were people who left. There were people who didn't want to be around me anymore, simply because of my challenges. It freaked them out.

And I can't say that it didn't freak me out either, but I had to do the necessary research to learn how to navigate a lot better. And I think when you learn to navigate and take control of your stage and take control of your challenges, then that makes it a lot easier on the other people. So I say to those out there to make sure you do the research and make sure you take the necessary step so that you are able to control your life and don't let your challenges control you, or even the people around you. I'm

grateful that I was able to just find my way in this visionary world and this visionary experience. It wasn't easy when I was diagnosed, but I found my way and I just said, "I'm going to use my voice to raise awareness for this." And there's been so many amazing research, some high case studies, and I felt very confident that we will make a way and we hopefully will be able to reverse the blindness. I hope so.

Ben Shaberman:

Well, you're right. There is a lot of a great progress going on made possible in part by the work that the foundation is doing, the Foundation Fighting Blindness. So yes, there is a lot of hope, but I'm so impressed that despite all these formidable barriers, the whole world around you, you found a way forward by taking control. Let's talk about some of the accomplishments and roles you've had because you got an internship at Disney, did you not?

Steven McCoy:

Yes, yes. That was my first official start.

Ben Shaberman:

How did that happen? How did you-

Steven McCoy:

It really is a story behind that. I remember I was in college and I was in the hallway. I had my hoodie on. Now I'm not a person that wears hoodies or things like that. I've always been just a happy soul. I'm a naturally happy person. But this particular time in my life, I had just lost my aunt, one of my favorite aunt, my dear aunt Candy. I went into a state of depression. During my times of... I would have a break in between classes and I would just walk around the school and I think I just looked absolutely depressed. And I remember just sitting in this area and my academic counselor, she came in and she was like, "Hey Steve, do you want to go to Disney World?" And I'm like, "What? No. No, I can't do that. I can't afford it. At this time. I'm also... I live alone. I'm making..." That was impossible to me.

And the reason why she came to ask me that is because in front of me was an advertisement with Disney on it. It was hung up in the hallway. And it's crazy because I actually was not looking at it. It was in front of my face, but I was so zoned out. That's crazy that the sign to my future was in front of my face. But nothing to net, we just had a discussion and I'm like, "But I don't know how I'm going to actually be able to afford to pay my rent in Jersey and also pay rent in Florida. I don't..." But guess what? It actually worked out. I was able to do that. I was very blessed. I had my family who we... Before I left to move to Florida, we had a big party and I got monetary gifts from family members and friends that truly wanted to see me win after all the... Because there was a lot of struggle even before the vision and during the hearing. I was going through a lot, a lot, a lot.

But I'm just so grateful that I had the support to be able to move to Florida to... And that was my first internship that was paid because prior to Disney, I did various internships for five years straight. And they wasn't paid. Now, I've never been a person that cared about the money or anything like that. But I will say it just felt good that I'm doing an internship where I had a card, a credit card to go buy lunch. Because without eating, you can't really do your best. In New York City, me running around doing internship with \$2 and 50 cents in my pocket and sweating and hot. It wasn't easy. It would be raining sometimes. And I'm running in the rain getting things done, and my boss wanting the receipt to be absolutely crispy, dry. It was just a lot of hard work and it just... Disney gave me that first opportunity to be able to be comfortable. I just felt good that I could finally buy whatever I wanted for lunch.

Ben Shaberman:

That's great. And so what exactly did you do for Disney in those early days and how has your work life expanded, all the different projects that you have going on?

Steven McCoy:

Yes. I worked in guest relations and live entertainment. We was able to work behind the things to assist with the parades and the characters, working with the Disney characters behind the scenes with that, being friends with them. It was really, really a cool thing to see because with that, Disney is a big production. I never thought that it was... Even at a park, that it had a big production behind it. And yeah, I learned a lot, a lot, even just business wise, I learned a lot as an intern and I was just like, "I'm going to soak up as much information as I can." And what happened was they actually wanted me to... At the end of my internship, they offered me a job. It was a really difficult decision for me because I only had six more months to finish school. And I said, "I'm going to respectfully decline so that I can go back to school and earn my education, earn my degree."

It was a hard pill to swallow because I just loved it. I fell in love with Florida. I had friends there, people who was accepting of me, even me wearing hearing aids, nobody... It was the first time where people just was... They looked and they asked, they might have asked, and then it was just like, "Eh," and then you move on. It wasn't a consistent list of questions and stuff. I just felt very included and very accepting. It was a great experience for me. But when I graduated...

Actually there's a story, but the sixth month that I had left, when I came back to Jersey, I applied for the Disney store in the mall in Jersey. I was working there and I bought a lot of the Disney magic into the store. So there was children that would actually be coming and I would do story time, story time with Steven. We would all sit on the floor, the little girls would have their princess dresses on, the boys would have their costumes on as well. And we would all just read stories so those parents would actually come back into the store and want to schedule a story time with me.

The district manager, she got a hold of what was going on and she heard... I never had met her before by the way. And she came into the store and I noticed everyone was very afraid. But she asked me a lot. She was very impressed with everything, the things that she heard and the fact that I just came from Florida. And she asked me what I wanted to do in the future. And I told her I really wanted to stay with Disney. I just wanted to use my voice. I wanted to be a host and to host on the radio and things.

And just so happened Disney was actually looking for hosts for a radio Disney in New York. And next thing to the next, I applied and they supported me. And I got the job to be a host working for Radio Disney in New York, which was pretty cool. I was very happy about that. I got a chance to travel all over so many different cities and create Disney magic by hosting different festivals in the Yankee stadiums. It was just really, really amazing. And eventually I was able to work for Disney Theatrical for a lot, and on Broadway, working behind the scenes there. Disney got the wave of all that I've been doing in the company and they inducted me into the Disney Alumni Association. It was a journey, obviously.

Ben Shaberman:

That's awesome. That really is an incredible progression of events. You had such an advancement in your career. And then you've done so many other things since then. A lot of journalism. You now have your own podcast Sessions with Steven. Now, when we talked a little while ago, you said you were working on a TV show, but maybe that's going to become a movie. Can you tell us more about what that is and where that's at?

Steven McCoy:

Yes, absolutely. We are actually still in the beginning stages. I'm really excited about it. All the parties that's involved are excited about it. Yes, it was going to be a TV series, but we couldn't get that to actually work. They have the budget for the TV film, and I just have my fingers crossed. I'm not at liberty to speak about it too much just yet, but it's going to be based off my life and it's going to be a special spin on it. I want to say, I want to say, I want to say, but I can't. But it's going to be a special spin on it. If you know me, you know I love the holidays, I'm going to say that.

Ben Shaberman:

Okay. Well, that's a little teaser right there. That is so exciting. Who would've ever thought about where you were as a kid and those early challenges? Now you're hopefully going to have a movie about your life. That is so cool. And you're also working on a memoir, right?

Steven McCoy:

Yeah. Yes, I am. I'm working on a memoir and that's been my most personal journey, to be able to write my story. I'm really hoping to come to a closing with this book because I have been writing it for a while. It just seems like... Things are just becoming nonstop. Every time I turn around, every week there's something new every day. Where most people don't look forward to Monday, I actually do, because Mondays is where I get my confirmations and what's new for the week. So I'm always looking forward to that.

But the book, yes, is going to be about my life and my experiences. There are still so many things that I haven't shared and I don't feel obligated to. However, just traveling around, being able to take my show Sessions with Steven on the road and speaking to so many different people. And I'm speaking about not only people that are my age or older, but the youth and teenagers. I feel like I have a bit of a responsibility, all of us do, to be able to just say "This is what I've learned through these situations. And you can read upon this and you can see how you can do it, or if this way would work for you as well." I think the book is definitely necessary.

Ben Shaberman:

That's great. And I'm sure it'll be so inspirational just given what you've made of your life from those proverbial very humble beginnings.

Steven McCoy:

Yeah, thank you.

Ben Shaberman:

Before we close out, tell us more about your Sessions with Steven podcast and who some of your guests have been. Because you've had some pretty cool guests.

Steven McCoy:

Yes. I've had so many guests, so many guests throughout the years. I've had Queen Latifah, Mary J. Blige, Ne-Yo. So many legends has come on the show. It's hard to pinpoint, but those are the names that popped up in my head right now. And Angela Bassett, I just had her on. Which was a beautiful thing to have Angela Bassett come on the show. Why? Because I actually was a extra in the movie Notorious based off the rapper B.I.G's life. And she played his mother and I was the extra in that movie. And I told

her that "One day I'm going to work with you, one day [inaudible 00:29:13] further more, whereas I don't have to be the extra." But I was the host. So it was great. And we had a really good moment there, the progression of life and how things... The circle of life.

But Sessions with Steven was created for me to be able to slowly get my way to sharing my story. Media is very cool. The things that are out there, the content that's out there are very loud. I just felt like I didn't want to conform to this lifestyle of mistreatment, of selling people out or it being a cutthroat experience, just because I've been cutthroat and just because the industry that I love to work in, simply because of the work that I do, not because of the flashiness that comes with it, that was not going to allow me to conform. I'm a lover, that's what I do. I wear my heart on my sleeve and I'm not afraid of that. And I think that to me is the most toughest thing you can do, the most bravest thing you can do. There's a lot of strength and vulnerability, and I know that.

And I said with my show, "Sure, come on, let's talk about your new fragrance. Let's talk about your new album, your new film. But also what we are going to do is implement some humility there. Let's share some personal stories, some heartfelt stories." A lot of times people are also afraid to share appreciation towards each other. For me, I'm not afraid to do that. My head isn't that big. I appreciate the work that is being done by the people that comes on to my show. There had been many people that I have declined to come on my show. They were very popular, but they may not have been doing something that I felt was positive. And I want to display positivity. However, someone once told me, never declined, always interviewed the best of the best and the worst of the worst. I tried that and I loved the outcome of it because of me and the questions that I asked. And me taking control of my very own interviews, people actually were saying, it was so many comments of how they actually liked the person after this interview.

And it was pretty cool and I liked that because I think it's just who that... You could be a person that's asking the questions that are very, very invasive and you want the good story, you want the shady remarks and stuff. And for me, I'm just like, "Why do you think this is. Let's do it this way. How about we just try it in a kind way?" You never know. So I just try to use my platform to even slowly share my story and my challenges. Because I have a audience from when I was with Disney and BET and those audience have stuck with me. The thing was, I just was so afraid to tell my story. But I knew down the line Sessions with Steven, I will be able to share my story.

In 2017, I think it was, I had this idea about taking my show on the road. That never happened until just this year in 2022. It took a long process for me to accept me, to be able to really tell what my challenges just are. It wasn't just me being black, it wasn't just me growing up in a urban area. And I never used those things as... Because as you can see, I've even at a very young age, started working for Disney. I never used any of those economic excuses, but though they were challenges, my biggest challenge really with just that I had something in my ear, which was hearing aids, and I was very... Sometimes you can be your worst enemy, that's what I would say.

It took a lot of self-evaluation a lot of times. Even from 2017 when I wanted to plan a tour, it did not happen till 2022. Now I get to travel, team up with different universities and rehabilitation centers, and I produce a tour and we travel many different state. And still I'll be... In October, I'll be in Texas. In January, we're going to South Africa. In June of next year, we're... Also be in Honduras. I never thought that my show, Sessions with Steven, a podcast could actually go on tour. I'm not sure if that has been done or not, but I just thought it would be a cool idea to bring the live experience. In my shirt, you see my shirts online, it says Sessions with Steven Live. If you go back, I then had those shirts, but I was... A lot of people thought it was just me going live online, but that wasn't it. I wanted to bring the live experience to them, to the audience and reach out and touch like Diana Ross.

Ben Shaberman:

That's so cool. How can people listen to Sessions with Steven and just learn more about you in general?

Steven McCoy:

Yes. Sessions with Steven is on all streaming platforms. That includes Apple Podcasts, Spotify, Google Play, it's everywhere. Audible, is on Audible as well. And to find out more about me, you can follow me on my social media pages, Steven McCoy. And also you can Google me, is some cool stories and interviews like this. You found out more about me here. And I'm so excited because when I was in Orlando, Florida, I shot a campaign for Fighting Blindness. I can't wait for people to see that. And I think that's such a very cool way to have the story be told. I thank Fighting Blindness for that amazing opportunity to team up with you guys.

Ben Shaberman:

Well, you're just such an awesome person and you bring such great enthusiasm and positivity to your life. It's so inspirational. And as I've been listening to you over the last several minutes, what amazes me is how really you've succeeded by just being yourself and being true to yourself. It's such a simple message, but yet I think a lot of us in this world struggle with that. And whether our listeners out there have RP or Usher syndrome or they're a scientist working on their next project, the theme that really comes out of this conversation, being true to yourself, is so critical. Congratulations on all that you've done thus far. You're still a young guy. You got a long way to go.

Steven McCoy:

Thank you so much. Yes, thank you.

Ben Shaberman:

I can't wait for the movie.

Steven McCoy:

Yes, me too.

Ben Shaberman:

That'll be really-

Steven McCoy:

Thank you so much. And I just thank you so much for having me and you guys are doing some amazing work and I would love to just see us continue the work in fighting blindness.

Ben Shaberman:

We're right there for you and everybody else that's looking for some answers to these challenging conditions. It's our honor and privilege. Steven, enjoy the rest of your summer.

Steven McCoy:

Thank you.

Ben Shaberman:

[inaudible 00:37:39] with all your projects. Thanks for taking time out of your busy schedule to chat with me. Best wishes moving forward, keep up all the great work.

Steven McCoy:

Thank you so much. Best wishes to you too.

Ben Shaberman:

Thanks. And thanks as always to our listeners for joining Eye on the Cure and we look forward to having you back for the next episode. Take care everybody.

Speaker 1:

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

Speaker 4:

Share your vision.

Speaker 5:

Share your vision.

Speaker 6:

Yeah, we all have a different story to share. It's literally all different. Share your vision.

Speaker 7:

I encourage you to share your vision.

Speaker 8:

The Foundation Fighting Blindness is asking those affected by blinding diseases to share their vision loss story. To celebrate this October, Blindness Awareness Month, share on social media using the hashtag [ShareYourVision](https://www.instagram.com/ShareYourVision). Go to fightingblindness.org/shareyourvision to learn more.