

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:

Hey, everyone. Welcome to another episode of the Eye on the Cure Podcast. I am Ben Shaberman with the Foundation Fighting Blindness, and I am very delighted today to have as our guest, Michael Stone. And Michael has a retinal disease, we're going to talk more about that, and he's an incredible athlete among so many other things. And to say that he hasn't let vision loss get in his way is quite the understatement. And let me tell you why I say that before we start talking to Michael here. He is a 17 time Ironman triathlete. And the Ironman, for those of you that don't know, it includes a 2.4 mile swim, 112 mile bike race, and if that's not enough, a 26.2 mile run after that. All in one competition. So anyway, he's done 17 Ironman's. And since 2000, he's competed in about 200 different races and that includes running races, biking, skiing, other triathlons.

So, in addition to all that athletic stuff, he's written a book called Eye Envy, which is a great collection of stories of people with vision loss who give their perspective and their tales. He paints tactile pictures and, I don't know, perhaps this is even more impressive than anything else, you play multiple musical instruments, including the guitar and the violin. How many people can play the violin? That's incredible. So, I got to meet Michael back... I want to say it was 2006, 2007. We were working on our annual report for the Foundation Fighting Blindness. He was our cover guy. And one of the pictures that we included in the annual report was you after this Viking wipe out. Michael, welcome to the podcast. But I want to hear the backstory of that wipe out.

Michael Stone:

Thank you. Gosh, it's funny. You just reminded me of our first [inaudible 00:02:37]. With respect to the violin, though, I didn't say I'm good at it, just for the record. That bike crash was very profound because that actually happened in Ironman Wisconsin in 2005. And that was a very profound race for me on so many levels. For one thing, was the first race I was doing to raise money for the foundation, for FFB. And it was my first time meeting other people, and it was spectacular. The local... A regional person that was in Chicago at the time really helped me through that period. But we were doing fundraising and I got... Actually, the Madison Blindness community came out for it. And there was a brother and sister, both with Usher, who came and just spent time with me. And it was a very emotional experience.

At the same time, it was on September 11th, and it happens to be my father's birthday. I know he shares it with another dreadful day, but it's... And he was out there at that race, and everything was coming to that. But what had happened was about a kilometer into the bike, triathletes, unfortunately, notoriously poor bike handlers. And I'm going on record saying that, which I'm sure that'll be interesting. And they were all warned. One thing about doing an Ironman on your bicycle for 112 miles, you have to have a lot of nutrition on there. And so, these people in front of me did not secure their bottles that were hanging on the rear seat. And they went over a bump and all of their bottles jettison and one of them lunged into my front wheel, just took a bad bounce and flipped me over.

And I'm only a kilometer into a 181 kilometer bike race. And I was sitting there on the side, my bike was broken, my shoulder was dislocated and I was completely lacerated. And it was the first time I've ever had any kind of a bike crash and I couldn't believe that my day was going to be over at that moment. And I was heartbroken. And I mean, it was just so... I was at the beginning of a time where doctors were saying I shouldn't be able to do the things I'm doing. I was riding a bike independently at that point. I

had a decent amount of peripheral vision back then because my eyes impacted my central vision first. And I had learned to compensate, and there's more as to how I did that. But I got up and I rode the bike, did the whole thing one armed, did the whole thing, raced, did the run. And I have spectacular memories of that community being out there.

And really, my father, in many ways, being out there. My brothers ran the finish line with me and my youngest brother also has RP, we have [inaudible 00:05:39] retinitis pigmentosa. And my middle brother, who's fully sighted, and has a great head of hair, by the way, lifted my arm up at the finish line and it just made a loud pop sound. And that's how it got put back into place. So, I did the whole race that way, including the marathon, just with my arm dangling there. To this day, it was not one of my best time finishes, but it was one of my highest placements because it was a very brutal weather day. It was extremely hot conditions, pushing a hundred degrees, and with high winds. And so, the majority of the field dropped out. That's why my placement was as high as it was. And I just had the ability to persevere.

But I think it was the local blindness community, specifically the people with inherited retinal disease that came out, that really pushed me through that. And this was the first time my parents had ever come to watch me do an Ironman. And it was such an important day. And out of all my races, that's a very powerful memory and it's amazing that you have that photo. I actually had forgotten about that, but obviously, I can remember it quite well.

Ben Shaberman:

That was the first photo I ever saw of you. So, my former colleague, Allie, was sharing your story and the photos, because she wrote that story. And I saw that photo and I'm like, "Wow. This guy has RP, he's doing triathlons, he wipes out." But yet, you kept going. And that's pretty remarkable. And I think an overarching theme for you is it's almost like your RP, your vision loss, has driven you to do more as opposed to maybe the average person with vision loss who might be a little reticent to take risks and do things. You're doing everything humanly possible to push the limits.

Michael Stone:

That's a very profound statement on your part, and I'll tell you why. Because I was terrified of sports growing up. So, growing up with a vision impairment that I didn't know that I understood, we didn't have it defined back then. It was a lot more common back there for people to go... Or undiagnosed. And part of that was because I had a grandfather who was misdiagnosed with macular degeneration, but actually had retinitis pigmentosa. And so, they were always looking for the wrong thing. And sometimes the stars have to align. But I was that kid, eight years old playing little league, who sat up there to bat and got hit in the face with a ball and I would run the wrong direction. I couldn't see the ball amongst other things in the classroom. I was humiliated and also just petrified. I used to have my mom write doctor's notes just so I wouldn't have to run the mile in PE class.

I was terrified of anything sports and I didn't have that drive to do it. So, I buried myself into music. And that's really where it was. I mean, it's ironic, music is my biggest passion to this day. So, what's amazing about that is I wonder sometimes if I had been properly diagnosed as a kid, if I would've done the things I would've done. And as an adult, I found out little by little... In my first Ironman, for example, I made a wrong turn. And I'll never forget the marshal's, it was in New Zealand, the course marshal yelled, "What? Are you blind?" And I remembered having that sick feeling because I've heard that my whole life. "What? Are you blind? What? Are you blind?" And I'm out there doing it the best I can, and it did motivate me to go on and try things and redefine what limitations are.

And sometimes I go too far and we have to figure it out. That's the one thing, with that level of blindness, you have to find your way of doing it. There is no right way to do it, there's your way to do it. And I think we're seeing that more and more. And because of these wonderful podcasts and all these [inaudible 00:09:44] stories and all these things that we're doing, we're finding more and more of that, that there's people out there that are finding their way of doing things. Look at Two Blind Brothers, one of the most creative things I've ever heard. And having a blind brother myself, it's always very affectionate. And obviously, I'm a big fan of those guys for a lot of reasons. Also, a customer.

But yes, it is my blindness, I think, in many ways. I don't know that I would've had the drive to keep trying to figure things out. And it's amazing, though, on how all of this reads into something. And I'm going to tell you an unsolicited story real quick because a lot of people don't know this. So, my greatest hero in the blindness world is Gordon Gunn, no questions asked. He is step above whatever human is, and I can go on for a lot of reasons. But that same year that you're talking about, I had the privilege of sitting down, having dinner with him. It was a breakout session where we used to have the day of science meetings. And in that room was my parents, and Lily was there, and the former CEO was in there. And it was like it was Gordon and me, and everybody else. They were doing their own thing. And Gordon said to me, I was moving through triathlon, and he wanted to talk about skiing. And skiing was special to him.

And I told him that was one of the biggest things I gave up. I gave up skiing in early 2000. Skiing was horrible. My family would take these awesome trips to Aspen and we're very privileged to be able to do things like that. And we'd come back and my mom would say, "How was your day?" Everybody would be joyful but me. And I'll save the word that I would use to describe the day. And I would be out there, I'd be skiing in the poles, other people, just tripping for no reason. It was just another sport I couldn't do. And it was heartbreaking for me, so I gave it up. And actually, that gave me a little bit of this desire to get into running and cycling and trying other things, to be honest. But Gordon sat next to me in that room, and I was down in Orlando, actually, that year. And he said, "I really want you to rethink skiing because I love skiing. There's nothing like it."

And he's describing what it's like to be guided. And it sat with me and sat with me because here I was trying something different. And skiing then, it was such a horrible thing. And now, of course, I'm doing it again. And I have to tell you, it really was Gordon who inspired me to look at it with a different perspective. And I could talk on and on in how much I love that man. But it's amazing. And I think about him every time I clip into my skis now every time. Yeah.

Ben Shaberman:

And Gordon really is our rockstar. And he's been inspirational for so many people with retinal diseases and without. I mean, he's my hero as well. One thing I want to get back to, you were talking about when you were a kid, how you were challenged by a lot of the team sports, which just about all requires some hand-eye coordination or following a ball or whatever. Was there a moment or something that happened that made you think, "Maybe I'll try running."? Or, "Maybe I'll try something else."? Was there a certain event that led you to think about one of those-

Michael Stone:

Yeah. But not as a kid. As a kid, I was way too fearful of it. It really takes an advocate. And I think... You see it's a very dovetailed scenario where you have some parents that are just amazing, "Okay. You're not going to do this." Or, "We're going to figure that out." David Brint did that with his son and they figured out how to swim and he became this phenomenal swimmer. Things were very weird sometimes growing up and your parents have their own stories and life is hard. At some point, you grow up and you realize

that your parents are people too, and you're not even aware of the challenges that they're having, sometimes physically. And plus, I had two younger brothers as well, so I stayed away from it.

But what happened was, the pivotal moment, believe it or not, was after undergrad, after college back in Chicago. And a buddy of mine, a good buddy of mine who actually came and surprised me at a ski race last year in Utah by the name of Joe Carpenter, introduced me to rock climbing. And then, years later, by the way, we found out that Joe's brother, who was that big brother, used to beat us up in a playful kind of way, actually has retinitis pigment. And it blows my mind that that's, in fact, the case. But Joe took me rock climbing and I was very scared and we did it. And then, I started climbing at a gym. And then, we used to take our weekend warrior trips from Chicago to places and go climbing. And I'm like, "Wait a minute, I can do this. It's hard. I can do this." And I had people that would call out some of the moves here and there for me. But I'm like, "I'm doing this."

So, that also got me back into hiking and appreciating the mountains. And I was also doing martial arts at the time and I started to try different things like, "Well, maybe this, maybe that." And in 2000, I was already living in Boulder at this time, I moved out here in '97, I was really struggling with rock climbing. It was taking me way too long. I couldn't see my hands or my feet anymore. And I got scared. And so, that's what inspired me to start running. And my then girlfriend, who's still a very good friend of mine, asked me if I was running this weekend. And I'm like, "What is that?" She's like, "It's the Memorial Day 10K that we have called the BOLDERBoulder." I'm like, "No." And I had to do the math, 10 kilometers, and I'm from US so, what do I know? I'm like, "Six miles." I'm like, "Okay. I don't know that I've ever run more than two in my life, but I'm doing it."

And I had the time of my life. To this day, it's probably one of the most magical things. I mean, I've done well over 220 races since then. And that was one of the most magical moments ever. I had no idea how fast was fast, I didn't care, but I ran 6.2 miles. And it was just a spectacular experience and a beautiful Colorado day. And that transformed me. I wanted that feeling over and over and over again. But one thing led to another, and then eventually, I found triathlon that year as well. And triathlon's a very romantic sport in many ways, because you could be a novice to below average in terms of pacing, swimmer, biker and runner and be a great triathlete just by persevering as we talked about with the Wisconsin race, if you have the heart.

And I think people with disabilities, in general, we just have that heart. We have this will to try to push through things. Sometimes it's maybe on the dangerous side and sometimes not. Contrary to popular belief, I am not an adrenaline junkie. I actually shy away from that feeling. I take a zen-like approach to things. I try to breathe and just stay very, very calm, even when I'm moving at high speeds, a whole other thing. But yeah, I think it all played into the other. But running pushed me to try something else, and eventually, next thing I know I was a triathlete. And triathletes in Boulder, Colorado grow on trees. Literally, everybody and their mothers and grandmothers are triathletes out here.

Ben Shaberman:

That's funny. You seem to have... As I listen to you tell your stories, you seem to have this interesting relationship with fear, in that fear has driven you to do so many things. And fear doesn't go away, either, it sounds like, for you. Can you talk a little more about that? When you decide, "I'm going to do this Ironman." Or, "I'm going to go skiing down this really steep mountain." Do you approach those situations with a little apprehension or fear?

Michael Stone:

Ben, I don't walk out my front door without fear. I live with it with everything I do. And as my eyes deteriorated, the most insignificant life tasks... I mean, putting toothpaste on a toothbrush, cooking my meals, all of these things, there's always this aspect of fear that's with it. What has happened, and as you pointed out, is I've developed a relationship with it. I think that people forget that fear is a part of us. And you can't go around beating yourself up. Beating yourself up is destructive. And fear is there for a reason, it's there to keep us safe. It's there for us for a reason. And if you can find an attitude towards befriending it and realizing that it's a companion, you come along for the ride. And let's figure out how we're going to do it.

And we have to learn little tricks on how to deal with it. It's like parents giving their kids timeouts. "Joey, do you need a time out?" Well, you got to give that to yourself and you may have to step aside for a second and breathe for 20 seconds or however long. I mean, today we had a massive snow storm and I went out with my dog. And my neighbors, rudely, have not shoveled so we had to figure this out step by step just to go out for a walk. And the guide dog's another conversation. But fear is this constant companion that I have grown, partially, to love. It isn't ambivalence, because, like I said, it's an attitude adjustment. Before the start, you and I chatted a little bit about attitude because it's the one choice that we have in life, is attitude.

The world could take everything away from us, as a lot of people have seen in the last couple years with the restrictions and challenges that have come along with this period of time, but our attitude is what keeps us going. But it's bold. You have to want to do it and you have to want to put one foot in front of the other and learn how to change your attitude towards fear. I don't believe it's an overcoming thing. I don't believe that fear is your enemy, that you're supposed to grid at it with aggression. I think it's a much more loving attempt and it's very important.

One of the great things that come along with having a disability is that we learn that the detriment of multitasking, we can hurt ourselves. We can cut ourselves if we're trying to cut our food or burn ourselves if we're doing things with that. You have to do one thing at a time. And that's the trick with fear, you have to limit it and you take on one thing in that moment and you try to do it the best you possibly can. And then, you move on to the next thing.

Ben Shaberman:

I think your comment about attitude is so important. And at the end of the day, sometimes, if I speak for myself, it's just a matter of putting one foot in front of the other and just going to the next step and getting a little momentum. And then realizing, "Okay. I'm on my way here." But I do want to get back to your guide dog because I've seen videos and pictures and your dog is amazing. Geo, is he a Lab? Looks like a Lab.

Michael Stone:

She is a Labrador, yes. And not happy with me because she's locked out of the room right now. But she is a canine Swiss army knife that came with... You just keep opening up the little tools and there's a one more cool thing that she does, and another thing. And guide dogs, in general, are amazing. And there's something very, very profound. There's a word that comes along with having a guide. Anybody who knows what that word is, it's forward. And most people will say that word, we don't think anything of it, forward, whatever it is. But when you're sitting there and you're holding that harness for the first time and you say, "Geo, forward." Now you are moving at a pace that you would never walk at with a cane.

And your instructor is standing behind you saying, "Go with her. Go with her." Because you want to pull back, talk about fear. And you're now walking at speeds that you would never walk. And you are

completely trusting yourself to an animal. And it's incredible to think about what's happening. You're moving, and you're moving independently, for the most part. And it's a very different response to obstacles. And I'll tell you, we're in the middle of winter and we're dealing with ice and all this stuff. Most of the time people wouldn't want to leave the house, and she's figured out. But yes, as you pointed out, she is spectacular. So, Guiding Eyes for the Blind and the gentleman, who's the CEO of it, has retinitis pigmentosa, Thomas Panek is his name.

And Thomas, they created a running dog program. It's spectacular in that they have now found a way with dogs with certain energy to, if they could guide at high enough speeds while they're walking sometimes, they test them to see if they will run, if they're desired. And Geo will run with me. And she runs at absurd paces, a lot faster than I ever wanted to go. Here she comes, by the way, this was driving her crazy seeing me through the...

Ben Shaberman:

She misses her buddy.

Michael Stone:

Yeah. Well, I have two dogs. I have my dog dog, too, which his name is Wrigley. Wrigley Fieldstone. Yeah. It's hard to try to figure out where I come from. I did a dry land biathlon this summer, and a buddy of mine... So, Geo was my guide, and then another friend was running with us. This was about a five kilometer run. And we were running at sub six minute miles, and the guy looks over to says, "I can run this fast, but I don't want to."

My dog said, "That's what we're doing." She turns into that Seabiscuit, that horse dog that just has to be ahead. And it's actually rather embarrassing, but she does not understand moderation. But what's crazy is that she's guiding at those paces. She's not just running, she's guiding just like she would if we were on a sidewalk on a normal Tuesday going there. And it's spectacular. There is no relationship in the world quite like this. Yeah. Not only am I madly in love with her, but I don't know where I would've been through this COVID without her. Finding humans to run with is not as easy as people think it is sometimes. And I go right out my front door with her.

Ben Shaberman:

Yeah, I know. I have colleagues who have vision loss and I've been the seeing eye human. And just walking with people who have vision loss can be really challenging if you're not used to doing it. So, to see Geo running with you, the one video I saw of you, running through this rocky, grassy terrain, I'm like, "That just looks crazy." But-

Michael Stone:

Yeah. That is a little crazy. She and I actually hiked that this morning through the snow, that same area you're referring to. And I was terrified the whole time, but man, when we get down she gets a big hug and it's spectacular because she's like, "Come on, blind guy. We're going. None of this stuff..."

Ben Shaberman:

She's in charge.

Michael Stone:

Yeah.

Ben Shaberman:

So, as we get toward the end of our conversation here, you hinted at what this answer might be, but let's go right to the heart of the question. So, for somebody young, old, whatever situation, who is hearing this and thinking, "Wow. Michael's done so much, maybe I'd like to take a step forward and try something." What advice would you give somebody with visual impairment who wants to do something new and has some apprehension about it?

Michael Stone:

Well, I would first say that apprehension is a great thing to have. Again, that just comes along with it. But I would say two things. One is you have to teach yourself to be your own advocate. It's very, very helpful. And I would say the same thing to some of the parents that are listening to this because there is a right way to advocate for your kids at the same time. But for those individuals, definitely walk before you run, take a very slow approach to it, find your way to do it, and baby steps. Don't try to go to the finish line so fast. And I think that's actually... It's funny, was something that I learned in my own racing, was to celebrate the start line, the finish line will take care of itself. But to pay attention to every moment that you have just like we do when we're walking down the street. Right foot, left foot, cane, cane, however we're doing it.

But what I would say to those people is that apprehension is good, it's healthy, but don't think about the thing that you want to do way down the road. Think about today. Whether or not... For some of us, just walking down the street to get to our mailbox, or whatever it is, is a big day for us. To realize that it's very normal to feel that way. And I will say that fully abled, fully sighted people, they have the same apprehension when they're doing this stuff. There's no question. Water seeks its own level, but we have that plus one factor. And if you have Ushers, it's a plus two factor. And we found a way to... For people to lose both their sight and their hearing.

It's very, very important just to take a big step back and just remember to breathe and arm yourself with as many tools as you can and find that person or people to do it with you, that you don't have to do it by yourself. And there are wonderful people and fantastic organizations out there that would love to do these things with you.

Ben Shaberman:

Thanks for sharing that. I think your stories and just coming out and saying that directly will help inspire people. So, one more thing I want to mention, and I believe this podcast will air before this webinar happens, but it's a webinar on a Para-Nordic competition. On the basic idea of Para-Nordic competition. I never said Para Nordic out loud.

Michael Stone:

It's hard.

Ben Shaberman:

It looks easy. And just so people know, Para Nordic, at least in our context, is P-A-R-A-N-O-R-D-I-C. And if people are interested in the webinar, it's on February 19th. And if you go to the Foundation Fighting Blindness website, it's fightingblindness.org. And if you search on Para-Nordic, you'll find it. If you go to the events tab, you'll find it. Spend a minute just telling us about what that's all about.

Michael Stone:

Sure. Well, the webinar came from our conversation with Jason Menzo and I. And just him running with it, as he does, and bringing you and your great colleagues into the mix. Nordic Ski is your cross country skiing, okay? And there's three aspects to it. You've got your classic cross country that is a very linear movement, it's almost like running in the snow, but you're in these tracks. And a lot of blind people like that because it's very tactile. And then, you have a skiing option in the Nordic skiing, which it's more of a lateral [inaudible 00:31:04]. You could picture yourself ice skating, but with long skinny skis. And then, there's the biathlon aspect of it, which is actually shooting non-projectiles, it's an audio rifle specifically made for blind people, that I have here in my house, that I can practice it there. And that involves the skate skiing along with it.

But what's amazing about it, Ben, is a lot of these sports that we have to do with others, if you're on a bicycle, you're on the back of a tandem. If you're running, sometimes you're running tethered to somebody. With skiing, it's strictly audible cues. So, when Gordon was talking about it, he wasn't tethered to anybody. He just had somebody saying left, right, turn, turn, turn, and giving them audible cues. And he got to feel the freedom of skiing. Now, with Nordic skiing, you're also going up the mountains. As you are going down, you're going uphill and downhill. And it's a constant movement. And it's a wonderful opportunity. And what's important for me to add is that I didn't know that it exists.

All my years of Ironman's and being a fearful... During the winters, I used to get so scared I would actually go to southern hemisphere countries like New Zealand and South America to race Ironman's to avoid the winners because I just thought of the winter as this very oppressive time for people with blindness. Ice outside, all these things. And although, of course, I had Gordon on my shoulders saying, "Hey, get over that. Embrace it." But I found it in the way of Nordic skiing as opposed to the alpine skiing, which is also wonderful. [inaudible 00:32:43]. I like this one because it's a lot more active and it's aerobic and a little healthier, it's a full body experience. And so, my hope is, yes, there's a competition side of things and it is a paralympic sport that's happening right now over in Beijing. But it's the recreational stuff that I'm really trying to push, okay?

And yes, I compete. I'm doing a ski marathon this week and I'm doing... In Crested Butte. But it's the recreational side of just being outside and experiencing that feeling of being on the snow and that freedom. And yes, you're getting audible cues, but it's just you, your skis, the snow and nature. And it's just a spectacular feeling that I really, really wish that more people with vision impairments knew existed for them. That's what my hope is from this, is that it's going to be the beginning of great things to come and we can learn how to advocate for the masses of people out there that don't know that existed. And I don't care if you're nine years old or you're 90 years old, it's open to you.

Ben Shaberman:

Well, thanks so much for talking about Para-Nordic competition and just what it's like to be out there. And again, if people are interested in the webinar, it's on February 19th, just search on Para-Nordic or go to the events tab on our website. And when you search Para-Nordic, do it on the Foundation Fighting Blindness website, fightingblindness.org. And I'll remind our listeners, if you have questions about podcasts in general or whatever, you can email those to podcast@fightingblindness.org. That's podcast@fightingblindness.org. Michael, it's just been a joy to see you again and chat with you. And I really appreciate you sharing your perspectives and stories and Geo with us on the podcast. It's been great to have you.

Michael Stone:

Thank you.

Ben Shaberman:

So, thanks everyone out there for listening to Eye on the Cure. Come back for our next episode. And again, Michael Stone, thanks for joining us. Hope to hear from everybody-

Speaker 1:

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