Hadley Presents

Vision Loss and Self Discovery

Presented by Ricky Enger

Ricky Enger: Welcome to Hadley Presents. I'm your host, Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode, director of community, Marc Arneson, interviews Hadley advisor Eddie Becerra to share his story of vision loss. Welcome to the show both of you.

Marc Arneson: Thanks, Ricky. Happy to be here.

Eddie Becerra: Thank you.

Ricky Enger: So glad to have you both. So, I introduced Eddie as a Hadley advisor, and what that is probably not immediately apparent. I know that Marc, you've been on the program a couple of times before and you, as director of community, have a chance to do a lot of support groups, as well as help select and interact with our Hadley advisors. So, these are people that get to share with us how they're feeling about what it is that we're doing, and they can tell us where we're missing the mark a little bit, and they can also say, "Wouldn't it be great if you guys created a workshop on such and such?" And so, we love our Hadley advisors and it's really cool to have one of them on the show. Marc and Eddie, I think that's how you guys met, right?

Marc Arneson: Yeah, that's exactly right, Ricky. I think we were trying to figure out a workshop that we wanted to look at. We weren't quite sure if it was moving in the right direction, and so I reached out to Eddie and he gave us some amazing feedback, some great insight, just to make sure that we were moving in the right direction. So yeah, Eddie and I got to spend some time together looking at a new workshop we were trying to put together.

Ricky Enger: That's awesome. And turns out that through that interaction, you realize that Eddie has a pretty cool story, actually. And that's what we want to dive into today. So Marc, I know you have a lot of really great questions, and Eddie, we've been talking predominantly so far, and so that's going to change now because you get to share your story and be a major part of the conversation now, too. So Marc, I'm going to turn it over to you. I know you've got some great questions.

Marc Arneson: Like Ricky said, you did such a great job helping us out with some of the things that we're trying to do and even more so, I just loved hearing your story, your perspective, and your vulnerability, and just hearing what life is like and what's going on. So Eddie, do you mind sharing with me what your diagnosis is and what your vision is currently like?

Eddie Becerra: So, I guess my sight loss story started about four years ago. One morning I woke up, I was getting ready for work, and I dropped something on the floor. And as I bent over, I noticed I started seeing a reddish blur in my left eye. So of course, that scared the bejesus out of me, and I didn't know what was going on, but it was significant enough to where it clouded my vision. When you lose sight in one eye, what do you do? You jump in your car and you drive to the emergency room.

Once I got there and they looked me over, they saw that I had a retina detached. I had to have emergency surgery, and then after that, of course, I did the meetings and the consulting with the ophthalmologist. And of course, it was a retina detachment, and it was due to diabetic retinopathy.

Once that was taken care of, they started looking at my right eye and they noticed that I had a lot of broken blood vessels behind the eye. Even though I could see fairly well, they still wanted to get in there, wanted to cauterize the bleeds that were in my eyes. And after talking with the ophthalmologist, I was trying to get an idea of how bad it was in the right eye, because at that point we pretty much knew I wasn't going to get sight back in my left eye. He says it was probably one of the worst cases and the most number of broken blood vessels he had seen in a long time. We started laser treatments and such, and at this point now I am completely blind. I don't have no vision in either eyes, no light perception, and I've been totally blind now for I want to say pretty close to two, two and a half years.

Marc Arneson: Wow, what an experience. Eddie, I hear a lot of people, they go into these initial appointments and they're spending time with their doctor, and people have different experiences when they're leaving the doctor's office, particularly after an initial diagnosis or something like that, maybe before some of the actual surgeries happen. Do you remember some of those experiences with your doctors and what that was like?

Eddie Becerra: I guess the whole process was just a long journey of hope. Every time I would go in, "Well, you have this issue and this issue, and we're going to have to do another surgery," but with that being said, they always used the term should. "After this procedure, you should retain some of your eyesight and maybe even regain some of it." And I just remember every surgery, it was always this big buildup and then this big let down because every surgery afterwards, the site, it just got worse, and worse, and worse. And that went on for almost a good 18 months.

Someone can only take that sense of hope and then the let down so many times, and it just really starts wearing on you. And it's kind of a sad thing, but the last thing I ever saw was my last surgery. The last thing I saw was the gentleman, the ophthalmologist who gave me more false hope. "When you come out of the surgery, you'll be wearing a patch for about a week, but then after this you, once again, should regain some of your eyesight back." Well, he was the last person I ever saw. After that last surgery, they were pretty much done with me.

Marc Arneson: Wow. So, the adjustment, an 18 month period, I think you had said, when you were first driving to the emergency room until the surgeries were done, what an adjustment you've had to ... adjustment you've taken over these last 18 months. What were some of the biggest challenges you think you faced during that 18 month period?

Eddie Becerra: Like I said, the back and forth of hope and disappointment, but once I knew that I was never going to see again, I'll be totally honest, Marc. I was quite devastated. I didn't know nothing about sight loss or blindness. I surely didn't know anybody else who was blind. And just judging from my initial experience, I thought pretty much life is over.

Before I lost my sight, I was very passionate, very busy, just always on the go kind of person. I always had to be doing stuff. I had a lot of hobbies, and very social person, and it all came to a screeching halt. So basically, my life turned from being this outgoing, straightforward person to just sitting around and not doing nothing. It was just horrible. It was a horrible experience and it changed me. It radically changed me. And of course, the blindness radically changed my life. And I don't want to sound too melodramatic, but I just pretty much thought life was over.

Marc Arneson: And so Eddie, I've gotten to know you a little bit better and I didn't know you when you first started losing your vision. I've gotten to know you since then. And I know that you're a very outgoing, very motivated guy. So, what inspired you to overcome some of these challenges that you were facing?

Eddie Becerra: To be honest, I don't think it was any one point in time that inspired me, I think it was more along the lines of anger and disappointment in myself, because like I said, I've always been this outgoing, very resilient person. I'm very adaptable. Like I said, it just changed me. I wasn't that person anymore. I spent almost six months just sitting on the couch every day. I had no reason to wake up.

And I don't know what point in time per se, but I just remember waking up one morning and I was just so mad at myself. I was just so mad and disappointed. And I just thought to myself, “You big baby. Here you are. You're sitting on the couch moping and crying, feeling sorry for yourself. This is not you. Pull up the bootstraps and let's do something about this.” So, once I decided that I was going to do something about it, I didn't know what to do. There has to be something I can do, but what?

When I left the ophthalmologist's office for the last time, it was basically, "Well, we did all we could do. I'm sorry. Have a good life," and he was off to the next patient. So, there I am, totally blind, sitting in this doctor's office. You would think of any place, a doctor's office, if they knew you were going to be blind for the rest of your life, they would give you some kind of resources, some information, a handout, a phone number, something, but they didn't. Now with that being said, I am not going to say that the level of care I got was substandard. This was one of the best eye clinics in the country. That's not their specialty. They don't deal with bedside manner very well. And I understand that's the nature of the business, but with that being said, there's other people in that doctor's office. Somebody in that place could be in charge of pulling somebody aside and giving them some information, and some phone numbers, some point of contact, something, and that never happened.

I ended up calling my friend, and he came over, and we got on my computer, and we started looking for things. And it was just a basic search. I think we punched in something like resources for blind folks. With that, one of the first returns was a facility called Outlook Nebraska, where they have employment opportunities for blind folks, and they also do extracurricular activities with blind and low vision people.

So, we ended up calling that facility, and we got talking to the receptionist, and I gave her a synopsis of what was going on with me. And so, I could tell she really felt sorry for me because I was pretty broken up when I was talking to her. She was trying to reassure me things were going to be okay. So, with that being said, she knew of a place here in Nebraska called the Nebraska Commission for the Blind and Visually Impaired. And basically, what it is, it's a state ran vocational rehabilitation center.

So, she called one of the supervisors. As a matter of fact, she's out of Omaha, her name is Nancy Flearl, and she told her what I had said to her. Within about a half hour, Nancy Flearl called me back, I told her my story. Once again, I was just really broken up because I think at that time, once I knew there was help, there was just so much of a sense of relief. It was just a really big emotional rollercoaster that day, and I think a lot of it was just I was just relieved that I knew at that point I wasn't going to be in my current situation the rest of my life.

So, Nancy set up an appointment where we would meet a week from that day, and I felt really good about it, and then about a half hour later, she calls me back and she says, "What are you doing today?" And I'm like, "Well, the same thing I've been doing for the last few months. I'm sitting on this couch." She's like, "How about if I stop over after lunch?" I'm like, "Okay, great."

So, I gave her my address and a little after lunch, she shows up. She comes in, and immediately we get started on the paperwork because at that time they had quite a long waiting line to get into the center, and she expedited my application, they bumped me up a little bit to get me in a little sooner. So, we're walking out, and I remember it was a really nice late spring day.

And we say our goodbyes, and as she's walking down the driveway, she's says, "Oh, wait a minute." She says, "I forgot, I have something for you." So, she come walking back to me. She says, "How tall are you?" I'm like, "I'm six foot even." She says, "I think I might have one that'll fit you." She goes to her car and she comes back with a white cane, a long white cane. She spent about a half hour with me just up and down the driveway, she just showed me the real basic fundamentals. I mean just basically how the cane sweeps back and forth, and how you alternate between your steps and your cane.

That was it. I mean there was really no other really techniques. Man, I'm going to tell you what, when she left, and I know there's blind folks out there, it was really hard for a lot of blind folks to accept the point in their life where they need a white cane, and I understand that completely. But in my case, oh man, I tell you, I thought it was Christmas morning. That was the greatest gift I ever got. It really was. And after she left, I'm out there, and I'm be-bopping back and forth, going up and down the driveway. And my buddy, he's just laughing at me. So, we ended up jumping in his truck and we went to a park. I was able just to walk in the open space of this part. And I didn't know what I was doing with the cane, I just knew enough to swipe it to make sure I didn't run into trees. And my buddy, man, he just laughed so hard, and it was great. It was freedom. It was independence. That white cane was my ticket off the couch.

Marc Arneson: Like I said, you're a much different guy that I know since I've met you than the guy is sitting on the couch. How would you describe yourself now and your life now compared to early on, after some of those surgeries?

Eddie Becerra: Before all of this, before the vocational rehabilitation, I was existing. Now, I'm living. I'm living life to the fullest. I'm having fun. And I tell a lot of my sighted friends and family this, and I really don't think they get it, but honestly, right now, I'm happier than I've ever been in my life. Before my blindness, it was all about material things, the nice cars, the home, and all that stuff.

And that stuff's important, but it shouldn't rule your life, and it did mine. And now I feel that I'm free. And again, I don't want to sound melodramatic, but the old me is dead and gone. I don't miss that person anymore. Like I said, I'm happier than I've ever been in my life. And I wake up every morning, and I just can't wait for my feet to hit the floor and to see what I'm going to do that day.

Marc Arneson: I get material things aren't the most important thing in life, but I do know that there are some material things that you really enjoy.

Eddie Becerra: Yeah, I like my tech. And that's the fascinating thing about tech, I didn't know anybody who was blind or visually impaired. When I finally lost all of my sight, I resided to a flip phone because I was a big Android guy before, I was a big tech geek before I lost my sight, so I didn't think I was going to ever get to use computers or smartphones. And I remember I went and got me this little Verizon, I don't even know what it was, but it was just some little cheap flip phone. And on those, you can actually text. You know how it has the letters on the numbers and you've got a cycle to ... That was just ridiculous. This is horrible. But once I lost my sight and actually once I got into vocational rehabilitation, they introduced me to a lot of the technology, especially in the beginning. It made it bearable that I could actually play with tech now, again.

That's the one thing that I'm really appreciative when it comes to vocational rehabilitation, especially for the state service that I attend, they have a really good tech program. They teach everything from how to use iOS, and JAWS, and NVDA, and Narrator. And I guess that's all I needed. I needed to know that I could get onto the information highway. And once I did that, then it was a no brainer for me. I just did all my own research. And so, one of the things I love now is technology, and after I leave the center, I'm pursuing a career in accessible technologies. Hopefully one day I'll be able to teach other blind and low vision folks how to use accessible technology.

Marc Arneson: Knowing you, the sky's the limit, Eddie. Whatever you want to do. Hey, so I want to go back to the doctor's office just quickly. I know that you had said being in an ophthalmologist office, you'd think they would have something that they could hand somebody to direct you, but if you could go back, knowing your experience now, is there any advice that you would give to some of your doctors as you were going through this journey?

Eddie Becerra: I think I would caution the doctor that I had about the false hope thing. I know people do not want to hear, "You're going blind, and you probably won't see again." I know people don't want to hear that. It would be helpful in the long run if they would have been a little more honest with me. I don't even really want to use the word honest, maybe straightforward. I don't think he meant any harm. I really don't. And maybe some of it also is the way that I interpreted the information that they gave me. Maybe I was at a point to where I had all this hope and I wanted to hear what I wanted to hear. At the very least, they need to be able to provide you with some resources and not wait until the very end to where they can't do anything else for you, because my vision was bad enough even at the beginning of all these procedures that they could have gave me some information, because there is that term legally blind, but I'm sure there was a point to where before I lost all my sight, that I could have qualified for some help and some resources.

Marc Arneson: Eddie, how about somebody who's going through this experience that is new to vision loss? Is there any advice that you'd give it to them?

Eddie Becerra: Seek resources. That's the most important part. Even if you're not a very social person, there are people out there that want to help you. There is great resources out there. Also, this is, I don't want to say an exciting time, but this is a good time to be blind because there's just so many technical advances that have happened just in the last four or five years. Things like accessible technology in the blindness world alone. And I'm going to use the term for myself, it's quite exciting, because if I would have lost my sight, let's say, 10 years ago, maybe even 5 years ago, surely there wouldn't have been the technical things that help me throughout my day, throughout my life. And especially now, with the social aspects of blindness, especially social media, and I think that also helps me too, being able to share experiences with other blind folks.

Ricky Enger: Yeah, I think all those things are important. So, the community, the reaching out and finding like-minded people, whether it's somebody who is blind or somebody who is interested in astronomy, like you are. So just getting that sense of community back. And then the other thing I liked that you mentioned was searching for resources, because I think that people who are experiencing a vision loss feel the same way you do when you were on the couch. I feel alone. I feel hopeless. And so, knowing that there is hope, and whether that's hope for regaining some of your vision or just hope that this isn't the end of what life can be for you, that's an important thing to have, right?

Eddie Becerra: I think what it also comes down to is the sense of independence, doing it my way. And I'm going to borrow this tagline from the NFB, but it goes something like, "Doing what I want when I want how I want without inconveniencing myself or others." That's priceless. I think that's another thing that really disturbed me when I was sitting on that couch, everything that I had to do, I had to depend on somebody else. When you're interacting with friends and family, and you're blind, and you can't help yourself, and this is no fault of them because they were like I was, I did not know any blind people, I did not know how to interact with blind people, but everybody did everything for me. And as somebody who, before I lost my sight, who is as independent as I was, that's what tore me down the most, not being able to do it myself. And that's what kept me on that couch.

Ricky Enger: And it's also what motivated you to get off the couch, right?

Eddie Becerra: Yeah, because like I said, I got tired of being a big baby and just sitting around feeling sorry for myself. I was embarrassed of myself. It's like come on, this can't be it. This can't be the rest of my life. So fast forward to today, I'm very happy. I'm finishing up my time at the training center. I'll be graduating soon and off to life's next big challenge.

Marc Arneson: Eddie, this is great. I mean thanks for sharing so much.

Eddie Becerra: And I wanted to say one more thing, we talked about networking with other blind folks, and I'm sure most of your listeners are familiar with your discussion groups, but way before Clubhouse, way before I got back on Twitter, I always loved going to the Hadley discussion groups. I would even attend things that I wasn't even interested in, like the crafts and things like that, because the people in there are just so nice, and it's just a great place to go and interact with people like yourself.

Ricky Enger: And we'll have a link to those discussion groups in our show notes. And also, if, Eddie, people want to reach you, maybe go follow you on Twitter, we can have that information in the show notes as well if you like, if people want to reach out.

Eddie Becerra: Yes, if you want to get ahold of me on Twitter, I'm @eddieisblind, all one word, of course. You can find me on Clubhouse at eddieisblind, and you can also find me on Reddit, eddieisblind.

Ricky Enger: Fantastic. Well, thank you so much for sharing just your journey of what it was like to ride that roller coaster, and then ultimately get into a place where you are happy and you're ready to share that with other people in a similar situation. Really appreciate your joining us on the show.

Marc Arneson: Oh, and Eddie, I mean I still enjoy every time I spend with you. So, I think there's so many people that are new to vision loss and trying to figure out this whole thing that are just going to relate to so many things that you were able to share and some great advice you're able to give, so I so appreciate that.

Eddie Becerra: Oh, you bet you. Thank you guys for having me. This has been a wonderful experience and I just really believe what you folks at Hadley are doing is such a good thing, especially since you've revamped your curriculum. It's just a great place for information and for networking, and I personally really appreciate what you folks do.

Ricky Enger: Thank you both. Got something to say? Share your thoughts about this episode of Hadley Presents or make suggestions for future episodes. We'd love to hear from you. Send us an email at podcast@hadley.edu or leave us a message at (847) 784-2870. Thanks for listening.