Hadley

Listen, Connect, and Share: Insights & Sound Bites

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, Hadley's director of community, Marc Arneson, joins us as Hadley members share insights from their journeys through vision loss. Welcome to the show, Marc.

**Marc Arneson:** Thanks, Ricky. So fun to be here.

**Ricky Enger:** It's really good to have you. And you've been here before.

**Marc Arneson:** I have.

**Ricky Enger:** And those times I'm like, okay, you get an intro, but you got to hurry it up so we can move on to the next guest. But today, what we're here for is actually to talk about community and just building that connectedness with each other and sharing things and learning from one another. And that is what you facilitate. So, this time you get a slightly longer intro to tell us about what you do at Hadley.

**Marc Arneson:** Oh, wonderful. Well, slightly longer? Ricky, I love my job and there's so many different pieces to it that I love doing. Probably the best part, I think about my job is being able to connect with folks. I get to spend a lot of time on the phone getting to know people. I join different support groups and attend different conferences to share about Hadley. And I just get to hear stories and things that folks are doing, managing their vision loss and the way that they're facing their vision loss and things like that. It's really a cool piece of my job is just getting to know people.

**Ricky Enger:** That’s awesome! And it is those stories and just getting to know people and hearing those small but powerful pieces of people’s journey that we are here for today. So, Hadley has another podcast called Insights and Sound Bites. And what we are going to do is, we have chosen a few, really short but just incredibly impactful and relatable episodes of that podcast. And we’re just going to take a quick listen and then chat a little bit about what we heard and kind of share our reactions. So yeah, let’s jump right into that. We’re going to start with Leah Moore.

**Leah Moore:** My name is Leah Moore and I live in Omaha Nebraska. Just a little over a year ago, I was diagnosed with Vitelliform Macular Dystrophy, late onset. At the time, I just figured, "Doctors have been wrong before. They've been wrong again. I'm not worried about it," and I just blew it off. And after about four months, everything started looking like it was crumpled up paper. If you had paper, somebody crumpled it up and then tried to flatten it out, have all the crinkles in it.

And at that time, I just thought, "Well, maybe I should probably have this in my medical record." I called and got the information. And when the doctor diagnosed me, she said, "Within two years, you will not be able to drive. You will not be able to read and you'll not be able to recognize anyone's faces." I felt like the doctor just threw me to the wolves. "You're going to go blind. Oh, by the way, make an appointment to see me in a year."

My biggest issue was just accepting it, knowing this is really going to happen because I was in denial for so long and trying to make excuses for everything. Once it hit me, we were on our way to the Grand Canyon to see before I couldn't see. And that's when reality hit me. It seems like all my life, I've heard people say, "You're not alone. You're not alone." For everything they say, "You're not alone."

And it just meant nothing to me until I was able to actually hear other people who really were going through the same things, or they've been through what I'm going through now. And they'll say, "I remember that time. And you're going to get through it just like I did." And it finally clicked, I really am not alone.

**Ricky Enger:** Wow. I love that. And she's so right. I mean, I don't know if you've experienced this before, Marc, but just that feeling of people are always telling you, "You don't have to do this by yourself." Whatever it is, it doesn't have to have anything to do with vision loss, just that people saying, "You are not the only one." And it never really does resonate until you're going through something where it gets proven to you. Right?

**Marc Arneson:** Absolutely, I can still relate to what she's saying there because it's true. You can hear people share, "You're not alone in this." And it really doesn't mean it anything until you find yourself in that place where you truly feel alone. And then what a difference it can make to realize you're not, right? I was thinking how it just becomes background noise or just not so useful noise when people are saying that.

**Ricky Enger:** Yeah, it feels like platitudes, right? Oh, sure.

**Marc Arneson:** Yeah.

**Ricky Enger:** Of course I'm not alone. Unfortunately, what was so relatable that we hear all the time is the doctor saying, "Oh, yep, you're going to go blind. Well, bye-bye. See you in a year." That is what must it feel like to be given that news and sent on your merry way?

**Marc Arneson:** That's exactly where I started tensing up, Ricky. I was like, can you imagine the weight of that conversation with her doctor? And then, I think she said, "It felt like I was thrown to the wolves. Where do I go from here? What do I do now?" And you're absolutely right from folks that I talk to, unfortunately, it seems to keep coming up way too often, those conversations like that with their doctors.

**Ricky Enger:** Well, thank you so much, Leah, for being willing to share that piece of your story with us. Clearly it resonates. Next up, let's hear from Ed McDaniel.

**Ed McDaniel:** My name is Ed McDaniel and I live in the foothills of North Carolina. I was diagnosed with retinitis pigmentosa when I was 28 years old. My older brother had already been diagnosed, so I knew it was a possibility that I would also have the eye condition. In addition to RP, I also have hearing loss. I was born with hearing loss. That really hasn't been so difficult for me. When I started losing my vision, that had a bigger impact on me because I had normal vision at one point.

I was still searching for some hope, and one of the ways I was doing that was finding out more information about treatment research, and whether that was ever going to be an option for me. I attended this conference in Florida. During the day they had all these presentations about research in treatment and all these different kinds of things. But in the evenings, they had the sessions where we could meet other people with RP, and that was really where I started to find some hope.

It wasn't really in the research, which was the main topic of the conference. But it was in the evenings where I met other people, and I met people who were all different ages, all different stages of vision loss. And I was able to see that they were living very productive and full lives. I came away from that conference feeling a lot more hopeful, where I was really have been struggling before that.

30 years later and there's still no treatment for RP. I'm glad there is research going on, and I think there could at some point be some treatment. But if I had been focusing on that for the past 30 years, I wouldn't be where I'm today by learning to live with my vision loss and not just putting all that hope into a cure for my vision loss.

**Ricky Enger:** The ending of that story is my very favorite part. And it resonates really strongly with me in that, if you are concentrating on one thing, you may be actually missing a piece of what's going on that could have a dramatic effect on who you become. If you're putting all your energy into when will there be a cure, if you're living for that, how many moments are passing you by that you might've missed?

**Marc Arneson:** Yeah, I'm learning to live with it. That's such a powerful statement, isn't it?

**Ricky Enger:** Yeah.

**Marc Arneson:** I think that's what you're talking about. Yeah. No, I think you're absolutely right, Ed is still hopeful. There's research going on and there's going to be a treatment, but I'm learning to live with this now. That's such a cool thing.

**Ricky Enger:** Yeah. And he's paying that forward in a way. He's doing his own support group, so meeting people where they are now. Because I think he recognizes the importance, hearing the right thing at the right time, and seeing other people who are maybe in different places in their journey than you are. And having that just be a beacon of hope for you.

**Marc Arneson:** Yeahm, Ed is a retired psychologist, and he's really dedicating his talents to trying to help as many people as he can.

The other thing that I think is so cool about this episode though, is the power of the example that other people can have. Ed is like, "Hey, there's people out there that have figured this thing out so it is possible. If they can do it, I can do it too. But there is a lot of, I mean, that can be very hopeful when you see, wow, if it's somebody else can do it, then I can do this too. I love that word hope. And I think that's what Ed talked about.

I think, Ricky, we were talking about themes that come up pretty frequently. And I think with Leah and Ed, we're hearing this theme of the importance of relationships and connection with others. I love how Ed talked about that.

**Ricky Enger:** Yeah, me too. Thank you so much, Ed. All right. Next up, let's hear from Angela.

**Angela Delgado**: Hello, my name is Angela Delgado. I live in New York City. I worked in a hospital for a long time. And I've always on the computer a lot. And I noticed that I started to see floaters in my eyes, and overall I just realized that my side view was going.

And when I went to the doctor, they told me that I have symptoms of glaucoma, and I'm like, "Glaucoma? What is that?" I've heard of it, but I just didn't know anybody that had that. They said, "Eventually you're going to wind up losing your vision more and more over time." And they said that there's no cure for glaucoma. And I'm like, "What do you mean there's no cure? You can't fix this? I went this fixed now." I started to lose most of the vision in the right eye. Now I'm using the left eye so I'm off balance when I'm walking because I have no peripheral.

They told me, "Oh, well, you should sign up for Commission for the Blind." I said, "Commission for the Blind?" I said, "What are you saying? I'm not like those people. My situation is different." They gave me the cane. I had the mobility training, the rehab, and they came out to where I live. I can't legally drive anymore. They declared me legally blind and visually impaired.

I had the cane inside my rain boots in the closet. It's like, "Well, I still got a little bit of vision left, so I'm going to use what I got. I don't want people to know my business." I said, "Because it's my secret." The secret was killing me. The secret was putting me in dangerous situations. I fall so many times, I bump my head so many times. I was taking a train and buses and people coming left, right, all different directions in the city. And I was like, " Oh, excuse me." They said, "Watch out, lady." They says, "What's wrong with you?"

My daughter came by to see me. She said, "Mommy, why you don't just take your cane with you?" And when she said that, it was a light bulb went off in my head. And here I am. It's not like I don't have a cane. We were going to the mall, and I remember the last time we went to the mall, I ran into a pole and I had a big old knot on my head. I almost split my head open. And I was afraid of that, but I didn't say anything. I just wanted to make them happy.

I have a brand new cane just in the closet in my rain boots. And I haven't even been wearing the rain boots because the cane was in it, so I felt like it was contaminated with the cane. She said, "This would help you so much." And all I could do was, and then I started crying. I started crying. I'm crying now, but I started crying because it made me realize that the only person that was embarrassed of my vision loss was me.

And I didn't want to burden nobody else. And they was more worried about me not using the cane. And I didn't know that. And I thought that they didn't want to be around me. Or when they was around me, I wanted to be like them. I wanted to go and act like I could still see as good. But when we went to the mall, I had the cane out and it just fit me. The cane was moving without me, put it that way. It was guiding me without my permission, if that makes any sense. Everything just happened so naturally, that was the best thing I ever did.

**Ricky Enger:** Wow. Talk about a roller coaster, right?

**Marc Arneson:** Right. I don't know what... Yeah, these episodes, I'm like, I get tensed up. And then by the end of it though, I'm smiling at each one.

**Ricky Enger:** Yeah, it feels so good because it's just that moment of catharsis. It's watching someone go from this place of just feeling so lost in a way. And in Angela's case, feeling shame. That's the thing that we've talked about before on Hadley Presents is that feeling of shame in relation to your vision loss. And then, there's the whole friends and family aspect of it. What are they going to think? And I think my favorite line was, "Blind? I'm not like those people." We do hear that.

**Marc Arneson:** Right? Yes. Yeah. Actually, I had a chance to sit with Angela over the phone. We recorded this together. And the thing that I think is so cool about Angela, is she's just, she's so honest and she's just so real. And you can hear that in her voice. It just really comes across. I just, I was reminded of our conversation together when I was listening to this again. But yeah, again, these common themes that we keep hearing. And I was thinking the stigma that she carries around about with the white cane, that was powerful too.

**Ricky Enger:** Oh, yeah.

**Marc Arneson:** With the rain boots are contaminated with the cane.

**Ricky Enger:** Right, it's contaminated.

**Marc Arneson:** But I imagine that's pretty common too, don't you think, Ricky?

**Ricky Enger:** Oh, for sure. We've talked about this in a couple of our episodes on exploring the white cane. And people have shared that, even professionals. We had Dorrie Rush who is a professional in the blindness field, share about her journey with the cane. And it was very much that. I don't want to admit that I need this and people are going to look at me in a different way when I have it. And then ultimately when you start using it, it's like, maybe I was thinking way more about this than other people were. And hey, I'm not bumping my head anymore.

**Marc Arneson:** Yeah. What did she say? I think she shared that she still wanted to act like she could see. And you're right. But her family members, and what a revelation for her, right? When her daughters, they wanted her to be safe. That was what was important to them, regardless of the cane or the contaminated boots, it was just like they wanted her to be safe. Which I think that's really a cool revelation that she came to as well.

**Ricky Enger:** Yeah, definitely.

**Marc Arneson:** I love that though. The cane was moving without me. Is that how she said it?

**Ricky Enger:** Yeah.

**Marc Arneson:** I think it was guiding her.

**Ricky Enger:** Yeah, I love that. It became a thing that was just natural for her, whereas I think she expected to struggle way more with it. And suddenly it's, "Hey, I'm moving through the world again. I'm doing my thing."

**Marc Arneson:** "And I'm doing it safely now." Yeah.

**Ricky Enger:** Yeah, yeah. Thank you, Angela. Such a powerful story. We appreciate it. And last up, let's hear from Bill.

**Bill Massey**: Hi, my name is Bill Massey and I am calling from Raleigh, North Carolina. In 2008 at the conclusion of a routine I exam for an eyeglass prescription, my optometrist suggested that I get a field of vision check to see if I had a glaucoma, but he was so complacent in his suggestion that I didn't take it seriously and ignored it.

That was my bad because two years later, in 2010 when I was back for another eyeglass prescription refill, he asked why I had not had the field of vision check, and then insisted that I get one. And gave me the contact information for the Duke Eye Center here in North Carolina.

Well, about a month later, I went in for my field of vision check, and it was determined that I already had a fairly advanced case of glaucoma. And I was prescribed a regimen of three different eye drops twice a day in each eye. But despite the eye drop regimen and several procedures to install in my eye what my doctor called the bleb. My vision continued to deteriorate until 2016 when I had to surrender my driver's license to DMV and my car keys to my wife. And so, to say that that was disappointing to me would be an understatement.

But a couple of weeks after that, I was back at Duke Eye Center for a routine eye pressure check. And I was sitting in the always crowded waiting room. And I was so wrapped up in my grievance about having lost my driving privileges and thus my independence, I didn't even notice this elderly snow-haired gentleman who plopped down in the chair beside me. And he said, "Good morning." And so I returned his greeting. And we struck up a conversation that was pretty much dominated by me lamenting my woes about having lost my driving privileges.

And he indulged me until I stopped to take a breath. And then he said in his soft southern drawl, "Well, I suspect you can't drive no more, but I suspect you can still walk." I didn't say anything. He went on and he said, "And I expect you can't see no more, but I suspect you can still hear." And so while I was formulating some kind of response to point out what I thought was his misplaced optimism, the nurse stepped around the corner and shouted out, "Mr. Webb." And without saying a word, the gentleman stood and shuffled off down the corridor with his walker and the nurse guiding him by his elbow.

Now, I had never seen Mr. Webb in that waiting room in the dozens of times I had been there previously. And I have not seen Mr. Webb in that waiting room in the dozens of times I've been there since. But I have concluded that that is because it's not often that we encounter an angel. And I'm convinced that that's who he was, because since that day, I have focused on my future and not my past.

**Ricky Enger:** Captivating storyteller. Right?

**Marc Arneson:** Oh my goodness. I feel like I could sit and listen to Bill all day.

**Ricky Enger:** Yes.

**Marc Arneson:** And again, okay, so true to form, Ricky, I find myself relating to Bill as well. That line, it's like, what'd he say? "Formulating a response to point out his misplaced optimism."

**Ricky Enger:** Yeah, very much so. We always want to tell people, "No, I'm right in my unhappiness. Don't try and tell me otherwise."

**Marc Arneson:** Yeah. No, but honestly, when I listen to Bill, and I've heard this episode before, but I think every time I listen to it, I get chills a little bit. And I think about this Mr. Webb and how he was able to help Bill look at the world from a different perspective. And that can be such a wonderful gift sometimes.

**Ricky Enger:** Yeah. And so much of it is about hearing the right thing at the right time. And you never know. Maybe you are the person who has that right thing to say to somebody else, but you're like, "Well, I'm not a born storyteller."

And so, if people are listening to this and thinking, "I actually do have something I want to share, but I feel self-conscious about it. I don't think I'm going to be able to come up with this perfectly crafted thing like I've heard on this episode." And so the cool thing is you don't have to make it a perfectly crafted thing, right?

**Marc Arneson:** Yeah. No, and I think that's part of why they're so relatable. And don't get me wrong, I mean, as we were joking, the minute the record button hits, I start freaking out and I get all nervous. And so I get it. And you always want to be perfect and say the perfect thing. But I think part of the reason I love these Insights & Soundbites is because they're not always perfect, but they're honest, they're real and I think that's what's important, right? It’s that you can just, people are just sharing their stories. And you're right. That's such a good point. You never know who it's going to connect with and make this huge difference like Mr. Webb did for Bill.

**Ricky Enger:** All of these stories have come, as I mentioned at the beginning of the episode, from Hadley's other podcast, which is called Insights & Soundbites. And it's where people can do just what we've heard here. They can share their stories with us, and then we take those and maybe do a couple of tweaks here and there. Or maybe you call and your dog is barking and you're like, "Oh, gosh, that didn't quite work. I guess I'll never have my wisdom shared with the world." But that isn't necessarily true.

I feel like we should actually go through that process. If somebody is thinking, "I do have something to share. I have a point that I think people will find relatable or it's something I wish someone had told me in the beginning of my journey." What is the process then of sharing something for Insights & Soundbites?

**Marc Arneson:** Well, there's lots of options, actually. There's a phone number that you can call and you can just leave a voice message. It's 847-512-4867. Call that number. You can leave a voice message, and sometimes we're just taking those voice messages and using them as episodes.

Also, pretty cool thing you can do right from our website. If you're online, all of our Insights & Soundbites episodes are right on our website. And on that page, there's a button that you can select and it says, "Submit your insights." And so once you select it, there's going to be another window that pops up and there's a button that you can select that says, "Record". And you select that, start talking, and then stop recording. And then those go directly to us, and we can get your message that way too. That's a neat way that you can do it.

But honestly, Ricky, you can also just call our 800 number. You'll get the help desk team, and you can just let them know that you want to share something on our Insights & Soundbites. And they'll pass you on to some folks here who will get back to you as soon as they can and just spend some time on the phone recording your story.

I get the privilege of being able to call people and sit down with them and hear their story over the phone. And then we're using a lot of those calls as some of our episodes as well.

**Ricky Enger:** That's great. Which takes some of the pressure off. If you don't get your message recorded exactly the right way that first time, there's a chance to just talk it through with someone. And we can pull out those parts that you're like, "These are the important bits. Let's share that." Then that's a way to do it, right?

**Marc Arneson:** Yeah, no, that's exactly right. And it's a nice way to do it, just getting on the phone and having a conversation.

**Ricky Enger:** Well, thank you, Marc, for sharing that process. And we really are so grateful to all of you who have shared with us thus far. And we hope that if you're listening now and you have something to share, that you will do that. If you want to catch the Insights & Soundbites episodes every couple of weeks, or if you want that information on how to submit one for yourself, those things are in our show notes. Or as Marc said, you can certainly call our 800 number. Is there anything else that you want to leave people with? This really has been a lot of fun and certainly a roller coaster. We go from laughter to tears and back again. Right?

**Marc Arneson:** I know. No, it's so true. But Ricky, again, just to restate your point that you made, it's you never know who's going to connect to your story. And the feedback that we're getting from folks who are listening to the Insights & Soundbites, like I said there, there's folks that are going back and listening to them over and over again because they're finding so much hope in them, and they're really connecting to the stories, and it's helping them feel like they're not alone. And so, sharing your story could give that kind of hope to somebody else as well.

**Ricky Enger:** Yes. Thank you so much, Marc, for joining us. And again, thank you for those of you who have shared your insights with us.

**Marc Arneson:** Thanks, Ricky.

**Ricky Enger**: 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. That's P-O-D-C-A-S-T@hadley.edu, or leave us a message at 847-784-2870. Thanks for listening.