Hadley

From Diagnosis to Support

Presented by Ricky Enger

February 28th, 2020

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, author and MD Support founder Dan Roberts, along with Hadley Director of Branding Marc Arneson join us to share Dan's story beginning with his diagnosis of macular degeneration. Welcome to the show of both of you.

Dan Roberts: It's great to be here, Ricky.

Marc Arneson: Yeah, thanks Ricky. It is great to be here.

Ricky Enger: So glad that both of you could join us and I know that you know, Marc, for you, listeners are actually familiar with some of your work, whether they know it or not because you do a lot behind the scenes that comes out in the things that Hadley presents every day. So could you tell us a little about who you are and what you do?

Marc Arneson: Well, as you said, Ricky, my title is Director of Brand Development. What it means is that I really get to try to help understand ways that Hadley can better serve those with a visual impairment. And so I spend most of my days visiting low vision groups and I'm meeting individually with different fascinating people and sitting down doing some group interviews and understanding of some of the challenges, some of the needs and where are ways that Hadley can be more helpful? Once we figure out a way that we can help, then my other part of my job is to try and go and tell as many people as possible about that and about the services that we offer.

Ricky Enger: That is awesome. So Dan, your reputation proceeds you as well and it's all good. But for those listeners who aren't familiar with who you are and what you do, tell us a little about yourself.

Dan Roberts: I don't do anything behind the scenes like Marc does. He keeps busy doing that. I can't afford the scenery, so I'm always out front. And enjoy what I'm doing, and I'm only doing it because I had to. It's something that I was called to do because of my own condition, and that's where I went, and I'm glad I took that road.

Ricky Enger: I think many others are as well because you do so much good out in the community and I'm so pleased that you're here to share your story with those who haven't heard what you do and provide these important resources and just your perspective on living with vision loss. So I know Marc, you have a few excellent questions to get us started.

Marc Arneson: I was hoping we could really start a little bit towards the beginning of your journey, and I know that you were diagnosed back in 1994 with macular degeneration. Can you recall that appointment with that doctor and do you mind sharing a little bit about what that experience was like?

Dan Roberts: When things started disappearing in my field of vision, I knew I had a serious problem with my eyesight. So since I had already been to the emergency room for that, I was told I needed a retinal specialist. That was the beginning of my journey. So I wasn't surprised when tests confirmed that I had lost a considerable patch of the visual field in my left eye and a small one in my right eye. I was surprised, however, when the retinal surgeon told me that he wasn't sure about the cause, but that it could be inflammation. And now remember, this was back in the mid-nineties. His answer was to give me a subcutaneous injection, meaning in the tissue around the eye, not into the eyeball, of a corticosteroid and sent me home. Within 24 hours, my blind spot increased about twice and that of course panicked me, and I immediately made another appointment.

That's when he told me that he was stumped, and he didn't really have an answer. I asked him if he thought I was going to get worse and if so, was it possible that I could continue teaching high school until retirement in about seven years. He smiled sympathetically, crossed his fingers, and left the room. It's not what he told me, but it was what he didn't tell me that was the biggest problem. He didn't tell me what was wrong, because he didn't know. He didn't tell me I wasn't going to go blind. He didn't tell me I didn't have cancer, glaucoma or any of the other things I later on looked up. And so he didn't take away that fear of the unknown. He actually made the unknown much larger for me, and I find this to be true in too many cases.

Marc Arneson: So he walked out of the appointment, leaving you to yourself. What were you thinking at that point and emotionally, what were you going through a little bit?

Dan Roberts: I also had my wife with me who is much more emotional than I am. Thanks to my wife, that emotion was definitely expressed and we both felt that together for a good year or a year and a half until we started finding out what was going on. As I discuss in my book, when I was a child, there was a monster behind my closet door. I think everybody has one of those, but it never came out. That monster didn't. I eventually put that fear away as I got older. But that day in the clinic, the monster shoved open the door. I saw it for what it was, and as I said, that was my fear of the unknown, scarier than anything I could have imagined. And I was totally defenseless. When the monster in my closet scared me, I went and ran into my parents' room. They protected me. Well, they weren't there this time. I wished somebody would have been there to tell me that as I learned later, my condition wasn't going to leave me totally blind. I needed someone who could have told me that even if the worst did happen, I would still be able to live a meaningful life. But instead I made the biggest mistake, and this is the first thing I tell people. It's like what a psychologist will tell a person who's grieving a death of a spouse. Don't take quick action, give yourself time to get over that first hurdle of emotion before you make decisions. But I retired early from my teaching. I spent the next year waiting to go blind. And the more I thought, the angrier I got.

I wasn't angry at the doctor who led me to believe that there wasn't anything anyone could do for me, but at myself for not asking what he meant when he said nothing could be done. If I had asked, he might've explained that nothing could be done medically. I could hope that he would follow that then with things that could have been done to help me remain independent and to maintain my quality of life.

Marc Arneson: Yeah, and Dan, it's interesting just in the few people that I've met, it's something that I hear that's relatively common is leaving the doctor's office with this impression that there's nothing that can be done. And I know in your book, the book that you had written the first year, and I think it's titled “The Essential Guide for the Newly Diagnosed,” you talk about that. Is there any direction that you wish your doctor would have pointed you in or shared with you in that appointment?

Dan Roberts: I wanted knowledge first. I wanted to know what I had. He couldn't tell me that. I ended up having to go to a doctor in New York, and I live in Kansas City, and that's where I finally got my diagnosis and learned what I had. If I could have just known that I wouldn't have been searching this new thing called the internet. I went out and bought a computer for the first time in my life just to learn about my condition, and I was finding all kinds of scary things. So if he would've just told me what direction to go to look for answers. Doctors are very busy, however, they're not too busy to spend another 30 seconds to direct us in the right direction. And then again, in their defense, where are they going to learn where these resources are? They don't learn them in medical school, obviously, they might spend one semester studying outreach and rehabilitation, but that's probably all they get from what I hear. If he'd had just given me that direction, I think that would've been the best.

Marc Arneson: So it sounds like you did get on the internet and you started to find some searches and I think you came across a resource called, was it MD List at that point? Do you mind talking a little bit about what that meant for you to find a resource like that?

Dan Roberts: Okay. That meant everything to me. As soon as I learned how to get on the internet, I just started searching for people who could tell me what was wrong because I needed someone who could have introduced me to low vision devices, computer technology, low vision rehabilitation, clinical trials, support groups, transportation options, and personal counseling. All of those things I needed that I didn't get from the doctor, but nobody told me where those places were.

Maybe somebody could have talked me out of retiring early by telling me that the progression of my particular diseases is usually tracked in years, not days, but no one did. And the sad thing is that there were people who could help. They were there. I found that out later. They were there the whole time, like my state agency and other organizations and resources like Hadley to help people like me. Why didn't I know it? Because no one showed me where to look, that's why. In 1997, it wasn't as easy as doing a Google search. There was no such thing as Google. We depended totally upon doctor referrals, which were and still are hard to come by, just to ask any low vision specialist how many referrals they get from the local ophthalmologists. Ask the optometrist how many times they refer to an ophthalmologist. There's just cross-referencing going on and that needs to be greatly improved.

So anyway, we turn for answers to that new thing called the internet, and it was my wife, Chris, who insisted that I start learning how to use that computer. And if it hadn't been for her, I might be telling a whole different story. But I listened to her and because of that, I'm okay, but not just okay. I've discovered the joy of helping thousands of others to understand that visual impairment isn't a dead end.

That group called MD List, that started with a group of 12 people on an email discussion group called a List Serv, and there were 12 folks sitting there waiting to meet me. We worked together that first year to find answers. They didn't have answers either, so we're sitting there, kind of stumbling around together. Then we started welcoming other people who found us and found our resources because I decided, okay, everything I learn, I better put on a website. So I had to learn how to develop a website and put it all on there. The MD List has since welcomed close to 2,000 members since that time and we registered in 1998 as a 501C3 Corporation, called it MD Support and, together with our partners now, MD Foundation, and The Prevent Blindness Association, our information and our support and our resources reach more than 40,000 people monthly.

Marc Arneson: You know, it's interesting, Dan, again, a lot of what I've been doing here at Hadley is just a lot of listening and so I'm hearing a lot of common things from different people that I'm meeting and community is something that that comes up over and over again and being around people or being able to talk to people who just get it and understand what you're going through. Can you talk a little bit about that when it comes to MD List or even MD Support and the importance of this community that you've created out there?

Dan Roberts: We had no choice when it came to losing our vision, but we do have choices when it comes to how we're going to live with it, and we have to make those choices. Choices like, do I buy better sunglasses, or do I keep the old ones that I've been wearing all my life? Do I wear a wider brimmed hat? These are simple choices. Do I learn how to use a long cane? That's a tough choice to make. Do I improve my diet? Again, that's going to make a big change in their life. Do I improve my personal environment for safer navigation? Do I label things around my house, do I put white paint on my doorframes and on my steps? Do I take these steps to adapt? Do I keep going to church or do I quit going to church or do I quit going to the community center just because I feel different than everybody else and they treat me differently? Hundreds more changes like that in lifestyle that may take us out of our comfort zone, but which we know we'll have to do to keep healthier both mentally and physically.

Marc Arneson: So I know that you also, Dan, in addition to all the work that you're doing with MD Support, I know also that you write a blog. There's a blog that you had had forwarded to me that I had a chance to read, that you titled Hidden Thoughts of the Visually Impaired. What are some of the biggest challenges that you see for someone who becomes visually impaired later in life?

Dan Roberts: Humility. That's one of the things I had to learn. Self-confidence, which comes from jumping in and trying things even though you might fail. Again, these are things that come right out of my personal experience. Stories about each one. Develop a sense of humor to be able to laugh with other people.

Ricky Enger: And the blog post is definitely worth a read. But I think that humor especially is something important to develop because when you can laugh, things seem just that little bit easier to deal with. I've been blind always so I didn't experience a loss in the same way, but I can certainly relate to doing things that happened because of blindness. Putting orange juice in the mashed potatoes instead of milk because I wasn't paying attention and they felt the same. What do you do? Well that's pretty funny in retrospect. And so just the ability to laugh at that kind of thing rather than see each of your challenges as a stumbling block I think can make things a little easier.

Dan Roberts: And have you ever had a pie crust with a tablespoon of salt? That's one I'd like to avoid from now on. My favorite story is when I went into the post office and saw who I thought was Sheila, who was a friend of mine, a fellow teacher, and she was taking a long time at the desk. And so I figured I'd rib her a little bit, and I said, "You know, if some people would hurry up, we could all get our mail done." And she turned to me and said, "I'm very sorry sir."

Ricky Enger: It wasn't Sheila.

Dan Roberts: No, and I can't go back to that post office anymore. I actually had to move.

Marc Arneson: And Dan, I know that in the work that you're doing and the support that you're providing, you've met thousands of people who are new to vision loss. If you had one recommendation for someone who is newly diagnosed, what would it be?

Dan Roberts: I mention tenacity and adaptability and support and knowledge. Well, if you put those words together, they spell task. I didn't do that on purpose, but I noticed that one day I said, well, we do have a task, and that is our task force. And so if we can just remember the word task and what it stands for. Tenacity, adaptability, support and knowledge. We can help protect ourselves, especially against the emotional assault of vision loss. It's self-perpetuating. It's a circle. Tenacity is the engine that drives you to want to adapt your environment and just strengthen your support system and expand your knowledge.

So that's the first thing right there. You've got to have the desire and the tenacity and sometimes you need help with that to maintain that tenacity. Just like we had to go on a diet, we need people to stay on us about eating well and that kind of thing. And then if they can do that, and if we can keep that wheel turning, that energy going, then we'll gain the confidence that we'll need to fuel that tenacity. So as I said, it's self-perpetuating. And we also have to actively pursue personal contact. So that goes along with that. Living with vision loss isn't easy, but many of us who are traveling this road know that it's much easier when we have the help and understanding of other people. So the main thing to remember is that no one needs to be alone.

Ricky Enger: Those are all incredibly important things. And even just that knowledge of there is someone else out there who has experienced what I'm going through now, can I think lessen some of that fear. If you feel like you're not the only person who is facing this and you see people who have been successful, ultimately it can give you something to look at in that here's where I am now and this is what I'd like to strive for. This is where I would like to end up at some point. So yeah, I think that's really important. And I want to thank both of you for taking the time and just having a conversation about this and Dan for sharing your story. If people want to learn more about what you do, Dan, and check out the resources that you've developed, just in your own journey, where can they go to get that info?

Dan Roberts: The first place is if they're on the internet, they can go to MDsupport.org. That's where they will be led then to preventblindness.org which is where I'm chief editor and run the news archives and all of the information, all of the, what they call the intellectual material, the support and the social groups, the internet mailing lists and that kind of thing are all found on MDSupport. And then we also have outreach to the non-internet community through the International Low Vision Support Group, which is as of yesterday, numbers 215 support groups around the world.

Marc Arneson: Wow.

Dan Roberts: That don't have internet access except through one person who has volunteered to be the facilitator of that group. And that person, I stay in contact with monthly, providing them with presentations and handouts and lesson plans and that kind of thing that they can use to run their monthly meetings.

So that's, we don't leave people out just because they are not of the computer age and maybe haven't learned to use computers or don't want to. A lot of them belong to that. Plus our tele-support group, which has about 60 to 65 people on it that can't even get to the live groups for one reason or another. And so we also provide the same materials by telephone. I do feel like I should give my phone number because if there are people who don't have internet, might want to get in touch with me, but that's a toll free, (888) 866-6148.

Ricky Enger: Excellent. And that too is a really important point because I think that for people who aren't yet on the internet and they're facing a vision loss and it's like, well now I not only am learning to adapt my environment, but I need to learn how to use the computer with the vision loss just to get access to some of this stuff. So I think it's great that support systems exist outside just finding something on the internet. As good as the internet is and as much as it has done to bring a lot of us together, it isn't the only way to reach out to other people.

So Marc, if people want to find you and drag you out from behind the scenes a little bit just to get in contact and say thank you or perhaps invite you to one of the support groups that they're running or any number of other things, how can people reach you?

Marc Arneson: Yeah, no thanks Ricky. Any opportunity I can take to share about what Hadley's doing I'm happy to do. And you can email me, my email address is pretty simple. It's just my name, which is Marc, M-A-R-C @hadley.edu or give me a call. My direct line is (847) 784-2775.

Ricky Enger: Thank you, Marc. Thank you, Dan. It's been such a pleasure having you both on the show. I really do appreciate it and I'm so glad you could share this valuable information with us.

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.