Hadley

Foundation Fighting Blindness: Where Research Meets with Support

Presented by Ricky Enger

**Ricky Enger:** After your vision loss diagnosis, you're likely to have many unanswered questions. In this episode, Ben Shaberman, Vice President of Science Communications for the Foundation Fighting Blindness, joins us to share how his organization can help. I'm Ricky Enger, and this is Hadley Presents.

Welcome to the show, Ben.

**Ben Shaberman:** Ricky, it's wonderful to be a guest on your podcast. Thank you.

**Ricky Enger:** I am so happy to have you, and I'm really looking forward to learning more about the Foundation Fighting Blindness. It's one of those things where I have known the name of the organization, but in terms of kind of learning what goes on in the day-to-day and how you all help people, I know you do a tremendous job. So, I have a feeling that some of our audience members may know a bit about the organization and some this may be the first they've heard of it. So, before we learn about the Foundation Fighting Blindness, let's learn a bit about you. Tell us about yourself.

**Ben Shaberman:** Well, I began with the foundation a little more than 20 years ago. I began as a science writer with the Foundation Fighting Blindness. And full disclosure, at the time, I knew little about the eye, the retina, or even biology, for that matter. And for the first few years of my career, I read a lot of research papers, I interviewed a lot of scientists, and my role was to report on research. It was almost like a constant college course in retinal research and retinal diseases. And after a few years, I felt like I started figuring some things out. And over time, my role at the foundation has expanded. I still write articles, I do a lot of talks, presentations live, I do webinars, I do a lot of education, and I have a podcast. And I work with a lot of patients and families to help them understand their condition and what research is underway that can potentially help them.

We've been around for more than 50 years. And our mission, our real focus, is to drive research for inherited retinal diseases like Retinitis Pigmentosa, Stargardt Disease, Usher Syndrome, LCA, as well as the dry form of macular degeneration. And we've raised nearly a billion dollars toward our mission since we were founded 1971. And we do a lot of other things, which I think we're going to talk about, Ricky.

**Ricky Enger:** Yeah, that's excellent, and what an incredible amount of money raised just in a relatively short amount of time. So, a lot of times we will get calls from people, or just in the process of interacting with people, we discover there's this commonality in their stories and they're like, you know, "I was diagnosed, I walked out of the doctor's office with my head spinning. I've never even heard of all these terms they threw at me, and I have no idea what to do next or how to even learn more about this condition that I've just now heard about." So, what does Foundation Fighting Blindness provide for people who are in that position, where they're like, “I know what my diagnosis is, but I know very little aside from that?”

**Ben Shaberman:** Yeah, Ricky, you're touching on something that is very challenging for patients and families, not only because the diagnosis is overwhelming. A lot of eye doctors don't really understand, especially the rare diseases, because they just don't see them that much. And that's where we and some of the clinical researchers we fund, can help. And our website and our team, we understand the conditions. We can help people understand what's going on. We provide no-cost genetic testing, because most of these conditions are caused by mutations in a single gene. And if you can identify that mutated gene, it really helps people understand the diagnosis, clarify the diagnosis. It helps them understand who else in their family might be affected or at risk. Maybe most excitingly for the patients and families, is it helps them understand what research might be relevant for them. Depending on where somebody lives and which doctor made the diagnosis, we could refer them on to a doctor at, let's say, a clinical research center, that has more knowledge about these inherited retinal diseases. That could really be helpful, they can get a more thorough comprehensive exam.

And going back to genetic testing, again, we have a no-cost program that people can sign up for. As part of that, patients are also put into a registry, My Retina Tracker Registry, which helps get them on the radar screen of researchers and companies that are conducting clinical trials. And being in a registry is very valuable for the patient and the researchers. I want people to understand, we never give away personal information. If a researcher or a company is interested in patients for trials, we actually run the query. We actually contact the patients and families and let them know, Retina Therapy Company of Nebraska, whatever, I'm making up a fictitious name, they're interested in you for a clinical trial, and we give you the contact information. So, we protect people's privacy and identity.

**Ricky Enger:** Right.

**Ben Shaberman:** So, the registry, the no-cost genetic testing, and then finally, we have chapters throughout the country, more than 45 right now, where people can find community and learn about local resources and just meet other people who are on the same or similar journeys. And that can be very powerful.

**Ricky Enger:** Oh, definitely. That's something that you don't have to tell us twice here at Hadley. We really do believe in that power of community. Finding someone, whether you are the person who is diagnosed, or maybe your spouse is looking to connect with others who are a spouse of someone with vision loss, and just finding those people who are on similar journeys, you can share that info between each other, and one person has the answer to a question you've been asking and vice versa. So, it is so, so powerful.

I want to rewind a little bit and talk just a little bit about the genetic testing again. So, one of the reasons, obviously, that you might encourage someone to do this is to figure out exactly what that diagnosis is, who might be affected in your family, and then get you into that registry. Let's say that you are not of the age where you're thinking about having kids anymore and you happen to know, hey, my diagnosis is age-related. Is there still a reason to do that genetic testing?

**Ben Shaberman:** You know, that's a great question. And for many years, up until fairly recently, the answer I would say is, no. And the disease I think of, related to your question, is age-related macular degeneration. And AMD is sort of a complex condition, or it's complex and there are many risk factors. Aging, your lifestyle, if you smoked or you don't eat a healthy diet, but there are genetic risk factors. But today, one reason you might think about genetic testing is that some therapies are actually targeting certain high-risk genes. And so, if you know have high-risk genes, there are certain gene therapies, for example, that would be appropriate. So, there may be in some cases, reason to get genetically tested if you're interested in, let's say, a trial for a gene therapy.

**Ricky Enger:** I know that a lot of what you do is research, whether it is your funding research or you're kind of collating this research that has been done and sharing news about treatments or potential advancements that are happening. And for people who want to know more about that, how can they do that through Foundation Fighting Blindness?

**Ben Shaberman:** Sure, and that's what’s so fun for me, is communicating the research and working with the foundation team to talk about the research because there's so much great science underway. But to answer your question, our website is chock full of great information on emerging therapies, related research, as well as the inherited retinal diseases and AMD. And our website is Fightingblindness.org. With that said, we have local meetings and events throughout the country that are educational. We have webinars that are international, that are open to just about anyone. In fact, we have a webinar on age-related macular degeneration, so that will be a webinar on, you know, what age-related macular degeneration is, some of the risk factors, and then of course, some of the emerging therapies. And I think we might also have some discussion of low vision resources for people with age-related macular degeneration.

So, there are many different ways that people can get engaged. And one thing that I try to do, and I know my colleagues try to do, is engage with people at the level they're at, because some people want pretty simple science and the broad overview, just the basics. There are other people that really dig deeply into the science and want to know the details. So, we try to accommodate everybody. The science can get pretty complicated, but we do try to keep it simple for a general audience, in many cases.

**Ricky Enger:** Yeah, I know on the website there are a number of educational videos that are exactly that. It's that place to get you started. You get that overview and then you can decide, you know, I would like to really dig down and get into the nitty-gritty of this. And it's great that you're providing info for both those types of people, because you may start out one way and just, you know, I want to know the basics. What can I expect? And suddenly it becomes a thing that you really want to learn more about.

So, we've gone through a lot. We've got those educational videos, you do webinars. We'll have a link to that in the show notes, the one about macular degeneration, as well as where you can find those additional presentations and webinars. The Retina Tracker, I believe that's called. How can people get involved with that? So, let's say someone is saying, "If there are clinical trials, if there are treatments I want to be called, if I'm eligible." What's the process to kind of get that interest documented?

**Ben Shaberman:** Sure, great question. And I'd say there are really three things that people should do if they're interested in clinical research. Being in the My Retina Tracker Registry is definitely a great way to do that. And you can go to Myretinatracker.org, and that's where you register. Whether, if you get a genetic test through us, you will automatically be registered, but we want you to come back in and complete additional surveys. If you didn't get genetically tested through us, or you've never even been genetically tested, if you have an inherited retinal disease, you can go in and just set up your own record. You don't need a genetic diagnosis to be in the registry. So, easy to do that yourself. Just for the record, right now, we're not really accommodating people with age-related macular degeneration in My Retina Tracker, it's something we're thinking about. We're more focused on the rare, inherited retinal diseases.

But in addition to My Retina Tracker, I strongly encourage people to visit our website. At the top of the website, there's a way to register for news alerts, so you're getting updates on emerging therapies and research, because through My Retina Tracker, you're not going to get notified about every trial.

In addition to that, we, and it's actually something I maintain on our website, we have a clinical trials pipeline chart that lists virtually all of the current clinical trials that are underway, and that's on the research tab on our website. So, those are the different ways to stay up to date on what's going on on the clinical trial front.

**Ricky Enger:** Excellent. Now, for someone who is looking for local support, I know there is a spot on the website where there are local chapters, and I think each chapter probably does its own fundraising and things like that. Do you have thoughts, or can you give just a brief overview of what might people find if they join one of these local chapters? Are there things that are common among all of them, or is it really that is something that's handled locally and each one sort of has its own flavor and things that it does?

**Ben Shaberman:** Yeah, you know, that's a great question. I'd say a little of both. One thing that we try to do at the local chapter level is provide a sense of community, so we try to bring people together. There is an educational aspect to the chapters, and it's not just about research. Often, we feature low vision speakers, people who know about resources and accommodations, much like yourself. And being connected to the community is just a great way to learn about doctors in the community and the different resources.

But like a lot of groups, each group has its own kind of personality and focus. We have volunteer leaders, a president, and some resource chairs and things like that. And then we do have our community managers, meaning staff who help organize and manage the chapters. And make no mistake, we fundraise, that's an important part of our mission.

**Ricky Enger:** Of course, yeah.

**Ben Shaberman:** So, the chapter is where you can get involved in a walk, or maybe a golf tournament, or a dinner, or people organize all kinds of creative do-it-yourself kinds of events for fundraising. So, there's definitely that element as well.

**Ricky Enger:** Wow! I feel like we've covered quite a bit and just this one website has so much information. I was looking through it just in preparation for this, and I found it fascinating myself, just kind of going down a rabbit hole or two of finding out some information. So, I think that our listeners can spend a great deal of time there learning more about what you do and how it might benefit them. So, is there anything else as we kind of bring this to a close? We've covered a lot, but is there something that you hope people will definitely take away from this, or something that we didn't cover that we should have?

**Ben Shaberman:** I guess just the other thing I'll say is, you know, we're all about community, we're all about putting information out there. But for me personally, I think helping people on an individual basis, on their individual journey, or their family journey is really important. Vision loss between people can vary a lot. The emotional aspect of their vision loss is personal, it can vary. And their interest in participating in research or trials can vary. So, we try to meet people where they're at in their journey, that's really important to me. So yes, we want you to be a part of the community, we want you to see all the great stuff that is in our website, but hopefully we can connect with people on a one-to-one basis and help them where they're at.

And you can go to our website and go down the rabbit holes, you can learn about the chapters, but if you'd rather just send kind of a single email, you can do that to info@fightingblindness.org. And just ask your question, whether it's about research, or what chapter would be right for you, or whatever question you might have. And we also have a live attended phone service, 1-800-683-5555. So, if you want to call up and talk to a living, breathing staff member at the Foundation Fighting Blindness, that person will be happy to help you.

**Ricky Enger:** Awesome! And we'll have all of that info in our show notes, along with a link to the “Eye on the Cure” podcast, which Ben hosts. And Ben, I just want to thank you so much for dropping by, talking about what it is that you do and what the organization does. It's clear by listening to you, you started out maybe not knowing much about the retina, or biology, or you know, any of that, but as you learned, you developed that passion for helping other people to learn about this as well. Thank you again, we really appreciate it, and it's been great having you.

**Ben Shaberman:** Well, thank you, Ricky. It's a pleasure and a privilege to be on the podcast and have this opportunity to communicate all about the foundation. And I just want to say, we're grateful to Hadley and other organizations that are providing resources to help people on their journey, because yeah, we're all about the research, and that's really important to a lot of people. The research takes a little time, it's challenging. There's a lot people want to do today to maximize their productivity, enjoyment, quality of life, and we really appreciate what Hadley does to help people. So, thank you and Hadley, for all you do.

**Ricky Enger:** Absolutely, thanks so much.

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