Hadley

Hear from the Scientists: Glaucoma and Macular Degeneration Chats

Presented by Ricky Enger

**Ricky Enger:** Having access to the latest info and research on your eye condition in a way that’s approachable and easy to understand, can make all the difference. In this episode, we learn about the BrightFocus Foundation from its Vice President of Scientific Affairs, Diane Bovenkamp and Hadley's Chief Program Officer, Ed Haines. I'm Ricky Enger, and this is Hadley Presents. Welcome to the show, Ed and Diane. It’s really good to have you both.

**Ed Haines:** Thanks, Ricky. Really appreciate it. This is going to be a lot of fun.

**Diane Bovenkamp:** Yeah, glad to be here.

**Ricky Enger:** Ed, I know you're pretty familiar with BrightFocus and in fact you’ve had a chance to do a presentation for them. So, I imagine that you have some good questions for Diane today. Let’s just jump right in.

**Ed Haines:** Thanks very much. Well, Diane, first of all, let me just thank you for being with us today. We're really excited to talk about BrightFocus, I think it's a wonderful organization. So if you don't mind, I'll dive right in with my first question. If you could just tell us a little bit about BrightFocus, your history and the mission of your organization.

**Diane Bovenkamp:** Thank you so much. This is so exciting to be here with your organization that's been around for 100 years, that's doing good in the community. I'm so excited. Yeah, BrightFocus Foundation has been around 51 years now, and our primary focus is to fund research around the world to find cures for macular degeneration, glaucoma, Alzheimer’s, and related dementia. So we funded $300 million for the past 50 years in 25 countries with more than 1,900 grants to more than 6,300 scientists.

**Ed Haines:** Wow.

**Diane Bovenkamp:** Yeah. We basically believe that there's no geopolitical border that we can't go and hunt down the next innovative idea. Maybe that next idea could find the cure. The second thing that we also do is translate all of the research that we fund around in the world into lay language for affected families so that you can understand and learn ways that you can become empowered to address and keep healthy.

**Ed Haines:** Boy, Diane, that's so important. I've worked with so many people that really don't understand their diagnosis and don't understand the implications. I think I read a statistic once that says about 25% of people with macular degeneration don't even really know the name of the condition that they have.

**Diane Bovenkamp:** Wow.

**Ed Haines:** So that's just fantastic that you're not only working with the medical community and researchers, but then translating the results of all of that research into language and information that people with a diagnosis can understand. That's just wonderful. So it sounds like you're serving almost two audiences. You're serving the medical community who's doing the research, and then it looks like you're also really trying to focus on the folks who have the diagnosis as well. So to that end, you have these great chats, and I think you have chats related to macular degeneration and glaucoma and it was a lot of fun to be on one of your chats just a little while ago. So I wonder if you could talk about these. Why did you start them and what was your goal?

**Diane Bovenkamp:** Yeah. We started, believe it or not, 10 years ago, these chats. And they're really cool, because just like this interview, they're audio only, they're friendly for people who are visually impaired and people can sign up and it is set up so that on the day of the chat, a telephone will call you. You just have to pick it up and listen to it. It's really very convenient and it happens every month. The reason why we did it was exactly like what you said, so that people can know more about their condition and to learn about ways to become empowered. I just recently had, last week, a chat that I did with Dr. Sheldon Rowan from Tufts University in Boston. We talked all about lifestyle modifications and the microbiome. The bacteria in your gut can actually affect your eye disease if that makes sense.

So yeah, there's all these things that you can do to become empowered and maybe take all these questions and there's a transcript every week and we push it out on many different medium that you could actually print out and bring it to your doctor and ask them about it. Yeah, it's all about trying to spread the information and become empowered.

**Ed Haines:** That's fantastic. So people sign up, they get a phone call, so there's no barrier there. They don't have to learn how to use their phone, if using the phone is difficult for whatever reason, for vision related reasons. Is there any opportunity for interactions? Can people ask questions of the speakers who are featured in your chat, or how can they provide feedback?

**Diane Bovenkamp:** Absolutely. There’re many different ways for feedback because that’s what we want. It's kind of like the Stephen Covey, Sharpening the Saw. We always want to try and improve. And so not only can people ask questions before the talk, and actually I encourage people to do that if you do go and sign up, because then I put that on my list if I'm the moderator of questions that I can maybe ask the speaker. But also, if you think of something in the middle of the chat, they can press a button. You can go and talk to a live person, tell them your question, and then get back onto the call. And then also at the end of the talk, we always ask people with a simple, press one, two or three, press a number, "Did you like this chat? Was it helpful or was it not helpful?" So I think that it's very important. We don't want to do podcasts or chats just for the sake of having a chat. It has to be serving the community.

**Ed Haines:** No, I totally agree. Now, how often do these chats happen? Is it once a month, or bimonthly, and how do you keep current and interesting with regard to your subject matter? It sounds like you have a lot of researchers to draw on. Are those primarily the presenters?

**Diane Bovenkamp:** Yes. In the 10 years, we've done 115 episodes to date so far. And you can access all of these on our website. But it's monthly. It's the last Wednesday of every month just so it's very easy for people to remember. The inspiration comes from many places. I am the chief of the scientific affairs team, so we go around the world, or virtually, to different scientific conferences, so we know that there are hot topics. We know thousands of researchers around the world, as well as clinicians, because we fund research that is basic translational and clinical. And we also do have our scientific review committee, our advisors, that can give us advice on what's the hottest topic.

And when we go to say, ARVO or ISER, which are two major vision conferences, just the topics there. We see all of the pharma companies and biotech companies that are in the exhibit hall, so we can keep track of what are the clinical trials going on because that's another topic to try and keep people abreast of what new treatments might be on the horizon. So yeah, I don't think we'll ever run out of things to talk about because I find that... you probably find this too, that people's curiosity is unquenchable.

**Ed Haines:** Yep, absolutely. I'm curious now myself, if you had to name five episodes that received the most interest from your audience, what would be a few of those?

**Diane Bovenkamp:** So I think that we do tend to repeat some of those topics with updates every few years. But I think the number one is when we bring on a clinician scientist that tells you what's the latest, clinically and medically, dealing with my disease. I think that's number one. The one that we just had right now, we had 450 live listeners, but normally the ones on lifestyle, food, and nutrition. There's been enough scientific proof in the last five or so years for people to say, "Ah, you know what, exercise and nutrition is great for either preventing the onset of the disease or maybe progression." Also with macular degeneration, all about the AREDS clinical trial and the nutrition. That one, I guess, is a third type of trial people want to keep on top of that.

And just as a summary, it's like a clinical trial that was led by the National Eye Institute, Dr. Emily Chew and others that shows that a specific combination of vitamins and antioxidants can help if you have intermediate dry AMD, that it might prevent the progression to wet AMD.

**Ed Haines:** That's exciting.

**Diane Bovenkamp:** Yeah. Yeah. So that's the third. I think that the fourth and fifth type, I did one chat on glaucoma and one chat on macular degeneration on stem cells. "What's the latest in treatment within the last year? How to regenerate the eye even if you fully lost your vision?" There are clinical trials and research on the horizon that maybe you could try and get your vision back. So those were really exciting. So you could look that up.

**Ed Haines:** I can imagine.

**Diane Bovenkamp:** And then I think just the fifth one is, "What's going on with upcoming clinical trials?" I think those five, and you can go in and find them, but what I understand is, on average, we have 600 live listeners every month for the Macular Chats. And then nearly 10,000 recorded listens on average per month.

**Ed Haines:** Wow.

**Diane Bovenkamp:** Yeah. I'm amazed. We started out 10 years ago with a hundred people live, so all of our vision chats are available to listen as podcasts on the go, on YouTube, Spotify iHeartRadio, Amazon Music, Apple Podcasts, and Pandora.

**Ed Haines:** Fantastic. I was just going to ask how you access those recordings. So that's wonderful. That's a big audience.

**Diane Bovenkamp:** Yeah. And it gives me chills sometimes thinking about the good that we're doing in giving information to people to empower them.

**Ed Haines:** Well, it's really, really important, particularly because folks often struggle, I think, to get that kind of detailed information from their personal ophthalmologist. There's just sometimes not a lot of time during that doctor visit. So it's wonderful they have this resource.

**Diane Bovenkamp:** There's actually a link where you could access all of this too. It's an offshoot of our main website. So it's brightfocus.org\macularchats.

**Ed Haines:** Wonderful. It should be mentioned, I believe you have Glaucoma Chats as well now because you also focus on Alzheimer's research, are there Alzheimer's chats too?

**Diane Bovenkamp:** We don't have an Alzheimer's chat. We actually have something called Zoom In on Dementia. It's a Zoom meeting, so you can go in and sign up on that with the Zoom In on Dementia, it's not a phone call where we call you like for the Glaucoma Chats and the Macular Chats. You sign up and you'll be either emailed or texted a Zoom link. So obviously someone would have to have Zoom on their computer.

**Ed Haines:** Sure. Really interesting. Now I just want to pivot a little bit and ask you to talk very briefly, if you can, about a newer program that I think you have called the Age-Related Macular Degeneration Community Circle. It looks really interesting. I wonder if you'd just care to talk about it briefly.

**Diane Bovenkamp:** Yeah, that's another program or service that we offer that we're especially proud of too. And it's all about affected individuals, helping each other and supporting each other. I guess in a way, this almost goes hand in hand with Macular Chats in that it enables people to get together and help each other. So it's not as structured as the chats. It's basically getting together every month and discussing whatever topics are relevant for them. So maybe there's something that came up in the news or they need to ask about caregiving or what transportation do you use or whatever. And we have someone who is a BrightFocus staff member, who's just on there as a moderator and a resource for everybody. The content and the familiarity, I guess, and the bonding between people is all directed by people who go on that program.

**Ed Haines:** Oh, that sounds great. Is that also a monthly event or a weekly?

**Diane Bovenkamp:** Monthly, yeah.

**Ed Haines:** Okay. And how do folks join that?

**Diane Bovenkamp:** I don't have it on hand, but it also is a link on the website. I'm sorry, I don't have that right now.

**Ed Haines:** Yeah, no problem. We'll make sure we get that link, and that'll be in our show notes, so that'll be fantastic.

**Diane Bovenkamp:** Great. Great. Thank you.

**Ed Haines:** Diana, this has been really interesting. Is there something that you'd like to tell us about the Macular Chats or about BrightFocus that I haven't asked about?

**Diane Bovenkamp:** Well, that's really interesting. What I want to do is put it on you and Hadley and a partnership between our organizations. I'm really glad that we met each other, and I'm going to actually highly encourage people to go and listen to your chat on low vision. I think that's one thing that a lot of ophthalmologists and eye care professionals don't think to refer people to go to low vision specialists. I think that's very, very important. No matter what level of vision issues that you have, you can always do something to maybe improve your vision or quality of life. So I think that our two organizations kind of go hand in hand, and we would love to promote you as well, because both of our expertise are complementary.

**Ed Haines:** Yeah, I totally agree. And there's lots of people in need out there. So any kind of partnership with organizations like ours are going to work for the greater good. I'm at the end of my questions, Diane. I think this has been really interesting and I enjoyed participating in the One Chat with you, and I really recommend anybody who's listening right now to sign up for the Macular Chats. They're really, really great. And as you said, they put a lot of tough medical information into really understandable terms, which is just a huge, huge thing for folks. So thank you very much for joining us today.

**Diane Bovenkamp:** It was really great conversation, and not only did I also want to mention that we have the chats, but we also have other materials. So you can go to our website and download PDFs and maybe use your reader to read out the materials on what is macular degeneration, what are clinical trials, but you can also call our info number 1-800-437-2423. You can call that and just ask someone to mail the information to you about macular degeneration free of charge and or sign up for a quarterly newsletter.

**Ed Haines:** Boy, that sounds really helpful. And I'm just thinking out loud here. I would think a lot of this information would be really great to have before your next doctor’s visit. In other words, having information from you folks to empower to ask questions of your own ophthalmologist would be really advantageous.

**Diane Bovenkamp:** Yes. There's even a sheet that you can ask for. What are the top ten questions to ask my ophthalmologist?

**Ed Haines:** Fantastic. That's really, really valuable.

**Diane Bovenkamp:** So yeah, go on our website and explore. So anyways, this has been so amazing to talk with you and thank you for inviting me.

**Ed Haines:** Well, thanks for being with us.

**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@hadleyhelps.org or leave us a message at 847-784-2870. Thanks for listening.