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Chats

Patient Stories About Geographic Atrophy

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Transcript of Teleconference with Rob Howden and Diane Marshall

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Please note: This Chat has been edited for clarity and brevity.

MS. DIANA CAMPBELL: Hello, my name is Diana Campbell, and I'm pleased to be here with you today for today's Macular Degeneration Chat, "Patient Stories About Geographic Atrophy." This Chat is being brought to you today by BrightFocus Foundation and many generous sponsors, including Apellis. BrightFocus funds exceptional scientific research worldwide to defeat Alzheimer's disease, macular degeneration, and glaucoma, and provides expert information on these heartbreaking diseases. You can find much more information on our website, www.BrightFocus.org. Now, I'm pleased to introduce today's guests, Rob Howden and Diane Marshall. Rob lives in Lincolnshire, Illinois, and was diagnosed with dry AMD in March of 2013, and Diane lives in Southern California, close to Santa Monica Beach. She was diagnosed with early-stage dry macular degeneration in 2001, and her vision remained stable until 2016, when it began to deteriorate and she was diagnosed with geographic atrophy. Rob and Diane, thanks for joining today.

MR. ROB HOWDEN: Pleasure to be here, Diana.

MS. DIANE MARSHALL: It's an honor to be here.

MS. DIANA CAMPBELL: So glad to have you both here. Before we get too far into our discussion, I'd like to explain what geographic atrophy is, and we will refer to it as GA along the way. Geographic atrophy is an advanced and severe form of dry age-related macular degeneration. In GA, or geographic atrophy, regions of cells in the retina waste away and die, or atrophy. Sometimes these regions of atrophy look like a map to the doctor who is examining the retina, hence the term "geographic atrophy." The regions of atrophy result in a blind spot in the visual field. Geographic atrophy can affect one or both eyes, and people with GA in one eye are more likely to develop it in the other eye. Geographic atrophy causes around 20 percent of legal blindness in North America. An estimated 5 million people worldwide have geographic atrophy, with roughly 1 million of them living here in the United States. Recently, the first treatment for geographic atrophy was approved by the FDA, so it is now more important than ever to learn about geographic atrophy and talk to your doctor about whether your dry AMD may progress to this phase. Now, let's hear from Rob and Diane about their first-hand experience with GA. Diane, let's start with you. Can you introduce yourself and share if you had any family history or familiarity with AMD prior to your diagnosis?

MS. DIANE MARSHALL: Hi, I'm Diane, and I live in Southern California, as Diana said. I have two wild and crazy kitties, Luka and Beau, that always make me laugh. I was an English teacher and high school counselor for 38 years. I retired 16 years ago. I love photography, writing, and reading. I currently have geographic atrophy in both eyes, but still have my central vision. I believe that my mother had geographic atrophy way back then. I don't think it was diagnosed, but I remember her turning her head always to look at me, and I think she was using her peripheral vision.

MS. DIANA CAMPBELL: Sure, that makes sense. Thanks for sharing that with us. Rob, what about you? Do you have any family history?

MR. ROB HOWDEN: I do not. In fact, when I was diagnosed with AMD, I don't think anybody in my family could even spell it, I mean it was just ridiculous. Nobody had heard of this. There's no history of it any place, so I have no history with GA whatsoever. It's like, "Where did this come

from?" Just as a little background, I've had it since 2013, again, like Diane, both eyes. And from the time I was diagnosed through today, it's been steadily progressing toward getting worse.

MS. DIANA CAMPBELL: We're so sorry to hear that, Rob. Diane, when was the first time you heard about geographic atrophy? How did you find out about what geographic atrophy is?

MS. DIANE MARSHALL: Well, I have to start way back when I was 54 and just went for a checkup to my optometrist, who said he saw these little spots in my eyes called drusen. Sent me to a retina specialist, who said I was in the early stage of dry macular degeneration, but not to worry because by the time it became problem, they would have a cure. Unfortunately, he was wrong. So, for many years my vision was very stable; there really wasn't a problem, and any kind of changes my optometrist was able to adjust my glasses. But about when I was 70—6 years ago—I began to notice that there were many changes, my eyes became blurry, and it was more and more difficult to read anything. And that's when I saw my retinal specialist again, and he said, "You have geographic atrophy." I had never heard of it, and I said, "Oh, is that a good thing?" and he said, "Well, not exactly." And so, that began my journey learning about geographic atrophy, Googling, joining groups, talking to people.

MS. DIANA CAMPBELL: Wow, what a strange situation to not even know if you're receiving good news or bad news. I'm so sorry about that. Rob, I've got the same question for you. When did you first hear or learn about geographic atrophy?

MR. ROB HOWDEN: I was actually at ... visiting my mom in Arizona, cracked open an eye in the middle of the night to look at a bedside clock, and there was a blinking LCD, and I thought, "Wow, that's really interesting." I'd never seen an LCD fail in that manner. And so, I kind of got up off the pillow a little bit, looked at the clock with both eyes, and it was not blinking at all. Laid back down, repeated the same thing, and I said to myself, "It's not mom's clock that's going bad here. It's me." And so as soon as I got home back to Illinois, I made an appointment

with my ophthalmologist. And he had the bedside manner of Attila the Hun. He told me I had AMD. I asked, "What does that mean?" and he said, "You're going to go blind. Next patient please." Luckily, the staff there gave me some coupons for AREDS2, and I got home and immediately made another appointment with another ophthalmologist for a second opinion here, because this is kind of serious, you know. And he talked all about AMD, but I really didn't hear about the term GA until working with BrightFocus and with another industry company as a consultant. So, GA, to me, is kind of a new term in a way, but that's how I discovered it.

MS. DIANA CAMPBELL: I think it's a new term for a lot of us, to be honest. It's already an alphabet soup with AMD versus, you know, age-related macular degeneration, and some people say ARMD. You know, we've got all these short ways of saying things, so to add geographic atrophy into that—or GA—and realizing that people haven't even heard of what that is makes it so much more difficult. Diane, what symptoms or changes in your vision prompted you to consult with your retina specialist?

MS. DIANE MARSHALL: Well, I had been going to my retinal specialist for 22 years. I went every year for a checkup, and then I started going every 6 months as he began to see changes. I was really concerned because things became more blurry. I couldn't read my iPad, my iPhone without a magnifying glass, and it's progressed to the point where my entire living room table is covered with different magnifying glasses, which sometimes work and sometimes don't. But I noticed also that detail was missing. I could no longer really watch TV without it being blurry. I couldn't use my computer. I knew something was happening. Many people see distorted lines, but I didn't see that. I kept checking my Amsler grid, which is a paper that you just ... can tell you whether you are losing vision in certain areas, but I could see that there were areas that had kind of grayed out, and I couldn't see the lines, so I made an early appointment with my retinal specialist and said, "Something is going on here. I'm really concerned." My optometrist could no longer correct my vision with glasses, and it just kept progressing to the point where the last time my vision was measured, it was 20/200, which is called legally blind. And it was at that point that I decided I really needed to do anything I could to slow down the progression, and so I had my first injection of Syfovre™ last week.

MS. DIANA CAMPBELL: Wow. Can you tell us a little bit about how that went? And let me just say for a second, a couple of months ago, the first-ever treatment for the advanced form of dry AMD, called geographic atrophy or GA ... the first treatment was approved, and it's named Syfovre, and that's what Diane is referring to. How did that injection go for you?

MS. DIANE MARSHALL: Well, you know, months before I decided to that, I just said, "No, not me. No way. Nobody is sticking a needle in my eye." But as my vision progressed, I became more and more concerned, and I knew I had to do something, so I just said, "Grow up and do it." So, with help from people in the macular degeneration support list, they encouraged me to do it, and I did. And they were right, it did not hurt. Everybody said, "You are not going to feel anything." And I didn't. There was no pain at all. They put lots of numbing drops. My retinal specialist came in, was talking to me, said, "Look up," and the next thing I knew ... it was a second, and it was over. It did not hurt. There was a little pressure, and it just felt strange—that's all I can say. And I was fine afterward. My pressure in my eye did shoot up to 32 and went down again after they put some drops in my eyes, and everything's been fine since then. I have another appointment in 6 weeks for injection number two.

MS. DIANA CAMPBELL: Thank you for sharing your experience. So, Rob, what was your progression like? You mentioned the blinking LCD lights back as far as 2013, and I know you didn't have major problems for a couple of years, but what happened after that with your progression?

MR. ROB HOWDEN: Yeah, after a couple of years, things started to slowly go bad, if you will, and all of a sudden I just couldn't do sports anymore. I certainly never could do them well, but it was really difficult. I was an avid sporting clay and trap and skeet shooter, and I started to lose the lead of a target. Even though, like Diane, my central vision I could still see and read a little bit, but the periphery of my central vision—if there is such a thing—was starting to go bad. And so, you couldn't lead a target to shoot it, even with a shotgun you need a little bit of skill, and the same thing with fishing. I used to love to cast a shoreline for bass, and you'd kind of drop a lure in there and hope that the guy was sitting there. But pretty soon, I'm spending as much time in the trees as out in the middle of the boat,

and my friends kind of frowned on that after a bit. So, part of the fishing experience was seeing how close you could get the lure to the shoreline and try to lure the critter in, and that went away. Now I'm still fishing, my friends still take me with, but I'm just drowning a minnow or a worm and not enjoying that aspect of it. And the same thing with simple things that require a lead, if somebody says, "Here's your golf ball bag," or "Here are your car keys," and throw them to you, all of a sudden they go into a blind spot, and you don't know where to put your hands to catch whatever is coming your way. So even in a simple game of catch, the blind spots affect what's going on.

And of course, as the years progressed, it was ... it got even worse, and really when I couldn't read well anymore; that was really sad because I just love to sit down with a good book and enjoy it, feet up, open the book, put your nose in it, and go. And so that got bad, and then in 2019 ... I still thought I could drive, and in 2019 I piled my car up into a crossing gate. I thought I could beat the gate from going down, but the gate was down already—and there was no train there, thank goodness. And then on the way home from that trip, I noticed some oncoming headlights in my lane, so now I'm focusing ahead trying to figure out what's going on and thank goodness slowing down. And meanwhile, I almost hit a construction worker because he was there holding a stop sign because it was down to one lane. And he stepped out with his stop sign and just scared me silly. And what I said about central peripheral vision is really important because I thought I could drive. I didn't know that that part of my vision was going bad, and I discovered that also by using the Amsler grid. So, for a couple of years I did not drive at all. I came home and told my wife, Gale, I said, "I'm through driving. That's it." And from then, another couple of years go by, eyes keep getting a little bit worse. My optometrist gave me a set of glasses called Max TV, which are still available through Amazon. I bought them from her and thought I was paying a lot of money, which I did, but they're the same price on Amazon, so I feel a little better about her charging now too. But I got those ... tell me if I'm taking too long, Diana.

MS. DIANA CAMPBELL: You're fine.

MR. ROB HOWDEN: Okay. So anyway, I got these glasses and watched TV. They really helped with TV. I went from a dead spot the size of a basketball to just a 12-inch ... baseball or golf ball, depending on how close I sat, so it really helped, and even reading the various menus and everything. So, I thought, "Wow, these are really great. Maybe I should drive with them." And I tried driving, and it seemed to work. They were about almost three power. And so, then I went to get my driving test. I thought, "Oh, I'll see if I can bluff my way through this," and the state of Illinois is a little bit picky about glasses—they call them binoculars. And I had to go through a whole special process and get those official state-approved binoculars and then take a driving test, which, to sum this all up, I just passed a week ago, but I haven't driven since. I'm not sure I should be driving yet. So, that's my long story, but I hope it gives some ... I just hope it gives somebody some insight, especially in the driving area.

MS. DIANA CAMPBELL: I think it will, and I know we've had a few questions, you know, about how hard it is to drive and do other things. One thing you can do is check with your local motor vehicle administration or department of motor vehicles, and actually there are low vision—driving specialists, as well. But yeah, what a huge journey that you've been on over this past decade-plus. So, I know Rob mentioned some magnifying glasses and that sort of thing, and Diane, you actually mentioned them, too, all over your table. I guess we'll start with Diane and then we'll go back to Rob. What other devices and adaptations have you grown to learn about over the years, and can you tell us some of the useful items that you might use on a daily basis?

MS. DIANE MARSHALL: Okay, well first of all I want to say that I gave up driving a year ago, and that was an amazing loss of independence. Thank goodness for friends who were there to help, but it's a big loss not to be able to get in your car and go, and I still haven't been able to sell it, so it sits there and holds my kitty litter and other things. I have found that the loss of vision due to geographic atrophy, just as the loss due to aging, is a challenge, but I have found that there are so many things out there that can really help. First of all, Apple has some wonderful devices. I use my Spoken Content, which will read to me whatever is on the page. I use my Dictate microphone, which will dictate whatever I say—and sometimes Siri

dictates words that I didn't say, which always gives me a laugh. There's a zoom feature. You can enlarge the text, you can increase the contrast, and Apple even has a special direct line for people who need help with their accessibility features. I got an OrCam, which is about the size of a lipstick, and you click it right on the side of your glasses, and it can read whatever is in front of you. It can identify faces once you've set them inside the device. It can identify objects in front of you.

Now, as your vision loss progresses, it's really important to have light, and I found a wonderful lamp called a Stella GO—S-T-E-L-L-A. It has all kinds of settings, and the important thing to me was I didn't have to keep it plugged in. I could charge it and then move it anywhere I needed to go because I didn't want any more wires that I could trip over. I learned a lot about devices from a YouTube video—not a YouTube video ... yeah, by Sam and The Blind Life. Every week or so, he would talk about different devices that you could use to help you with your vision loss. I also have something called an Alexa Echo. I don't want to say it too loud because she's going to start talking to me, but it can tell you anything you ask and sometimes things you don't ask. It can tell the time, the weather. It can tell you anything that you look up. You can set a timer. It can even control devices around your house and tell you who's standing outside your door, so there are many things out there that can help.

MS. DIANA CAMPBELL: That's really a wide spectrum of different techniques, Diane. Thank you for sharing. Rob, what are some of the adaptations and different types of magnifiers or other types of things that have helped you to get along over the years?

MR. ROB HOWDEN: I'd started with a plain old magnifying glass. And like Diane, I have several around the house. I have a favorite one that I don't know what's going to happen if I ever lose it. And I'd hate for this to start to sound like an Apple commercial, but I would be lost without my iPad and my iPhone. And because of things like the accessibility feature, you can adjust the text size, again, the contrast. You can have Siri read to you or you can, like Diane said, dictate into it for an email or a text. And I'd just be lost without those devices, and more ... and also the fact that you can use your camera or an app on the phone as a magnifying glass. It really

helps out in restaurants, for instance, if you're looking at a menu. So, the various apps and settings that you can have for your "iStuff," as I call it, is just fantastic. And I understand that the Android system has similar features, I'm just not as familiar with them, so I can't say one way or the other if they're better or worse, but the Apple stuff especially.

MS. DIANA CAMPBELL: I've heard that a lot, and I'm sure there's parallel-type "stuff" in Android. We did a Chat about that a few months ago. If anybody is interested, we can send it to them. Aside from actual devices and apps and that sort of thing, Rob, where have you found additional, really important information and support outside of the tools and technology realm?

MR. ROB HOWDEN: BrightFocus, of course. You guys deserve a big "Attaboy!" for the stuff you do and the programs you put on. I do truly appreciate that, and it has helped quite a bit. I've also ... when I first was diagnosed, I went to WebMD and Mayo Clinic, those websites. There's a website called Hadley that I've used, which is a really good site for learning how to use the technology you might have in front of you, so they have a lot of helpful hints on how to do things. In fact, their website alone, you can set the size of the font as soon as you go onto the website. I used Eyes on GA, which is an Apellis website, and they have a really good website that talks all about the disease and the various aspects of it, and that has helped quite a bit with understanding the disease. An app called Flipboard, which is like a news clipping service, and that's enabled me to try a couple of different things. I read an article there that talked about statins in a small Harvard study. I talked my doctor into giving me the extra dose of the statins to see if it would help. You can't prove a negative; it may have slowed it down, I don't know. And I think Diane told me about a GoGoGrandparent app, so there's all sorts of stuff that—oh, Audible. I almost forgot about Audible.com for books. It's a fantastic app. As well as the library—if you sign onto your ... have a local library card, a lot of libraries will allow you to download books and have it read to you. And even if the book isn't available in Audible, you can scan the page and have it read a page at a time by Alexa or Siri. So, those are some of the things that I've used, and there's lots more out there that I didn't think of or name even.

MS. DIANA CAMPBELL: Sure. There is really so much out there, and I know you've been also a great participant in our AMD Community Circle group and shared much of this on there, as well as provided others information or support. Diane, where do you find additional support outside of the magnifiers and lights that we've already discussed?

MS. DIANE MARSHALL: First of all, I'd like to say that vision loss can make you feel very vulnerable and alone, and it's so important to connect with people who are dealing with the same vision loss. It can be ... it was vital to me, and I want to shout out to two people who really helped be through some dark nights: Tracy Simon, who is a peer counselor for the program Eye2Eye, she taught me the importance of acceptance and then adjusting; and my very special friend Maryse Wicker, who I also met in a group, the ASPECT Advocacy Group, and we have been friends ever since. She always reminds me of what I can do, not what I can't do, and as I see her go on with her life and do all the things she loves—like gardening, going to the museum, and traveling—it encourages me to do the same.

Now, I have a list of things that have been great sources for me: BrightFocus; the MD Support List with Dan Roberts, who will get back to you quickly with all of the questions answered beautifully; the ASPECT Advocacy Group; Community Circle, which I look forward to joining; Prevent Blindness; the Audible books, as he just told you about, it's wonderful and although it costs something, it's worth it; and the library, you can check out books for free. And Rob also mentioned GoGoGrandparent. That is a concierge ride service. It's very hard [with most ride services] to put in information about where you want to go, what time you want to be picked up, and with GoGoGrandparent, you call them and they do everything for you. So, there's so much out there for help and support. And your friends: They're there for you too, and don't ever be embarrassed—although I have been—to ask for help because people do want to help.

MS. DIANA CAMPBELL: I was just going to say how hard it can be sometimes to ask for that help, you know, and other people may not know how to approach you, either, without ... not wanting to offend you or upset you, you know, so I think mentioning what you need and asking

for that help is a really important thing to mention, so thanks for bringing that in. We're going to shift slightly about your experiences—for both of you—with a low vision optometrist or low vision therapist or low vision specialist—there's so many different designations. I know you both had appointments for this type of evaluation. Rob, could you start us off with your experience about how that helped you use the vision that you still have?

MR. ROB HOWDEN: I'm sorry. I've had really good luck with my normal optometrist, and in fact, he set me ... a couple of years ago, he said I should start seeing a retina specialist, and the one I found or the one he sent me to didn't seem to know much more than he did, and so I stayed with my optometrist. But now, as of July 28, I have an appointment with my retina specialist again to see if I will qualify or if he thinks this Syfovre will do me any good. So, I'm going to start going down the same road that Diane has to see if we can do something to slow this down. Did that answer your question Diana? I'm not sure.

MS. DIANA CAMPBELL: Yes, and I'm happy to hear that your optometrist has been helpful in assisting you with your low vision things, as well. I know that I have a wonderful optometrist; she does so much more than the standard sort of, you know, eyeglasses and that sort of thing. And yeah, we'll look forward to hearing back from you on what happens with your appointment in July. Diane, how about your experience with a low vision optometrist or a therapist or a specialist—has it been similar for you or different?

MS. DIANE MARSHALL: Well, my low vision specialist spent so much time with me, and a lot of the things she thought might be helpful, like changing the filters in glasses, didn't seem to work. But she had a room full of devices that she showed me—CCTV, which will enlarge things—and, you know, at least I had an idea of what was out there. Unfortunately, I have found that sometimes even though my optometrist is wonderful and my retinal specialist is amazing—he's there from 7:00 in the morning until 7 at night and will answer an email as soon as he gets it—but sometimes they're more busy as clinicians, and they're not there to say, "Okay, this is what's going on, and would you like to speak to someone who

can support you and tell you what's out there?" So, I think that's really important, and I hope we're moving more toward that.

MS. DIANA CAMPBELL: I agree with you completely. I do. Okay, well let's close out with insight or advice you want to share with those listening today. Rob, what do you wish you had known about GA, and what do you think is important for those listening to know?

MR. ROB HOWDEN: I wish I would've had a better definition, like that's available today on EyesOnGA.com, about what the disease is and where it's going to go. And I wish I had known 10 years ago that there was actually some help finally coming. I hope I'm not too old for it, but I'm really, really glad that Apellis has come out with a drug that should help us, and that's just awesome. And I guess from an advice ... things that you should know standpoint is I would really, really emphasize to be very, very careful with driving. It's possibly the most dangerous thing we do. And like Diane said, I'd really like to emphasize my friends. They're just absolutely awesome, and on Tuesdays and Thursdays I get picked up to play golf, and not only are they my ride, but they're also my bird dogs for wherever I'm going to hit that stupid ball, because once it leaves right below my feet, after that I can't see it period, it goes into a blind spot, and it's gone, so my friends are just so unbelievably important to me. It's just ... I can't emphasize it enough: Take care of your friends.

MS. DIANE MARSHALL: Yeah.

MS. DIANA CAMPBELL: That's an important message. Diane, what about you? What do you wish you had known about geographic atrophy, and what do you think is important for people to hear today?

MS. DIANE MARSHALL: I wish I had known that it could really happen to me. I guess I was kind of in denial because my vision was so good for so long. And I wish I'd known what I could have done to prepare more for the vision loss. You know, as vision progresses, I look at this little sign I have on my refrigerator that says, "You can't prevent the bird of sorrow from flying over your head, but you can prevent it from building a nest in your hair." Often, there were a flock of birds in my hair laying eggs, and I had to remember something that I read. Frank Rooney, the writer for the New

York Times who lost his vision suddenly to an ocular stroke, wrote in his beautiful book, "The Beauty of Dusk," that even though bad things might happen, you have a choice about how you can handle it, and knowing that gave me back some sense of control in my life. So, what I'd like to say in closing is connect with others, ask for help when you need it, and don't forget that you are far more resilient than you ever thought you could be.

MS. DIANA CAMPBELL: I love that message, Diane. Thank you. So, we're going to start closing out. I sincerely hope you found today's Chat helpful. Our next BrightFocus Chat will be on Wednesday, June 28, and we will share details about that Chat coming up very soon. Rob or Diane, before we conclude are there any final remarks you'd like to share with the audience?

MR. ROB HOWDEN: I just wish everybody luck. First of all, I thank you, Diana and BrightFocus, for all the good work you do. It's very much appreciated. I would encourage anybody to join BrightFocus, maybe attend a meeting or two or continue to sign onto these meetings, as well. It has been an incredible help to me, and I really, really appreciate it. Thank you.

MS. DIANA CAMPBELL: Thank you, Rob.

MS. DIANE MARSHALL: I'd like to thank BrightFocus for allowing me to join in and tell my story. And just from my own experience, you'll be okay. Just keep on, and you'll be okay.

MS. DIANA CAMPBELL: Thank you. I think the stories are what are really helpful and what makes it easier for people to identify with others regarding what's going on in their lives rather than feeling so isolated and by themselves. So, I thank you both for agreeing to share your stories and your experiences with us today. Without any further ado, this concludes the BrightFocus Chat. Thank you so much for joining.

Useful Resources and Key Terms

To access the resources below, please contact BrightFocus Foundation: (800) 437-2423 or visit us at www.BrightFocus.org. Available resources include—

- [Amsler grid](#)
- [Apps for People with Low Vision](#)
- [BrightFocus Foundation Live Chats and Chat Archive](#)
- [Clinical Trials: Your Questions Answered](#)
- [Healthy Living and Macular Degeneration: Tips to Protect Your Sight](#)
- [How Low Vision Services Can Help You](#)
- [Macular Degeneration: Essential Facts](#)
- [Research funded by BrightFocus Foundation](#)
- [Safety and the Older Driver](#)
- [The Top Five Questions to Ask Your Eye Doctor](#)
- [Treatments for Age-Related Macular Degeneration](#)
- [Understanding Your Disease: Quick Facts About Age-Related Macular Degeneration \(AMD\)](#)

Other resources mentioned during the Chat include—

- Syfovre™
- Max TV glasses for distance viewing
- iPhone and iPad accessibility features
- OrCam MyEye
- Stella GO lamp
- The Blind Life YouTube channel
- www.Hadley.edu
- www.EyesOnGA.com
- Flipboard app