

Glaucoma



Chats

**Building Connections and Community:
Take Charge of Your Glaucoma Diagnosis**

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Transcript of teleconference with Amy Zhang, MD & Carolyn Edward

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

MS. KACI BAEZ: Hello, and welcome to today's BrightFocus Glaucoma Chat. My name is Kaci Baez, V.P. of Integrated Marketing and Communications at BrightFocus Foundation, and I am happy to be here with you today as we talk about "Building Connections and Community: Take Charge of Your Glaucoma Diagnosis." Our Glaucoma audio Chats are a monthly program, in partnership with the American Glaucoma Society, designed to provide people living with glaucoma and the family and friends who support them with information straight from the experts. Now, I'd like to introduce today's guest. We're excited to welcome back Dr. Amy Zhang, who is an Assistant Clinical Professor of Glaucoma Services at the University of Michigan Kellogg Eye Center. She was also Assistant Clinical Professor at Case Western University, where she was a Glaucoma Fellowship Director. Among her many interests are her work in minimally invasive glaucoma surgery and home tonometry. She also has an interest in improving ergonomics and looking into the drivers

of burnout and is the Wellness Director at Kellogg Eye Center. We have another guest here with us today, a glaucoma advocate named Carolyn Edward, who was diagnosed with the disease in 2006. Her treatment has included multiple eyedrops, SLT, trabeculectomy, and most recently, a combined cataract removal and MIGS procedure. Carolyn has had six different glaucoma specialists, mostly due to job transfers, which has made her passionate about patient advocacy and the responsibility to take ownership of one's own health. Welcome, Dr. Zhang and Carolyn. We're so excited to have you here.

MS. CAROLYN EDWARD: Thanks, Kaci.

DR. AMY ZHANG: Thanks, Kaci, for having us.

MS. KACI BAEZ: Great. So now we'll dive in, and our first question is for Dr. Zhang. So when you embark on your journey with someone who has been newly diagnosed with a type of glaucoma, what are typically their first reactions and questions?

DR. AMY ZHANG: Usually, the first reactions are of fear and uncertainty of what that means, so what does having glaucoma mean? What does that mean in terms of my vision? How is this going to affect my activities of daily living? Certainly, the concern about, "Is this going to result in blindness? How quickly will the disease progress?" There are also a lot of questions regarding, "Is this hereditary, or are there other members of my family that I need to notify or have my kids be checked?" And some other questions related to, "Why did this happen, how did it happen, and what did I do?" Also, questions regarding, "What can I do now moving forward? Are there specific foods? Are there diets? Are there exercises I can do to kind of improve upon this diagnosis?" Or just the general, "Why?" I think I'm certainly interested in hearing what Carolyn has to say about that, as well.

MS. KACI BAEZ: Great. Thank you, and Carolyn is joining us from the beautiful Hawai'i. Carolyn, can you take us through your diagnosis journey? How were you feeling when you received this diagnosis, and what questions did you have afterwards?

MS. CAROLYN EDWARD: Sure. It feels like Dr. Zhang was in my head in 2006. So, it's been a long time, but I do still very clearly remember that day and the time after. I do have a family history of the disease, and I had a maternal grandmother at the time; she was in her 80s, was blind from glaucoma, and so I know I needed to have regular screenings. But when I was diagnosed, I was only 38 years old, so I was very surprised. I was told, really, this is something you need to be careful of later in life, so I was fairly young. It definitely took some time to absorb the gravity of the diagnosis. I think once I got over the initial surprise, shock, being scared—all of those emotions—I did believe it could likely be managed just with eyedrops. My case ended up being a little bit more complicated, and I've needed some other interventions. Probably, my biggest fear is, will I go blind? And thanks to good doctors, I do understand certainly now and through my journey that even if you do have complications and a more challenging case, that there is a lot they can do these days with new interventions coming all of the time. So, I guess that's what was going on in my mind then and, to some degree, still today.

MS. KACI BAEZ: Wow! That had to have been so shocking at 38 to get that type of diagnosis, but it seems like it's becoming more and more common, and I'm sure Dr. Zhang could weigh in on that. And so, when people are receiving that diagnosis and are spending time at their doctor's, we know that doctors increasingly have extremely busy schedules and maybe not as much time as they would always like to spend with each person they see every day. And so, what tips would you have for people who have been diagnosed with glaucoma in order to maximize their time with their doctor, particularly as they start on their journey at whatever age they may be and as they move along their journey?

DR. AMY ZHANG: Sure. I think one aspect that Carolyn touched upon, which is so important, is understanding whether they have a family history of glaucoma, maybe asking some members of their family or just saying that if they are not aware of any family members, certainly writing down some of the questions that you may have ahead of time would also help facilitate that conversation. If the patient is transferring their care, either from their optometrist or from an outside ophthalmologist

who may not specialize in glaucoma, making sure that the office has those prior records or even bringing your own copies of those records, specifically, prior visual fields, as well as optic OCT—nerve OCT—testing; those would be super helpful for the physician—for the glaucoma specialist—who’s seeing that patient. And sometimes, just realizing that we may not be able to address all of the questions and concerns in that visit, and that, especially with glaucoma, it’s definitely of a more longitudinal relationship, and that we may need to follow up in a couple of months to answer further questions. I also think from the physician’s side, if there is any control over the design of your own templates, to account for longer times, especially for your new patient glaucoma evals. If you can somehow build that into your existing schedule so that you’re given the opportunity to spend more time with the first introduction of the diagnosis of glaucoma, that would be great.

MS. KACI BAEZ: Thank you, Dr. Zhang. It seems like in any instance that you have to embark on a new diagnosis journey with a doctor, having copies of those medical records and writing down the questions ahead of time is really so critical especially, if you’re one of the people who might get nervous when you go to the doctor and then you forget things—like me. And so, that’s super helpful advice. And so, Carolyn, from your perspective, how do you get the most out of your visits with your doctor?

MS. CAROLYN EDWARD: Right. I’ve definitely had visits where I feel like it’s productive and visits where either the doctor is very busy or I am, and maybe I wasn’t as focused or prepared for the visit. And I do think that responsibility goes both ways. I was fortunate the first time I made a move after my diagnosis, my specialist did give me hard copies of all of my key information, so I brought that to the next doctor, and she was very surprised and appreciative, so that is a best practice for me is that I asked for hard copies of those tests, and I do keep one file. So, I have pretty much my entire history going back, which I think can be helpful, might be overwhelming to a new doctor; they’re not going to need all of it, but at least I’ve got it if they ask questions. I do try to make sure I spend a few quiet minutes and write down any questions before I go, because again, you can go in with the best of intentions and then it gets rushed or you get off on another topic or maybe you’ve had a pressure spike or they’re

suggesting a change in treatment and don't get to the thing you really wanted to speak with them about. And I would say that I'm someone who thinks of myself as very independent, and I usually go to doctor's appointments by myself, but I am lucky enough to have a really supportive spouse. And on a couple of occasions where my case has gotten tricky and I might not understand them, a little overwhelmed by the information, I have brought him with me, and that's really helpful, even after the appointment to kind of go back and forth and make sure we heard the same thing and somebody else can back up and support what I've heard and what my next steps should be.

MS. KACI BAEZ: That's excellent to have that person there with you. It seems like that's so helpful when you're just back and forth at different providers and trying to remember everything, to build that support. And so, what do you look for in a glaucoma provider—specifically, Carolyn—and have you ever had to seek a second opinion?

MS. CAROLYN EDWARD: You know, I got close once. I am fortunate that I haven't. I looked for a couple of things. Again, I've got a fairly aggressive case. I was advised early on that I really do need to see a glaucoma specialist, so to me, that means an ophthalmologist, which has fellowship training in this field. But as important, I think you need to find someone that you personally connect with, and that most importantly, you feel like really listens to you and is open to questions. Regarding that second opinion question, my vision loss was progressing, and it was 20/12 before I had a trabeculectomy, which is the gold standard but a fairly aggressive eye surgery, and I was very scared of doing it, and I wasn't convinced it was the right step because, again, I couldn't perceive my vision loss. I had vision loss in one eye, but your brain compensates for a very long time, and I wasn't convinced. So at that point, I brought my husband, and I asked him, I said, "How would you feel if I got a second opinion?" Because, again, I wasn't convinced. He was completely supportive, which to me is a sign that you have the right doctor. He suggested a couple of additional tasks, redoing a couple of tests, and again, encouraged me to get a second opinion if I felt more comfortable doing that before the surgery. I ultimately decided not to. I felt like he was the most qualified person to do the surgery, and by that point I was convinced, but I would tell anybody

with any medical condition, if you're not comfortable and there is another specialist in your area—I realize for some people, that's limited based on where you live, different insurance plans, or whatnot—I think whenever you can do that, it is advisable if you're not comfortable.

MS. KACI BAEZ: Thank you. Always second and third opinions out there. And Dr. Zhang, how important is it for your patients to have connections with others who have glaucoma, and are there health benefits to maintaining social relationships for someone with low vision?

DR. AMY ZHANG: My patients have shared with me that it is really helpful to have connections with others living with the same disease process, like glaucoma, whether it be a support network or if their own family members also have glaucoma. I think they state that having someone who's gone through similar experiences, either with eyedrops or surgical procedures, it's really helpful to have that community. In that sense, there's also some caveats in terms of not being too tied up with someone else's either complication of their surgery or their medication use. There are certainly health benefits with maintaining a social relationship with everyone as we all age, and especially for those who have more low vision or decreased vision that predisposes you to being even more isolated. A lot of the research regarding social connections has been done in aging, with correlation of both dementia and depression, so I think having a good social network is super important. I'm interested in hearing Carolyn's perspective on this as well.

MS. KACI BAEZ: Thank you. So, Carolyn, what does your support network look like in addition to the support you've mentioned previously from your husband, and how can others with the disease overcome any anxiety or fear they have around accepting their diagnosis more openly in support-based or community settings, or just getting over the fear that comes with talking about something like an incurable disease? It's a disease with no cure, so I mean it's scary, so how should somebody go about that?

MS. CAROLYN EDWARD: Right. It's a great question. Again, I did mention my husband. I would say my broader family is a really important support network for me to start. Since my diagnosis, my mother, interestingly enough, was diagnosed after me but still is really considered a borderline

case, really more of a glaucoma suspect, and she's 78, so that's been quite a while. I do have a younger sister—I'm the oldest of four kids so, I do have one sibling also with glaucoma, and two at this point who do not. And again, they're both younger, so who knows what happens there. But that's an important part of my network. Again, when I was diagnosed, there was not much in terms of support groups. My first two doctors really didn't have a lot of advice there. I think I perhaps asked the question after a couple of years, but I don't think I did at the beginning. And it was really only when my case was progressing and was proven difficult to handle that I started looking for some of the Chat group discussion forums. I think Dr. Zhang, just kind of word of caution there, is spot on because I believe you tend to get patients that have probably the more serious cases, again complications, really upset by the diagnosis, and that can be a rabbit hole that you go down. So, I do think you need to be making sure that you're with reputable sources, right? Such as this one, for example; however, I think any discussion group, people you can talk to, anything that's sponsored by a reputable organization or is moderated can be really helpful, and I do, too, these days. That's how I ended up with AGS. Again, being connected to a couple of the glaucoma support organizations and charities has given me some options to work with and talk with really reputable doctors and other patients that have gone through the same thing.

MS. KACI BAEZ: Thank you. I agree that there are some forums out there that, if you're not careful, you could spiral into a rabbit hole that will worsen your fear rather than provide hope. And so, going with those reputable organizations is always a good thing, and so, Dr Zhang, what resources do you provide or suggest to your patients or others who have been diagnosed with glaucoma?

DR. AMY ZHANG: So, some of the resources that we provide for our patients include the education guides from the American Academy of Ophthalmology, specifically with treatment guidelines. Our own American Glaucoma Society's subcommittee on patient engagement has been working on formulating our own sheets about "What Does That Mean?" "Diagnosis of Glaucoma," "Driving with Glaucoma," certain treatments with laser or surgery, so we've been formulating these informational

guides to allow for ophthalmologists and glaucoma specialists everywhere to share that with their patients because there's just so much online content that's out there on the web, and it's hard to validate whether it's true or just peoples' opinions, and I think that's super important when you're looking at disease processes. Certainly, like a modality, like what BrightFocus is doing with these Glaucoma Chats, is also an opportunity for patients to find out more because it's both the patient as well as the physician moderating as well as regulating some of the questions that are answered. So, I think these modalities are probably the best rather than just a resource where there's not really a professional opinion. I would just be wary of those resources.

MS. KACI BAEZ: Thank you. And so, what are the barriers to obtaining resources or support as a person diagnosed with glaucoma? Are there resources out there available for those who might have transportation or technological or financial limitations?

DR. AMY ZHANG: I think some of the barriers to obtaining resources and support as a glaucoma patient have been in the avenue of if your vision is poor and we're giving you a pamphlet, it's probably very difficult to read that pamphlet if the vision has decreased. So, looking at audio sources in which you can get that information is also important. With regards to the barriers for obtaining resources, there has also been a national shortage of certain glaucoma medications due to the ophthalmic supply chain in terms of getting the drops, so I know for a lot of my patients, especially during the pandemic times, there were limitations on what they could get or not get in terms of their glaucoma medications, and that can be certainly very scary. There's only a few ophthalmic supplies out there, and so when there's a national shortage of these medications, what could you do, or what do you do in those circumstances? For those that have more of a transportation or financial limitation, for the transportation, we're fortunate enough we're big enough of an academic center that we could leverage the resources of our social workers to help coordinate care in terms of that, and they're also very helpful for looking at some of the financial ways to gather around that. I do want to point out with a lot of the branded glaucoma medications, there are forms that could be filled out for financial assistance for some of these glaucoma drops that may

be more expensive, so looking into that would be good for all patients. Sometimes as a patient, you may have to fill out a portion of it, and then there is a portion for your glaucoma specialist or your ophthalmologist to fill out as well. But certainly, we have a lot of traction and a lot of need to improving the resources on all those things that you had mentioned.

MS. KACI BAEZ: Thank you, Dr. Zhang. So, Carolyn, what is the best piece of advice you would offer to our audience and somebody trying to build more of a connection following a glaucoma diagnosis?

MS. CAROLYN EDWARD: Right. I think it is a long game, right? It is a chronic disease that you will live with for the rest of your life, and so, I guess, most important, educate yourself with reputable resources and be an advocate for yourself, while at the same time, don't let your glaucoma diagnosis consume your life. And even those with aggressive cases can lead, in my opinion, a perfectly normal life. You have to make time for your appointments. You have to take your eyedrops. You have to be more open to more indifferent interventional procedures, if you need that, but at the end of the day, it is easy to be consumed by it, and I've certainly had a couple of periods in my life where I have done that but try not to. At that point, talk to somebody, and most of us can live with this for a very long time, hopefully without losing too much eyesight.

MS. KACI BAEZ: Thank you, and there's new research discoveries every day.

MS. CAROLYN EDWARD: All the time.

MS. KACI BAEZ: We're so hopeful, and every day there is something new that is coming out about glaucoma research. And so, do you have any final advice for our listeners on how they can take charge of their glaucoma diagnosis and build connections and support that will improve their wellbeing?

DR. AMY ZHANG: I think Carolyn actually gave a really good summary of the importance of being your self-advocate for yourself, in terms of your diagnosis, as well as one thing I want to highlight is the importance of finding that physician who will work with you on the management of

your glaucoma, so I think because it's such a longitudinal relationship, it's really important that you find somebody who is actively listening to what you're saying. They may have the best ideas of what types of procedures or eyedrops to use, but if they're not listening to how it's impacting you in terms of your lifestyle and how it may be difficult to do eyedrops at certain times, then perhaps that's not the best fit. So, I think finding that fit in your glaucoma specialist is super important because you do have a very long relationship with that person, and it's important to feel comfortable to ask those questions. It is certainly important to set up a network of those that can support you. There are holistic approaches that help with general wellbeing, and some limited literature showing the effects of meditation and some forms of exercise may actually help to decrease the oxidative stress on the body, which may then also help with intraocular pressure lowering. But, of course, the research around that is more limited, but I think what Carolyn was saying about, you can live an active lifestyle, it doesn't have to be a diagnosis that defines you, is super important.

MS. KACI BAEZ: Thank you so much, Dr. Zhang and Carolyn, for all the important information you've shared with us today. Our next Glaucoma Chat, "Glaucoma Imaging: Trends in Detection and Diagnosis," will be on Wednesday, April 10. Thank you again for joining us, and this concludes today's BrightFocus Glaucoma Chat.

Useful Resources and Key Terms

BrightFocus Foundation: (800) 437-2423 or visit us at BrightFocus.org.

Available resources include—

- [BrightFocus Foundation Live Chats and Chat Archive](#)
- [Glaucoma research funded by BrightFocus Foundation](#)
- [Overview of Glaucoma](#)
- [Treatments for Glaucoma](#)
- [Resources for Glaucoma](#)
- [Expert Advice for Glaucoma](#)
- [Get the Facts on Glaucoma](#)

Other resources mentioned during the Chat include—

[American Academy of Ophthalmology treatment guidelines](#)

- American Glaucoma Society Patient Engagement Subcommittee