Hadley

Vision Loss and Advocating for Change

Presented by Ricky Enger

**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, Hadley's Director of Community, Marc Arneson and Director of Patient Advocacy, Julie Grutzmacher, join us to discuss the Prevent Blindness ASPECT program. Welcome to the show.

**Marc Arneson:** Thanks. It's great to be here.

**Julie Grutzmacher:** Thank you so much for having us.

**Ricky Enger:** I always enjoy learning more about new programs for people with vision loss, especially the ones that promote and encourage self-advocacy, so I'm really looking forward to hearing more about the ASPECT Program. Marc, I know you have lots of great questions, so take it away.

**Marc Arneson:** Ricky, it's great to be here today. As I mentioned, my name is Marc and I am the director of community, here at Hadley. Mostly, I get to talk to people and spend time getting to know folks and then sharing with as many people as possible about some of the ways that we can help here at Hadley. I'm really excited to be here together with Julie. Julie, I don't know if you want to introduce yourself quickly, I know you're going to talk about this wonderful ASPECT Program that you guys have through Prevent Blindness.

**Julie Grutzmacher:** Thank you all so much for having me. This is Julie Grutzmacher. I'm the director of patient advocacy at Prevent Blindness and I've been there for about four years leading the ASPECT Program among other initiatives.

**Marc Arneson:** Wonderful. Like I said, Julie, I was actually really excited to be a part of this conversation today. Honestly, I don't know that I know a lot about the ASPECT Program and so I'm really curious to learn more. Do you mind if we start just getting a general overview of the program itself?

**Julie Grutzmacher:** Absolutely. So what is the ASPECT Program? It's an acronym that stands for advocacy, support, perspective, empowerment, communication, and training. This is a program that is meant to introduce advocacy skills and knowledge and to build that among individuals who have visual impairments and blindness as well as their allies. So it's a unique program in the sense that it brings together those who have some sight loss as well as providers who are in the field, like eye doctors, researchers, mental health therapists. We all come together for a 10-session educational training, and we talk about advocacy related topics.

And in doing so, we kind of demystify advocacy and we present a number of types of advocacy. It's not just advocating for policies per se, although that's very important. But we also talk about self-advocacy, how you can better advocate for yourself in the healthcare setting or just out and about in life, getting your needs met as a visually impaired person. It could also be advocating for another person, a family member, a spouse, a loved one. We talk about strategies for doing that better. And in these discussions people really find a sense of community and they learn a lot from each other.

The clinicians in the group are learning from the patients and the patients are learning from the clinicians. It's a 10 session educational series and we recruit two cohorts each year. There’re typically about 30 to 40 participants in one cohort, usually from about 15 different states per cohort, so it's a national program.

**Marc Arneson:** It's so cool to hear about that Julie. When you talk about the patients and the clinicians working together and collaborating, I think that we've found that sometimes it’s not always easy to do. I also love how you talk about advocacy not only on a policy level, but on a self-advocacy level too. Can you share a little bit about how some of that works? The reason I ask is because we often hear how folks sometimes don't feel like they have a voice with their doctors or their treatment and things like that. Did you come across some of that?

**Julie Grutzmacher:** Absolutely. Well, first of all, there's been several initiatives that have come out of the discussions from ASPECT, and that's been a really wonderful benefit. Initiatives such as trying to train sighted mental health providers on the mental health impact of sight loss, as well as training eyecare providers about questions that they can ask to communicate empathy. A lot of patients report that they may be given a diagnosis and not a lot of resources or expectation of what this means for their life. There are many reasons for this, and we understand all of that, the confines of a short appointment time.

Through these discussions it kept resurfacing as a theme, an augment need, and through the discussions we've been able to develop these training modules. That's just one example of what we've done as a result of the themes that continue to arise, which is absolutely, like you say, feelings of not being heard, maybe not being listened to.

**Marc Arneson:** It's such a vulnerable place to be sometimes as a patient and learning about this new condition that you've just been diagnosed with or trying to find treatment for. So I can imagine the importance of feeling empowered to advocate for yourself. It sounds like a wonderful, wonderful thing that you guys are trying to do.

**Julie Grutzmacher:** I just wanted to say too that the added benefit is that we have individuals in the program who have been blind since birth, others who have lost their sight due to trauma or injury and others who are maybe just losing it now later in life due to progressive conditions. There is an incredible benefit in having all of those individuals together in one cohort because we find that the ones who have been blind since birth and they have really incorporated their blindness into their identity. And so they have different coping styles and strategies that can be of support, and they offer hope to those who are newly coming to terms with sight loss.

**Marc Arneson:** Such a great point. That is such a good point. Can you tell me a little bit about how long it's been around and when you got started with the program and why?

**Julie Grutzmacher:** So the program's been around since 2020, we launched the program shortly after I started, which was in May of 2020. We started by recruiting a small advisory committee, and the majority of those members of that committee became members of the first cohorts. That first cohort started in November of 2020. We took several months to get their insights into the topics that we had developed. They gave feedback on the format and the structure of the sessions and what would be of interest to the community, and then we were able to implement the program in November of 2020. Since then, as I mentioned, we train two cohorts every year, and they're usually about 30 to 40 participants per cohort.

When Prevent Blindness identified that there was a need to connect trainees, so individuals who have sight loss and their allies with opportunities that are out there for advocacy. And because we as an organization have a lot of partners, we've been around since 1908, we're truly national in scope. There are opportunities that come to us, and we identified that there was a need to be able to not only connect those opportunities to the people that could speak on the lived experience of what it's like, for instance, to have glaucoma if it's a glaucoma initiative. But also to empower those individuals to feel really confident to continue to share their story and continue to advocate for whatever that meant for them.

That could be, as we mentioned, sort of more at the changing minds within their families. It could be more at local opportunities, or it could be at the federal systemic level. And so with this training program now, we were able to continue to refer those individuals to that opportunity and to connect to be that liaison as an organization to our partner organizations.

For instance, it might've been hard for some of our pharmaceutical partners to get in touch with the individuals who have lived experience to talk about and give input on what a treatment protocol might mean for them, what it's really like to have this eye condition on a day in, day out basis. So far, it's worked well in the sense that we now have a community that just continues to grow and people are empowered not only by what they learn in the program on advocacy, but also learning from others and learning from the discussion and picking up tips and tricks from others in the group. And that really empowers people to continue to use their voice.

**Marc Arneson:** I imagine that that's such a rich experience for folks to hear from somebody who's been there and done that or maybe can just understand what they're going through and can offer some insight. So you mentioned it's two different cohorts per year, is that right? About 30 folks?

**Julie Grutzmacher:** Yeah. (affirmative).

**Marc Arneson:** Somebody who's interested in this program, an individual perspective, what kind of time commitment does that look like, maybe day to day or how long does the program run? It's 10 weeks, I think you said. Is that right?

**Julie Grutzmacher:** It's 10 sessions. We skip a week, so it's every other week and each time we meet over Zoom and it's two hours at a time. The day of the week that we meet really varies. So we go with what works for the majority. We've met in the evenings for two hours and now we're meeting on Saturday afternoons. We do have to accommodate all the time zones, so that can be tricky. We work around that. And so it's 10 sessions, two hours at a time, and there is very little homework. However, everyone is encouraged to work on their story and work on the five-minute version of their story. So we present frameworks for doing so.

We have a couple of tools that we encourage people to use as they develop their story and try to get it down to just five minutes as well as the 30-second version to elevator pitches as well. And so with that, if they're telling their story to the group, there might be some additional time commitment that comes along, maybe another additional five hours perhaps to develop their story and to practice it. They always have the option to practice with me one-on-one ahead of time, or at least to get feedback with me ahead of the session. So that's roughly what the time commitment looks like.

**Marc Arneson:** Gotcha. Do you graduate from the program? Do you complete the program? For folks that have finished the ASPECT Program, other kind of expectations as far as involvement ongoing and things like that?

**Julie Grutzmacher:** So you do graduate from the program, you get a certificate at the end. There have been several people that have asked to go through the program more than once, and I always encourage that because I think if they're asking, they must need something. That's been a wonderful benefit. But as far as the expectations go after completing the program, we just hope that you will stay connected to us as an organization, Prevent Blindness, but then also that you'll continue to find ways to share your story for the purpose of impacting change. And so that is very individual and we're not prescriptive at all with what that looks like.

We as an organization continue to let all of the graduates know about opportunities that come along. And there are an average of about two opportunities per month, and we usually send out an email to let people know of what that might be. Not every opportunity is applicable to everybody. For instance, there is an FDA hearing or a congressional briefing. Would you be interested in talking to members of Congress on your lived experience with having age-related macular degeneration, for instance?

Or we have our advocacy day every year and all of the graduates are invited to participate in that to get exposure to the legislative advocacy and what it's like to meet with members of Congress and how those meetings are run and the talking points and all. So we invite them to do that. Or there might be more state-based opportunities. We have six affiliates in different states, and so they have their own initiatives going on, and there might be an opportunity to get involved in vision and eye health initiatives more at the state level. We really do continue to let people know about the opportunities that come along, and we just hope that people will stay engaged and active.

Of course, we know that it can ebb and flow, that advocacy can be an exhausting experience. And at times we don't have the energy to participate, but that they find a community in the ASPECT Program that we continue to try to create opportunities where people are also coming together even after they graduate the program, whether that's online or in person. Every two years we try to bring people together in person.

**Marc Arneson:** My title is director of community, so it might speak that I love the idea of community. I'm curious, I imagine that there's a lot of really important connections that happen within these 10 sessions that folks are traveling together through. Do you find that sometimes people stay connected even outside of the opportunities that you give them to stay connected?

**Julie Grutzmacher:** Yes, definitely. We have seen that where mentor relationships occur. There's one example of an individual who was considering becoming an ophthalmologist and was in the very early stages of completing some prerequisites for medical school and identified a mentor, an ophthalmologist. They created a relationship outside of class and it just really served to help that student along. And now she is in residency to become an ophthalmologist.

There have been examples of people connecting across the country. In cohorts, they continue to call each other almost every week where they just check in and share resources and provide support to each other. And then it's also led to some new partnerships and collaborative sort of professional opportunities as well.

**Marc Arneson:** I'm so glad that we had a chance to talk about this. I really appreciate all the information you're sharing. One of the other things that I find myself just being drawn to are personal stories. I'm wondering if you have any to share from folks who have graduated from the program, what their experience might've been like.

**Julie Grutzmacher:** There are so many stories that live within me and in my memory from being part of the program from the beginning. But I think some that come to mind are about an individual who wasn't asking a lot of questions when they went in to see their retina specialist. And after going through the ASPECT Program and hearing ways that others had phrased things and questions that they had asked, she started asking questions and she started having... I believe it was a family member take notes and really make sure that she understood everything that was going on.

And so that was one example of how just the discussion and the relationships with others had really influenced and empowered her to do something different.

**Marc Arneson:** That's wonderful.

**Julie Grutzmacher:** I'm thinking of another person who had multiple losses at once. So she had lost her job, and her marriage had ended shortly after she realized she was losing her sight. She was depressed and anxious about what was coming next. When she joined the ASPECT Program, she had found a community again in her local town through, I think, it was the Commission for the Blind. But it wasn't until the ASPECT Program where she was challenged with trying to tell her story. She had never told her vision related story before, and just the practice and the exercise of doing so and having an audience for it, one that could provide some feedback, some suggestions of maybe how even to modify it for the purpose of advocacy, how to adapt a message for the audience she was trying to reach in particular.

She said that she didn't realize how she really felt about everything until she was asked to write her story and to tell her story. It was really incredibly therapeutic for her because it sort of brought her closer to herself and left her feeling energized to continue to help others. And that I would say is such a common thread among participants as they join to learn about advocacy to help others, so others don't have to go through necessarily what they went through, or others don't have to be as isolated as they once felt. To provide that hope, which is so important in life. And that sense of community and being seen and heard, validated.

**Marc Arneson:** I kind of got chills listening to you share that, the importance of being able to tell your story and how your identity can be found in that is such a powerful thing.

**Julie Grutzmacher:** It really is.

**Marc Arneson:** I have a couple more questions. I think you brought up allies a couple of different times. Family members or spouses, are they able to be a part of this program as well?

**Julie Grutzmacher:** Yes, they are, and we encourage it. We've had a married couple who ended up sharing one Zoom screen for a little bit of time, and then they found that they actually wanted their own Zoom square. So they took up different rooms in their houses and they both joined, but absolutely. We had one case where a mother participated first and then she encouraged her son to join the subsequent cohort. So we've had kind of all of the above, but it really does add to the discussion, and it is encouraged.

We find that each person kind of picks up something different from the discussions and so the discussion can continue after we log off of Zoom, if it's a family that is attending, a couple, et cetera. So that's fun.

**Marc Arneson:** That's wonderful. The only other question I had is how someone can become part of this really important program that you guys have?

**Julie Grutzmacher:** Absolutely. We have a website. So they can go to preventblindness.org/aspect, A-S-P-E-C-T, so that's preventblindness, all one word, preventblindness.org/aspect. And you can read more about the program, there's a video that gives a little bit of an overview with some short little testimonials. There's also an online application on that same webpage. Once you complete an online application, it goes straight to my inbox. I reach out then and usually schedule a time to talk and learn more about you and your advocacy related interests. And then if it seems like a good fit, I'll invite you to participate in the program.

**Marc Arneson:** We'll have all that information available in the show notes for the podcast as well, so they can access it pretty easily. Julie, is there anything that I didn't ask or that we didn't get to that you want to make sure folks understand and know about the program?

**Julie Grutzmacher:** I would just add that some of what we've heard about what people really love about the program, other than what I touched on of having it be allies and patients together, is that they really learn how to tell their story succinctly. So if that's 30 seconds or a five-minute version, that's the goal and the challenge, and they really value that experience. They also learn to advocate for eye health in general. People have reflected on how they have felt that they could talk to their insurance companies about their eye health in a less emotional manner, for instance.

So that's for themselves, but then they also learn to advocate for the eye health of others and whether that's participating in an FDA hearing or congressional briefing or things like that, just broadly speaking about the condition to help others. Lastly, they say that they really value learning and getting exposure to more of the state and national legislation and what advocacy on that level looks like and how can you organize meetings?

What roles do people play? What are some of the talking points? So those are the real takeaways for us to date of what people have said that they really enjoy about the program.

**Marc Arneson:** It's wonderful. Well, Julie, thank you so much for spending this time here today with us, with me.

**Julie Grutzmacher:** Absolutely. Thank you again for this opportunity, and it was a fun discussion.

**Ricky Enger:** What an informative discussion. I know I learned a lot, and I hope you all did as well. Again, be sure and check out the show notes for more information on the ASPECT Program, as well as contact information for Julie Grutzmacher. Thanks for listening.

**Marc Arneson:** Thanks, Ricky.

**Julie Grutzmacher:** Thank you.

**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. That's P-O-D-C-A-S-T@hadleyhelps.org or leave us a message at 847-784-2870. Thanks for listening.