

EXECUTIVE SUMMARY



Prevent Blindness

ASPECT Patient Engagement Program

Evaluation of the Prevent Blindness ASPECT Program and Its Impact

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Purpose

In Spring of 2023 focus groups and interviews were conducted to learn how graduates of the ASPECT Patient Engagement Program (ASPECT Program) of Prevent Blindness leveraged their new skills as vision advocates to improve eye health. Data was also gathered to identify the strengths and challenges of the ASPECT Program and recommendations for developing peer-to-peer relationships among graduates and new ASPECT Program participants.

What Alumni Learned Through the ASPECT Program

How to tell my story impactfully and succinctly

“Those 30 seconds you often get means you have to be real quick and fast in order to get attention. ASPECT has helped me do that.”

How to advocate for my eye health

“ASPECT helped me to be able to talk to my insurance company in a less emotional way and to give them more facts. It helped me hone my skills to advocate on all levels.”

How to advocate for eye health for others

“The FDA advisory committee met...and needed a parent story. I was able to share my son’s story and journey with ROP [retinopathy of prematurity] and how I had to go to the doctor.... I was one of many people who shared their story regarding why it is important to have treatment for children who have ROP. It did result in getting the treatment approved.”

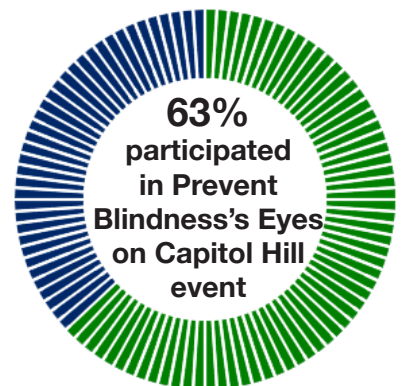
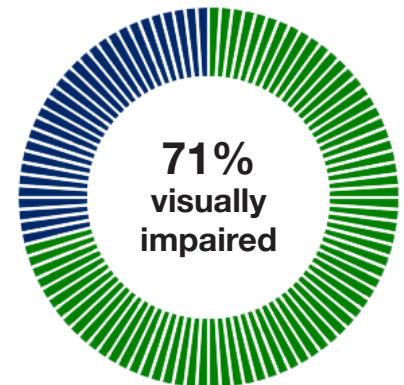
How to influence state and national legislation

“The training for [the Eyes on] Capitol Hill experience was incredibly beneficial. I had an opportunity recently with a bill in [my state] not specific to visual impairment, but to disabilities in general, which was very discriminatory. I got to use the training and my experience with Eyes on Capitol Hill. All of that helped in setting up meetings with senators and helped make those meetings more successful.”

Participants

Thirty-one ASPECT alumni participated in 8 focus groups. Four ASPECT Program interns and 10 individuals with whom ASPECT Program alumni interacted participated in interviews.

The ASPECT Alumni in the study:



What Alumni Liked About the ASPECT Program

- Building one’s storytelling skills
- Learning about the eye and eye diseases
- Being part of a community
- Meeting in breakout rooms to network and discuss in small groups
- Experiencing the program staff’s strong group facilitation skills

“[Hearing the stories of cohort members who were visually impaired] gave me a lot of perspective as to how I can help my clients better as well as advocate to physicians to be able to tell my story better and help more people.”

ASPECT Alumni and Intern Recommendations for Future Training of New Cohorts

- Have a stated, specific goal for each session
- Provide more structure in the breakout rooms (e.g., designated leader, topic to report back on)
- Group those in breakout rooms (e.g., clinicians, family members) periodically
- Establish “social opportunities” outside of the structured sessions
- Examine other ways to provide those telling their stories feedback (e.g., written feedback rather than full group oral feedback)
- Provide lecture content in multiple formats (e.g., video, podcast)

“It was very beneficial to me to hear from self-advocates as well as from professionals who work in the world of vision. I think if there was a way to have... breakout sessions that were specific to your area it might help with networking.... If you have people who have that common ground, it would be easier to form those networking relationships.”

Recommendations for Expanding the ASPECT Program

- Have participants select topics and make the program participant driven
- Go in depth on advocacy continuing to build participants’ skills
- Showcase the work of alumni (e.g., blog posts, newsletters)
- Allow time to work together on advocacy-related projects
- Provide opportunities to continue to build one’s storytelling skills

“The face-to-face meeting] was so amazing, emotional, and engaging.”

Continuing to Build the ASPECT Community

- Host social events, topical discussions, and/or training events on Zoom
- Bring current trainees and alumni together for face-to-face meetings such as the Patient Engagement Summit held in May 2022
- Have a forum, Facebook group, dedicated app, and/or other tools to engage individuals – ensure they are accessible!
- Have projects related to advocacy, eye health, or another topic of importance that alumni can work on together



The Perspective of the Interns

Four ASPECT alumni worked with Julie Grutzmacher, the program director, as interns for either one or two cohorts. Responsibilities of the interns included:

- Improving their own stories
- Using pre-survey and post-survey data to work with Julie to improve curricula
- Facilitating breakout groups
- Working with Julie and the other intern

“Julie gives a lot of room for creativity.... Julie is always receptive to new ideas. She always wants to do something different, which is one thing I really appreciate about her.”

Perspectives from Individuals Interviewed

Ten individuals who interacted with one or more ASPECT graduates were interviewed. All interviewees were very positive about their experiences with ASPECT Program alumni.

The leader of the [Eye2Eye](#) support network shared about volunteers participating in ASPECT and how they shared what they learned and applied it in their work.

“Everyone was so enlivened by the program. It promoted so much personal growth, reflection, and excitement.... [Participants reported] an increased sense of community building and networking. [By engaging with professionals who were part of the cohort] they had a sense that professionals can get to know patients...as more than symptoms.... Recognition that you’re a whole person.... Being heard was so powerful.”

One interviewee worked for a pharmaceutical company which supports the ASPECT Program. The company has had two ASPECT alumni join their patient advisory boards.

“I’ve heard [the two alumni] tell their story both before and after they participated in the ASPECT Program. I have heard from them anecdotally that they just got so much out of the program.... They learned that lawmakers want to hear their story.... [Both alumni] talked about learning to craft and hone their skills of storytelling in a way that makes people connect with them and want to act and do something on behalf of people who have vision issues.”

An interviewee in the biotech sector shared their experience with Christine Gustafson, an ASPECT Program alumnus.

“Christine really helped me visualize what she went through.... How she felt alone...went to multiple doctors, and had surgeries. Christine [told her story] in 5 minutes. It wasn’t like it took an hour to tell the story. She did it in a way where it was impactful and succinct and made me understand what someone like her goes through.... My ah-ha moment was how long it took [her] to really understand the disease and put a name to it and then how long it took to get an effective treatment for it.”

Those who took part in focus groups and interviews were overwhelmingly positive about their ASPECT experience. Prevent Blindness and its sponsors have invested in a program that truly is having a positive impact on those with visual impairments and their allies and that impact extends to those with whom alumni interact as they tell their stories and advocate for themselves and others.

“I have told everyone about the ASPECT Program and the things that I’ve learned from the cohort about the eye, about being able to advocate for better services. I’ve shared with people on the board and family members with vision loss. My brother has glaucoma and I shared more with him about glaucoma. I have told everyone in my family to get annual eye checkups. That came from one of the optometrists in our cohort. I’m a member of a low vision support group and we had a person who came from the state to speak to us about disabilities. I shared with him our transportation issues. He was willing to possibly put together a taskforce to figure out how to improve transportation issues.”



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