

# The Importance of the Patient Advocate in Vision Health



## MODERATED SESSION

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Focus on Eye Health Summit:  
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# The Importance of the Patient Advocate in Vision Health

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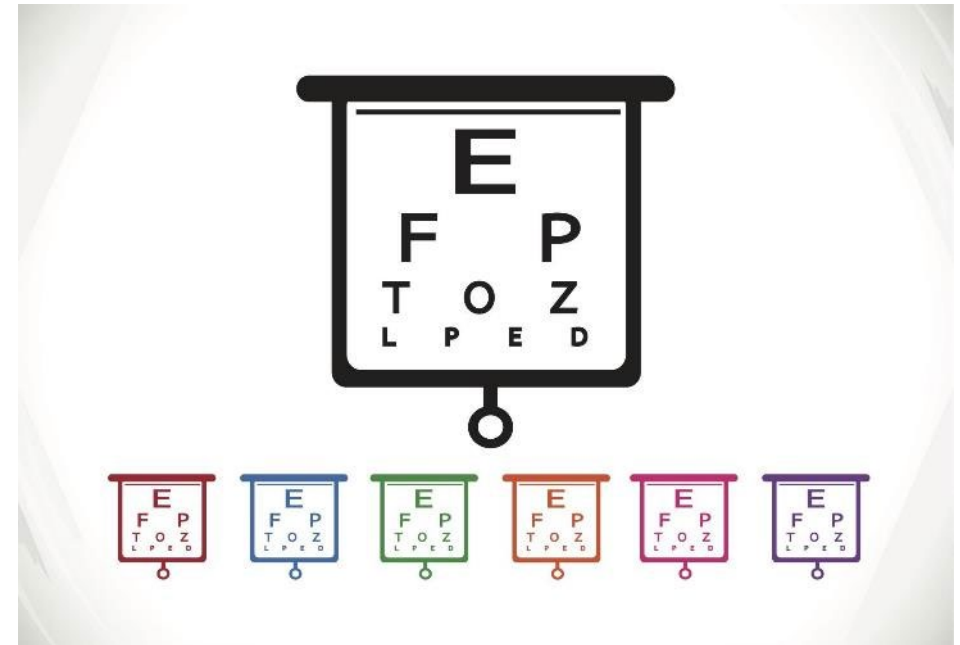
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# Traditional Eye Care Services

- Focus on treating or curing eye diseases
- Routine appointment length is quick & directed at conducting comprehensive eye examinations and eye care services (surgical, medication)
- Lack a focus on other important areas that are impacted by vision and vision loss such as:
  - quality of life
  - functioning in everyday living
  - social support
  - mental health
  - relationships
  - employment



# Why is it Important Patients are Included as Advocates in Vision Health?

- Patients often feel they lack control
- Worried over their vision prognosis, employment, finances, impact on self and others, how to navigate the their health conditions and/or health care system
- Do not always know where to locate resources that are evidence-based
- Feel they don't have time to share concerns with their eye care provider during eye appointments given:
  - busy nature of the clinics
  - feel like they are bothering their provider
  - feel like they're asking a silly question
- Chronic or progressive eye diseases often require repeated follow-up and life-long therapies; other eye conditions are preventable



# What is Advocacy?

- Broadly speaking, advocacy helps to draw attention to patients' needs and challenges
- Advocates may include patients, family, health care providers, policy makers, public health experts, legislators and others!
- Advocacy stakeholders work to promote:
  - access to eye care
  - public health policies and initiatives
  - quality of eye care services
  - eye health outcomes
  - quality of life
  - resources
  - support





# Development of an Eye Health Advocacy Program

- Prevent Blindness recently developed a new, innovative patient engagement program called **A.S.P.E.C.T** to empower individuals to be engaged in their eye health from every direction in every way
- In July 2020, Prevent Blindness began recruiting patients, allies, representatives, clinicians, and researchers to participate in the new program



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The consequences of patients not engaging is borne most heavily by the patients themselves and their families, in the form of emotional, physical, social, and financial costs; but it also has a significant impact on social and healthcare systems with respect to duplication of efforts, decreased capacity, wasted resources, suboptimal outcomes and increases in health inequities.

## A.S.P.E.C.T. Program

(Advocacy, Support, Perspective, Empowerment, Communication, & Training)

### Why is the A.S.P.E.C.T. Program needed?

The patient has been described as the ‘greatest untapped resource in healthcare’, and patient engagement termed ‘the blockbuster drug of the century’.

Health-focused efforts must incorporate factors identified by the patients and allies themselves, and the only way to achieve this is by having robust program in place to incorporate their voices. To date, no such program exists to support the patient’s role as a leader in vision and eye health in the U.S.

### What is the A.S.P.E.C.T. Program?

To address the lack of a program supporting patients in vision health, Prevent Blindness developed the A.S.P.E.C.T. Program—Advocacy, Support, Perspective, Empowerment, Communication, and Training— which aims to strengthen our patient empowerment efforts for vision into a coordinated program that engages the individual in a more comprehensive manner. The goal of the A.S.P.E.C.T. Program is to empower individuals to be engaged in their eye health from every direction and in every way.

The Prevent Blindness A.S.P.E.C.T. Program is recruiting both allies—

individuals who are at risk of or care for someone with vision loss as well as patients who have experienced vision loss due to a chronic eye disease.

### Who Participates in the A.S.P.E.C.T. Program?

Patients/allies who are engaged in all aspects of their health not only experience better outcomes, but are able to contribute to advancements in the healthcare of their communities. A.S.P.E.C.T. will create a resource of patients and allies, acting in leadership roles to make a difference specifically in improving the experience of care and promoting a strong quality of life.

# What are the A.S.P.E.C.T. program goals ?

A – advocacy

S – support

P – perspective

E – empowerment

C – communication

T – training

# Structure of A.S.P.E.C.T.,

In three months we met eight times for 90 minutes and covered the following topics:

- Storytelling as an advocacy tool
- From self-advocacy to public policy
- Basic anatomy of the eye
- Identifying and educating stakeholders
- Clinical trials 101
- Patient advocacy boards
- Peer to peer support



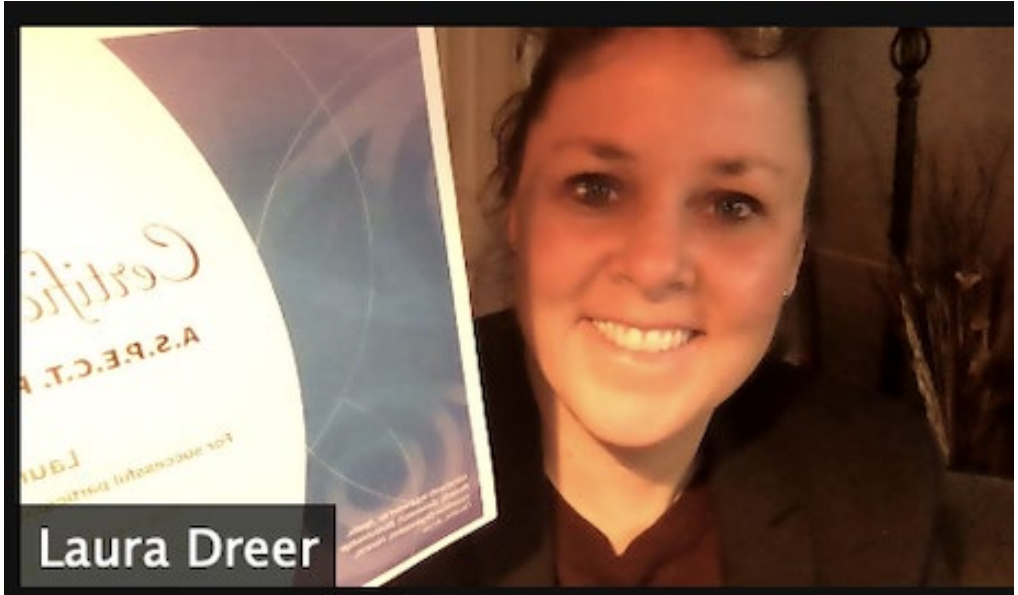
# Eyes on Capitol Hill Event

- Two day event where we (virtually) met with members of congress and/ or their staff to advocate for vision health
- ASPECT participants were oriented to congressional & political landscape & federal appropriations process
- Provided with the advocacy agenda from Prevent Blindness, given meeting materials, and had meeting logistics coordinated.

# A.S.P.E.C.T. Virtual Program Graduation 2021



# Discussion of Experiences & Lessons Learned: Mandie & Laura's Perspectives



# Question & Answer Discussion





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