

# 2023 Stakeholder Meeting



VISION HEALTH  
ADVOCACY COALITION

Millions of people across the United States live with vision conditions, including thyroid eye disease, inherited retinal disease, Sjögren's and dry eye disease. With a growing aging population in the United States, it is expected that vision conditions like glaucoma, diabetic retinopathy, cataracts and macular degeneration will significantly increase in the next 30 years, and vision impairment and blindness will increase by 150%.<sup>1</sup> To better understand and address challenges impacting those with vision conditions, VHAC convened an in-person stakeholder meeting.

The Vision Health Advocacy Coalition works to raise awareness and ensure appropriate access to services, devices and life-changing treatment for all affected by vision conditions. VHAC is comprised of 13 organizations committed to advocating for vision patients and raising awareness of vision conditions. At its first annual in-person stakeholder meeting, the coalition welcomed member organizations to discuss access barriers that vision patients face, strides in innovation for treating vision conditions, and educational opportunities for the coming year.

1. "Looking Ahead: Improving Our Vision for the Future." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 7 Nov. 2022, <https://www.cdc.gov/visionhealth/resources/infographics/future.html>.

## CORE THEMES

VHAC member organizations discussed the following as core themes for 2023:

### 1 Patient & Provider Education

Fostering new education initiatives on vision conditions and treatments for patients and providers is a key component in increasing vision condition awareness.

### 2 Barriers to Diagnosis

To properly address the growing number of people suffering from vision conditions, targeting the barriers that impact vision patients' access to timely diagnosis is essential.

### 3 Access to Vision Treatment

Once a patient has a diagnosis and treatment plan, there can often be many barriers to accessing treatments for their condition; ensuring appropriate access is key to preventing further vision loss or damage.

### 4 Innovation

Continued innovation is critical to ensuring all vision patients can ultimately access a treatment. Supporting and fostering policies that increase innovation in vision care is crucial for the future of vision health.

## 1 Patient & Provider Education

Creating vision-specific educational programs and materials is a foundational function of VHAC. Stakeholders discussed ways to continue these efforts and leverage curated materials. Disease-specific patient empowerment forums, like the ones done for those affected by thyroid eye disease, is one example of directly connecting patients within their communities with other patients, local providers and educational materials.

Additionally, the coalition discussed leveraging vision health awareness events to educate policymakers on various vision conditions and other associated health topics like mental health and caregivers. The coalition discussed the creation of social media toolkits and the sharing of information between organizations as these opportunities arise. Through educating patients and providers, VHAC can move the needle on awareness of vision conditions and treatments, improve patient education, and address access challenges.

## 2 Barriers to a Diagnosis

Stakeholders explored the barriers and challenges in a vision patient's path to diagnosis. Coalition members highlighted the value of genetic testing for vision patients; however, coverage of genetic testing can often be a barrier. Genetic testing and counseling can help pinpoint a diagnosis, which may lead to a more targeted treatment plan.

Coalition members discussed the ongoing

physician shortages within vision specialty fields. Physician shortages can lengthen a vision patient's path to diagnosis. The group discussed the need to advocate for additional funding to support increases in vision specialty residencies and loan forgiveness programs for those who practice in vision specialties. There is also a shortage of genetic counselors, which may also lengthen the patient's path to diagnosis – addressing this shortage through policy change is critical in ensuring timely access to diagnosis and, ultimately, treatment.

## 3 Access to Vision Treatment

Patients with vision conditions often face barriers that prevent them from accessing appropriate treatment. For patients who have a diagnosis, vision rehabilitation services may help. Coalition members highlighted that many vision patients are unaware of vision rehabilitation services or the value they bring. And in many cases, because professionals who offer vision rehabilitation services are often not medically licensed, insurance does not cover these treatments.

Coalition members also expressed frustration over the harm caused by inappropriate insurance tactics and discussed advocacy efforts to improve patients' access.

Barriers discussed included:

- **Prior authorization.** Vision patients may have to wait for their insurance company's approval before receiving a treatment or procedure. The delay can last days, weeks, or even months, while their vision conditions go untreated.

- **Step therapy.** Before accessing prescribed medication(s), vision patients may be forced to try cheaper and less effective alternatives to prove they don't work.
- **Co-pay accumulators.** Some patients utilize co-pay cards to help pay for their prescriptions. Co-pay accumulator programs prevent these coupons from counting toward a patient's deductible. Patients are then left to choose between paying expensive out-of-pocket costs or going without their treatment.

Discussions also emphasized the need to educate insurers and policymakers on the harm utilization management tactics present that can limit patients' access to appropriate care.

## 4 Innovation

Top of mind for many coalition members was the need for greater innovation and investment in vision research. Coalition members stressed that funding federal institutes like the National Eye Institute and others within the National Institutes of Health could help eliminate gaps in research and lead to better treatment options for vision patients.

Additionally, federal policy can support increased innovation. Policies like the accelerated approval pathway and the orphan drug tax credit are critical in increasing available therapies.

## NEXT STEPS

Following this meeting, VHAC convened a panel on the "Unmet Needs of Rare Vision Patients" and invited outside stakeholders to participate. This panel will result in a policy paper to be utilized by all participating members.

VHAC leadership will utilize core themes and discussions derived from this meeting to create materials and programs to further the mission of the Vision Health Advocacy Coalition.

## GET INVOLVED

To learn more, contact Kimberly Serota at [kserota@allianceforpatientaccess.org](mailto:kserota@allianceforpatientaccess.org).

[VisionHealthAdvocacy.org](http://VisionHealthAdvocacy.org)



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