



VISION HEALTH
ADVOCACY COALITION

2025 | Stakeholder Meeting

Summary

On June 12, 2025, the Vision Health Advocacy Coalition hosted its in-person stakeholder meeting in Washington, D.C. Member organizations and sponsors gathered to reflect on shared progress and collaborate on future priorities to improve awareness, access and outcomes for people living with vision conditions.

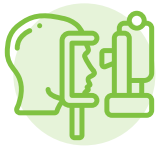
Participants shared updates from the past year and discussed key areas of focus for the next year.



Awareness, Education and Early Diagnosis

Stakeholders emphasized the need to raise awareness of vision conditions among patients, providers and policymakers.

- **Many patients do not recognize the severity of their symptoms until the disease has progressed.** Confusion around specialty care, limited awareness of rare conditions and inadequate early screening all contribute to delays in diagnosis and treatment.
- **Participants discussed expanding efforts to share materials directly with patients** through providers, using art and storytelling to reflect the lived experience of vision loss, and expanding content to broader outreach across the vision community.
- **Educational efforts should highlight the progressive nature of many conditions** and the importance of early intervention and diagnosis.



Access to Treatment and Insurance Barriers

Access to appropriate treatment remains a widespread challenge. Stakeholders discussed the role of utilization management tools, including prior authorization and step therapy, in creating delays and disruptions in care.

- **There was strong support for patient education** around appeals, insurance navigation and open enrollment, particularly for those managing complex or high-cost treatments.
- **Participants expressed concern about the administrative burden placed on patients and providers**, and the continued influence of insurers in treatment decisions.

Members agreed that VHAC should continue supporting policy reforms at the federal and state levels to promote timely, patient-centered care.



Equity and the Patient Experience

The group emphasized the importance of addressing social determinants of health and access disparities, especially for seniors, rural residents and people with low vision.

- **Stakeholders noted that transportation, insurance coverage and cost** remain major obstacles.
- **Medicaid and Medicare access** were highlighted as top priorities, with a particular focus on vision rehabilitation services and support for older adults.
- **There was agreement that culturally tailored materials and more visible patient storytelling** can help reduce stigma and empower individuals to seek care.



Vision Research and National Policy Engagement

Participants expressed ongoing concern about funding challenges at the National Eye Institute, or NEI, and NIH.

The elimination of projects and grant delays in FY25 created momentum for collective advocacy. Stakeholders urged continued outreach to policymakers and support for legislation that restores and protects vision research funding.

VHAC'S member organizations discussed opportunities to **continue advancing efforts to elevate vision as a public health priority** through collaborative education and advocacy efforts.



Looking Ahead to 2026

As the coalition plans for the year ahead, members recommended continuing to build on VHAC's education and awareness efforts around TED while exploring opportunities to develop patient-facing materials and public campaigns that include a broader range of vision conditions.

- **Suggestions included mapping provider shortages**, increasing strategic coordination with other coalitions, and hosting a future VHAC Hill Day.
- **Members also discussed ways to make future in-person meetings more inclusive** of the full vision community and align VHAC events with legislative opportunities.
- **Members emphasized the importance of expanding VHAC's reach** by growing its membership, including recruiting new organizations that reflect the full diversity of the vision and patient advocacy landscape.

Thank you to all VHAC members for your continued leadership, partnership and commitment to ensuring every person with a vision condition has access to education, care and support.

