THE HEADACHE ALLIANCE

2025 IMPACT REPORT

OUR MISSION, OUR IMPACT, OUR FUTURE

TABLE OF CONTENTS

BUILDING MOMENTUM, DRIVING CHANGE

LETTER FROM THE EXECUTIVE DIRECTOR

JULIENNE VERDI
Executive Director

Dear Supporters and Friends,

2025 has been a transformative year for The Headache Alliance (THA) and our sister organization, the Alliance for Headache Disorders Advocacy (AHDA). Together, we have worked to ensure that the more than 40 million Americans living with headache disorders are seen, heard, and supported.

The Headache Alliance continues to focus on education, awareness, and equipping patients and families with the tools to thrive. AHDA leads the charge on legislative advocacy to bring systemic change. By working in partnership, our organizations are building a comprehensive movement that connects lived experience, public awareness, and policymaking.

This year, we brought unprecedented national visibility with the **Flags for Headache Installation Project on the National Mall**, a powerful call to action seen across the country. We launched the **first-ever Make Art, Make Headache Visible High School Art Competition**, giving students a creative way to share the impact of headache disorders. We expanded programming at Headache on the Hill with **new youth programming, new adult affinity groups, and a new headache care room**, providing spaces for advocates to learn, connect, and lead. We also introduced **new traditions**, including our first **Headache on the Hill Awards Dinner**, honoring Dr. Robert Shapiro and Bob Wold and launching the Shapiro Scholarship Fund for advocates living on SSDI.

At the same time, AHDA advanced critical policy change through four Congressional briefings, the introduction of the **Headache Education, Access, Diagnosis, and Care Health Equity (HEADACHE) Act**, and continued momentum following the Department of Education's December 2024 release of the landmark **504 Guidelines for Migraine** the AHDA worked tirelessly to secure.

As we close this year, I am filled with gratitude for our advocates, volunteers, partners, and donors who power this work. You are helping us build a future where no one has to face headache disorders alone. I'm excited and hopeful for the work ahead, especially with each of you by our side.

With gratitude,

Julienne Verdi, JD (she/her)
Executive Director
The Headache Alliance, Inc.
Alliance for Headache Disorders Advocacy

OUR MISSION.
OUR VISION.

MISSION STATEMENT

The Headache Alliance is committed to empowering those impacted by headache disorders through advocacy, education, and action.

VISION

A world without stigma for those living with headache disorders.

2025 IMPACT AT A GLANCE

FLAGS FOR HEADACHE INSTALLATION PROJECT (THA & AHDA)

In June, we launched a historic public awareness event on the National Mall with 30,000 flags representing people living with headache disorders. The Installation reached over **five million** people through in-person contact, social and earned media. Nearly 1,000 letters to Congress were tied to the campaign. More than 300 donors, 50 fundraising champions, and 60 volunteers came together to make it possible.

Programming at the Installation included the **Speak Out for Headache Health Press Event,** which featured patients, clinicians, Congressional staff, and actress Bellamy Young. More than 50 people attended in person, with over 200 additional virtual participants and replays online. To amplify voices further, we recorded more than a dozen interviews with patients, clinicians, and caregivers for a national storytelling series that were shared widely during Migraine and Headache Awareness Month.

This was also a truly national movement. We trained and organized advocates across the country to secure more than 50 state and local proclamations, light over 50 landmarks purple, and host more than 60 pop-up installations in their communities across the country. Together, these efforts showed the strength of a growing movement nationwide and made invisible pain impossible to ignore.

Involvement	**300 donors, 50 fundraising champions, 60 volunteers**
Letters Sent to Congress	**Over 1000**
In-person contact, social, and earned media	**Reached over 5 million people**

2025 IMPACT AT A GLANCE

MAKE ART, MAKE HEADACHE VISIBLE (THA)

2025 marked the launch of our first youth art competition, Make Art, Make Headache Visible. Winning entries were featured at the Flags for Headache Installation and on our digital platforms. The program gave students a creative platform to share their perspective on the impact of headache disorders and brought fresh voices into the conversation. Centering youth voices ensures our work reflects the lived realities of young people and the barriers they face in school, at home, and in care. The act of making art proved healing for many participants and helped audiences connect with the issue in ways that data alone cannot, shifting perceptions and inviting empathy. Building on this strong start, we plan to expand the program in 2026 by reaching more classrooms and clinics, showcasing student work at additional community events, and creating new opportunities for youth leadership and storytelling.

LUNCH & LEARN SERIES (THA)

Our Lunch & Learn webinar series continued to be an important way to share timely education and resources. This year's sessions covered topics such as workplace accommodations, VA Headache Centers of Excellence, and disability rights. Over 1000 registrants joined throughout the year to learn and connect, underscoring the value of ongoing education as a tool for empowerment.

2025 IMPACT AT A GLANCE

HEADACHE ON THE HILL: EDUCATION AND ADVOCACY IN ACTION

Headache on the Hill continued in its two-time-a-year format, with advocates gathering in person in Washington, DC in March and again virtually in September. Together, more than 400 advocates from across the United States took part in educational training and programming designed to help them share their stories and advocate with confidence. Participants then applied these skills in meetings with congressional offices during both sessions.

This year we expanded Headache on the Hill with three important new components:

- **Youth programming** gave young advocates their own dedicated workshops and opportunities for leadership and healing. Youth participated in educational activities, community building, and art and movement activities. These sessions helped young people build skills and confidence while creating a pipeline for future leaders in our community.
- **Adult affinity groups** created space for advocates to connect around shared experiences such as being a veteran, a clinician, or part of historically marginalized communities. These groups deepened belonging, surfaced new volunteer leaders, and strengthened peer support that continues beyond the event.
- **A new headache care room**, both during the conference and on the Hill, provided a safe, accessible space for advocates to relax and recover. These accommodations reduced missed sessions and helped more advocates remain fully engaged throughout the day.

In addition, we introduced the **Headache on the Hill Awards Dinner**, a new tradition that brought advocates and leaders together to celebrate progress and honor champions in our field. At this inaugural event, we recognized Dr. Robert Shapiro and Bob Wold for their extraordinary contributions and announced the creation of the Shapiro Scholarship Fund for advocates living on SSDI. The celebration energized our community and elevated support for expanding access and participation in the years ahead.

LEGISLATIVE ADVOCACY HIGHLIGHTS

AHDA
ALLIANCE FOR HEADACHE DISORDERS ADVOCACY

INTRODUCTION OF THE HEADACHE ACT

In September, AHDA proudly celebrated the introduction of the **Headache Education, Access, Diagnosis, and Care Health Equity (HEADACHE) Act** in the House of Representatives. This bipartisan legislation was introduced by Rep. Lori Trahan (D-MA) and Rep. Brian Fitzpatrick (R-PA), who serve as lead sponsors of the bill. The HEADACHE Act is the first standalone bill dedicated to addressing the headache disorder crisis in the United States. It represents years of advocacy and a turning point in federal recognition of the burden these diseases impose.

CONGRESSIONAL BRIEFINGS

AHDA hosted and participated in four Congressional briefings in 2025. These events provided lawmakers and their staff with science-based information and powerful patient perspectives on the urgent need for improved headache care, research, and policy. Each briefing built momentum for legislative change and ensured that the headache community's priorities remain front and center on Capitol Hill.

504 GUIDELINES FOR MIGRAINE

In December 2024, the Department of Education released the first-ever federal guidance clarifying schools' obligations to provide accommodations for students living with migraine. **AHDA played a key role in this milestone** by advocating for the guidelines and then working tirelessly to educate families, school administrators, and advocates about what they mean in practice. Our outreach helped ensure that these guidelines are not only known but also understood and applied in schools across the country.

LEGISLATIVE ADVOCACY HIGHLIGHTS

AHDA
ALLIANCE FOR HEADACHE DISORDERS ADVOCACY

HEADACHE ON THE HILL LEGISLATIVE IMPACT

Alongside THA's educational programming, AHDA coordinated the legislative advocacy side of Headache on the Hill. In 2025, our advocates conducted nearly **500 Congressional meetings**, sharing personal stories and pressing for action. Our consistent presence helps to build rapport and cultivate positive relationships with Congressional offices. These conversations directly advanced our legislative agenda and built bipartisan support for lasting change.

LETTERS TO POLICYMAKERS

This year, AHDA also coordinated an organizational sign-on letter to the Make America Healthy Again Commission. The letter focused on the unique challenges faced by children with headache disorders, ensuring that their needs are represented in national policy discussions. We also organized a sign-on letter in support of the bipartisan HEADACHE Act and our advocates sent over **7,000** messages to Congress throughout the year in support of our legislative agenda.

LOOKING AHEAD TO 2026

THE WORK AHEAD IS AMBITIOUS, BUT THE MOMENTUM IS STRONG.

- **Flags for Headache Returns:** The Installation will return to the National Mall from June 13–28, 2026, with expanded programming, more local pop-ups, and potential global coordination to engage partner organizations.

- **Headache on the Hill 2026:** Both the Spring in-person and Fall virtual events will continue, with expanded youth, art, wellness, and affinity group programming.

- **Lunch & Learn Expansion**: We will add more sessions to reach patients, caregivers, and clinicians with the knowledge they need to navigate healthcare and advocacy.

- **Policy Momentum**: The AHDA will continue to build bipartisan support for the HEADACHE Act while advancing additional legislative priorities to improve care, research, and equity for all people with headache disorders.

WHY YOUR SUPPORT MATTERS NOW

The Headache Alliance turns lived experience into change. Your gift powers what comes next in 2026, including stronger advocacy training, expanded youth programming, more clinician and public education, and wider reach for awareness efforts like Flags for Headache.

SHAPE YOUR IMPACT

- **Empower advocates**
  - Help patients and caregivers build skills, meet with decision makers, and stay engaged year-round through trainings, mentorship, and community support.
- **Elevate youth voices**
  - Give young people a platform to create, learn, and lead. Youth storytelling and art help people see headache disorders with empathy, not stigma.
- **Advance education and awareness**
  - Support practical webinars, resources, and outreach that help people navigate care and help communities understand the burden of headache disorders.
- **Build the movement**
  - Invest in the tools, staff, and partnerships that keep programs running, measure results, and grow a diverse national network for headache advocacy.

WAYS TO GIVE

One-time or monthly • Donor-advised fund • Stock or wire • Employer match • In-kind services and supplies • Corporate and foundation partnerships

VOLUNTEER AND SHARE YOUR STORY

Join a committee, lend professional skills, or serve as a state captain. Share your story to help others feel seen and to move public opinion.

Let's work **together** to get people care sooner and build a stronger national movement for headache health.

THA LEADERSHIP

The success of The Headache Alliance in 2025 would not have been possible without the guidance, dedication, and leadership of our Board of Directors, staff and key volunteers. These individuals have provided invaluable oversight and strategic direction as we continue to grow and expand our reach. We are deeply grateful for their expertise, commitment, and passion for our mission.

THE HEADACHE ALLIANCE

Staff Leadership

- Julienne Verdi, JD, Executive Director
- Courtney Mentzel, Administrative & Program Coordinator

Volunteer Committee Leaders

- Eileen Brewer
- Divya Gordon
- Nancy Harris Bonk
- Jenn Heater
- Laura Miller
- Mikaila Milks
- Karla Neville
- Jenn Attridge Schacht,
- Anna Williams

Headache Alliance Board of Directors

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- Amaal Starling, MD, FAHS, FAAN, Vice President
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- Stephanie Nahas, MD, Secretary
- Mirabella Macias, Board Member
- Karla Neville, Board Member
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- Mandee Schaub, Board Member
- Jenn Attridge Schacht, Board Member
- Nan Cheng, MD, Board Member
- Teller, Board Member
- Felicitas Huber, MD, Board Member

AHDA LEADERSHIP

AHDA | ALLIANCE FOR HEADACHE DISORDERS ADVOCACY

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- Shirley Kessel
- Chaouki K. Khoury, M.D., M.S., F.A.A.N., F.A.H.S
- Hallie Koch
- Jennifer Schoon, DPT
- Amaal Starling, MD
- Bob Wold
- William Young, MD

AHDA Member Organizations

CHAMP Coalition for Headache and Migraine Patients

Southern Headache Society

Global Healthy Living Foundation

spinal csf leak Foundation – because your dura maters®

National Headache Foundation

Miles for Migraine

American Headache Society

American Academy of Neurology

AfPA Alliance for Patient Access

Are You Aware? Chronic Migraine Awareness

Clusterbusters

Headache Cooperative of the Pacific

HCNE Headache Cooperative of the Northeast

American Migraine Foundation

U.S. Pain Foundation

FacialPain Association

AHDA | ALLIANCE FOR HEADACHE DISORDERS ADVOCACY

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