Advocating for Equitable Policies for People with Headache Disorders

2020 ANNUAL REPORT
The Alliance for Headache Disorders Advocacy (AHDA) is a 510(c)6 nonprofit membership organization. We are comprised of nonprofit organizations that are concerned about the health of patients with headache disorders, including migraine disease, cluster headaches, chronic daily headache, new daily persistent headache and tension-type headaches.

Since 2007, AHDA has advocated consistently for increased recognition of, and more equitable federal policies toward Americans with disabling headache disorders. Our advocacy efforts include our annual signature event, Headache on the Hill (HOH), a congressional fly-in event in Washington, DC, as well as multiple other activities throughout the years.

Headache disorders cause more than 1 percent of all disability and 9 percent of all lost labor in the United States every year. Migraine is the #1 cause of U.S. neurological disability, and the #10 cause of all U.S. disability. Headache disorders are the most prevalent neurological disorders, affecting more than 90% of all Americans.

The U.S. annual direct and indirect economic costs of headache disorders exceed $31 billion.
Dear Friends,

What a busy year it has been at the Alliance for Headache Disorders Advocacy (AHDA)! We cannot thank enough the amazing advocates who help us and our member organizations give voice to those living with headache disorders and migraine. Since 2007, AHDA has been on the front lines of advocating for more equitable federal policies toward Americans with disabling headache disorders. We look forward to continuing our efforts in 2021 with the new administration and engaging more individuals to stand and be counted in the legislative process. In this annual report, you can learn more about our work and accomplishments in 2020!

We hope this holiday season, you will consider making a donation to AHDA. As many of you know, funding for AHDA activities is entirely derived from the contributions of our member organizations and individual donors. No donations have ever been accepted from corporate, commercial, or industry sources. So, your support is very important to us and will assist us in starting an endowment to help ensure the financial strength of the organization.

Your donations also will help support AHDA in successful initiatives such as:

- Securing $10M in funding for seven regional VA Headache Disorders Centers of Excellence
- Securing more than $18.5M funding for “chronic migraine and post-traumatic headaches” research funding under the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) of the Congressionally Directed Medical Research Program (CDMRP) since 2010
- Helped draft the “Safe Treatments and Opportunities to Prevent Pain Act” (STOP Pain Act, S.2678) and saw this signed into law in 2016

Donations also will support us in ongoing initiatives such as:

- Working to determine why migraine, the 2nd leading cause of all global disability, is not currently listed in the Social Security Administration’s Blue Book Listing of Impairments
- Appealing Center for Medicare & Medicaid Services (CMS) long-standing policy for not covering home oxygen for people with cluster headache.

No gift is too small or too large! We appreciate every dollar we get to use to affect policy change. Visit our website today to make a donation. Thank you in advance for your contributions!

On behalf of the board and staff, we wish you and your families a safe and happy holiday season!
2020 Accomplishments Timeline

**February 10-11** - Hosted the 13th Annual Headache on the Hill event.

**February 18** - Submitted questions to Rep. John Larson to ask SSA Commissioner Saul about the discriminating policies existing in the current SSA Sequential Evaluation process & following up on the SSA refusal to comply with our FOIA request. We asked for co-sponsors on H.R.3414/S.2892. Nine new House co-sponsors (5 of which we visited) & 4 new Senate co-sponsors on (3 of which we visited).

**February 25** - Bob Shapiro, Katie MacDonald, Bob Wold, and Eileen Brewer had an in-person meeting at CMS with their Coverage and Analysis Group personnel to further discuss their delay in addressing the appeal submitted to CMS in January 2019 for coverage of home oxygen for Cluster Headache for Medicare/Medicaid beneficiaries.

**March 23** - Submitted written testimony to House LHHS Appropriations Subcommittee for the annual Public Witness Hearing.

What an amazing 2-day gathering we had in February, with 173 participants from 45 states! This represents an 8% increase in participation from the 2019 event.

Patient and medical professionals gathered the first day for an advocacy training, where AHDA's Bob Shapiro and Katie MacDonald outlined the legislative items and the requests we had for members of Congress. Thank you to Joe Gagen for providing the great information on how decisions are made on the Hill and the "Dos" and "Don'ts" of congressional meetings.

The second day, we took our annual group photo and we visited 225 Congressional offices!

We are grateful to Lindsay Videnieks and the Headache and Migraine Policy Forum (HMPF) for sponsoring our annual luncheon on the Hill. And we give a special thanks to our advocates for their tireless efforts in giving voice to those living with headache disorders and migraine. You are our heroes, and together, we can affect change!

**SAVE THE DATE**
14th Annual Headache on the Hill Goes Virtual on March 23, 2021!
April 1 - Submitted written comments for the NIH Strategic Plan.

June 15 – Signed on to a letter led by Healthy Women addressed to NIH Director Collins and FDA Commissioner Hahn urging them to hold more public meetings to gather input about the patient perspective and individualization of pain treatments.

June 16 - Submitted public comment to the CDC Pain Management Program sharing our concerns about the lack of effective, non-addictive treatments for people with migraine and headache disease and encouraging the CDC to promote optimal principles of migraine care.

June 22 - Joined the Disparities in Headache Advisory Council being led by CHAMP.

June 30 – July 7 - Held first Walk, Run or Just Relax virtual fundraising event with 209 participants. We raised $26,514. The funds will support a scholarship fund for future patient advocates to attend HOH in DC.

July 8 – Supported a successful proposal by the Spinal CSF Leak Foundation for implementation of new ICD-10 codes for spontaneous and iatrogenic intracranial hypotension, cranial and spinal CSF leaks, and other associated codes.

We are proud to have submitted written testimony in March on behalf of our community to the House Labor, Health and Human Services Appropriations Subcommittee for the annual Public Witness Hearing. Our testimony focused on the following issues:

(1) All Americans deserve equal access to the benefits and hope that come from tax-payer funded NIH research,
(2) The Social Security Administration is unlawfully discriminating against Social Security Disability Insurance claimants on the basis of their disability, and
(3) It is unethical for the Center for Medicaid Services to withhold safe and effective oxygen therapy from Medicare and Medicaid beneficiaries in excruciating pain with cluster headache.

CMS announced a 30-day open comment period in response to our formal appeal to reverse a policy denying the coverage of home-use oxygen for cluster headache, submitted originally in January 2019.

AHDA worked with CHAMP and other member organizations in August to launch a call for comments from patients and member organizations.

In October, AHDA submitted a draft letter to the Ways & Means, Social Security Subcommittee Chairman John Larson to be sent to Social Security Commissioner Andrew Saul, and we submitted critique of Social Security Ruling (SSR) 19-4P outlining our concerns with the Ruling issued in August 2019.
2020 Accomplishments Timeline

**July 9** – Issued formal statement on racial inequities in healthcare and headache medicine.

**July 13** - We ensured the following language was included in the FY2021 House Appropriations Committee Report: “Headache Disorders - The Committee strongly urges NINDS to consider funding applications on fundamental, translational, and clinical research on headache disorders, including migraine, posttraumatic headache, the trigeminal autonomic cephalalgias, and intracranial hypo/hypertension, that align with the HEAL Initiative's goal to achieve rapid and long-lasting solutions to the opioid crisis.”

**August 15** – Added Dr. Larry Charleston, IV as Member at Large to AHDA Board.

**August 17** – CMS announced a 30-day open comment period for oxygen appeals submitted originally in January 2019. AHDA worked with CHAMP and member organizations to launch call for comments from patients and member organizations.

**SUMMER VIRTUAL FUNDRAISER**

**RAISING FUNDS FOR THE HEADACHE ON THE HILL SCHOLARSHIP FUND**

From June 30-July 7, 209 individuals from across the country participated in AHDA's first Walk, Run or Just Relax virtual fundraising event! We raised $26,514 for a scholarship fund to support future patient advocates attending Headache on the Hill in Washington, DC.

Thank you to members of AHDA and CHAMP participants who helped coordinate this wonderful event for us. And thank you to all of our participants for helping us to advance our mission!
AHDA and HMPF worked with Congresswoman Madeline Dean’s office on H.Res.1160, a resolution to raise awareness on migraine disease and headache disorders.

In September, Representatives Madeline Dean and Barbara Lawrence introduced H.Res.1160. Many thanks to HMPF and our partner organizations for their input to help ensure the resolution covers topics such as:

- Disability (including Social Security Administration issues)
- Workplace Impact (including presenteeism/absenteeism)
- Stigma
- Disproportionate Impact on Black, Indigenous, and People of Color (BIPOC)
- Specific Focus on Cluster Headache (including formal recognition of lack of treatment access)
- Access to Treatment
- Federal Research Funding

In October, AHDA launched a Voter Voice campaign requesting support from the community to contact their Representatives about H.Res.1160 to acquire additional co-signers for the resolution. Thank you to our advocates who submitted 344 messages to their Representatives requesting co-sponsorship of this resolution.

“H.Res.1160 highlights the migraine and headache disorders that impact nearly 20% of women and occur nearly three times more often among women than men. It’s important we cancel the stigma that is often coupled with migraine and headache disorders, and recognize the severe symptoms and physical pain that is often dismissed.” - Representative Madeline Dean (9/30/20 Press Release from Dean’s Office.)
"I knew I wanted to try to use my sister's story to ensure that folks didn't forget the struggle of those who are chronically ill and struggle with mental health issues and migraine."

“I remember my sister being gone with my mom a lot,” says 25-year-old Billy Dwyer. “My mom, in addition, to working a full-time job, was my sister’s full-time caregiver. I remember them going to the hospital and seeing specialists – in and out – trying to find some sort of relief or a cure.” Billy’s older sister Melissa, who struggled with chronic migraine, died by suicide in 2013 right before her 23rd birthday and a few days after Billy graduated from high school.

Billy is an Illinois native who lives and works in Washington, DC as a legislative correspondent and assistant scheduler for 2nd District of Illinois Congresswoman Robin Kelly, a position he started almost two years ago. He received his Master’s degree in Social Work from the University of Illinois at Urbana-Champaign with a focus in Leadership and Social Change. Billy remembers one of his policy professors telling his class “that you can be the best clinician in the whole entire world; you can be the best therapist. You’ll see 100 or 200 people maybe if you’re lucky and you will impact their lives very deeply. But if you want to help millions and thousands of people – you have to be involved in the legislative process and you have to be at the table where decisions are being made. You can do advocacy as part of your job.” Billy says that statement struck a major chord with him. He took these professor’s words and began to envision how he could use the common pain of folks and their stories and storytelling in way to influence change.

“Following the loss of my sister, I really wanted to focus on how to use my story. I always felt like I had an empathetic nature in me and I really didn’t know how that would manifest. I felt compelled in those weeks and months afterwards in talking to other suicide loss survivors and other folks who had completely different experiences, who had some pain in their lives. I knew I wanted to try to use my sister’s story to ensure that folks didn't forget the struggle of those who are chronically ill and struggle with mental health issues and migraine,” says Billy.

Melissa’s struggle is familiar to many in the headache and migraine communities. Her migraine seemed to progress in middle school and high school. Billy can remember his mom watching his sister suffer and seeing her try to find relief. Melissa would find a treatment that would work for a short period of time. She tried her best to work a regular job, and she also attended the local University for a while. Eventually, she had to stop those activities and she ended up being permanently bedridden.

Billy says he for a long time, as a boy, he didn’t grasp the severity of what his sister was experiencing. “I was the baby in the family and in my selfish stage where it’s me, me, me. I wrestled with feeling sort of forgotten about, which I think is common with folks who have siblings or who have experience with someone who is chronically ill.”

Migraine is a misunderstood disease, he says. Melissa didn’t know anyone else whose struggle was so severe. Many of the organizations today that
focus on headache disorders and migraine were in their infancy stage when Billy’s sister was alive. There were events and an online community that helped, and continue to support, so many people who felt so isolated and misunderstood in their entire existence. “Being able to open those doors and see that someone else gets it is so empowering for these folks. It can be such a healing place for people,” says Billy.

Shortly before Melissa’s suicide, she had gone to see some of the best specialists, filling her with great hope that she would be cured this time. When this round of specialist visits did not bring healing, there was a profound sense of hopelessness. Billy believes that it was the ups and downs – getting your hopes up way high for a treatment and the isolation that contributed to his sister’s decision to end her life. “She was such a social person, the life of the party, a drama queen, and I can say that as her loving brother,” he says smiling. “A lot of her friends couldn’t understand, relationships fell through. Your friends are no longer answering your phone calls or your texts after a while, and you cancel plans with them again for the 15th time. They're sick of it because they just don't get it. I think that only added to the loneliness. The physical head pain and the lack of hope for a treatment and the isolation feeling.”

When asked what advice he would share with others who know someone living with a headache disorder or migraine, Billy says it is important to be able to validate someone’s pain. “In the mental health realm, they always say, if someone has a broken arm, you can see it. They have a cast so you can appreciate the pain they are in and validate it. If someone is lying in a dark room for 20 hours a day because their brain feels like it is on fire, you can't see it so it is easier to dismiss it and say your pain is not as a real as someone else’s. I think just being able to validate someone else’s pain.

You don’t have to understand it. One of the most valuable lessons in my life has been – I don’t have to have ever lived the experience that you have had – and you don’t have to have those experiences for me. Just being able to see the pain in someone else and being able to say, 'I don't know what you're going through, but I am here for you and I am going to walk down this path with you.’ Those are the most valuable words.”

Billy and his mom, Becky, have participated in several of AHDA’s Headache on the Hill events. “Just 2 ½ -3 years ago, I was on that side of the table, advocating – sharing my sister’s story with a group of fellow advocates, and caregivers and people living with migraine, and now I’m going to be the one receiving those meetings. That's quite the full circle,” he says smiling. We look forward to working with Billy to coordinate a meeting with Congresswoman Kelly for the 2021 Headache on the Hill event.

Billy states, “When it first happened, I was screaming from the roof tops, ‘hear my pain, this is my story’ and everybody listened to me. Now, I am much more comfortable, healed and able to talk about this from a place where it's not ‘hear my pain’. Now, it's ‘here's my story and how can I help you get from a place of feeling hopeless or feeling lost? How can I connect you to resources? How can I help you engage and be a successful advocate?’ It's ‘tell my sister’s story and help someone else.”’ We are so grateful to Billy and his mom, and to all of the advocates who help to amplify the voices of the community to create legislative change and increase awareness.
AHDA thanks its member organizations for their commitment and dedication to serving the headache community. Through their tireless efforts, individuals living with headache disorders and migraine are a part of a vibrant community of knowledgeable experts and caring people that are advocating for increased research funding, fighting for equitable federal and state policies, increasing awareness and supporting one another. Together, we are working to improve the quality of life for the headache community.
MEET THE BOARD OF DIRECTORS

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In September, we hired Carole Bernard as our new part-time Executive Director. She has 20 years of nonprofit management experience. Most recently, she served as the Director of Communications for the Sickle Cell Disease Association of America, Inc. and the Executive Director of the Scleroderma Foundation Greater Washington, DC Chapter.

We are so appreciative of the great work that Katie MacDonald has done for AHDA. Katie will continue working with the organization as the Director of Federal Policy.

Sign up for our newsletter to stay up-to-date on our current legislative initiatives and be the first to know when we announce new action alerts! And visit our social media sites to stay connected. Please take a moment and visit our pages and and like" or "follow" us by clicking on the social media icons. We look forward to bringing you lots of great information and keeping in touch. We hope you will comment on our posts, ask questions and share our content with your friends and family who would benefit from the information. You can help us spread the word about AHDA with your network and a broad audience! We ask that you use these hashtag suggestions when sharing posts: #AHDA #HeadacheDisorders #Migraine #HeadacheDisordersAdvocacy #MigraineAdvocacy.

Click here to donate to AHDA today!

Please remember AHDA this holiday season and support our efforts!
FY2019 REVENUE: $181,152.53

- Individual Donations: 37.1%
- Member Org Donations: 55.2%
- Member Org Dues: 7.7%

FY2019 EXPENSES: $55,280.35

- Program (HOH): 63.8%
- Administrative: 36.2%