



ALLIANCE FOR HEADACHE DISORDERS ADVOCACY

# THE LEADING VOICE FOR HEADACHE POLICY



For nearly two decades, the Alliance for Headache Disorders Advocacy (AHDA) has been the leading voice in federal headache disorders advocacy. Whether drafting legislation, making comments to regulatory agencies, or fighting against discriminatory practices, policies, or laws, the AHDA is at the forefront.

The AHDA envisions a brighter future where public policies will ensure the maximum potential of those living with headache disorders.

## WHO IS THE AHDA?

The Alliance for Headache Disorders Advocacy (AHDA) is an umbrella organization uniting headache advocates nationwide. Our ongoing mission is to make life better for the millions of Americans living with headache disorders. AHDA advocates include organizations, medical providers, researchers, caregivers, and people living with headache disorders.

## MEMBER ORGANIZATIONS



## ACHIEVEMENTS

Past AHDA initiatives have led to beneficial policy changes for headache disorder patients, including:

# 21

Establishing **21 Headache Disorders Centers of Excellence** within the Veterans Health Administration. These centers treat more than two million veterans living with migraine and other headache disorders. The number of Centers is expected to grow to at least 28 due to the AHDA's continued advocacy.

## SECURED HIGH-FLOW OXYGEN COVERAGE

through Centers for Medicare and Medicaid (CMS) for patients with cluster headaches.

# SSDI

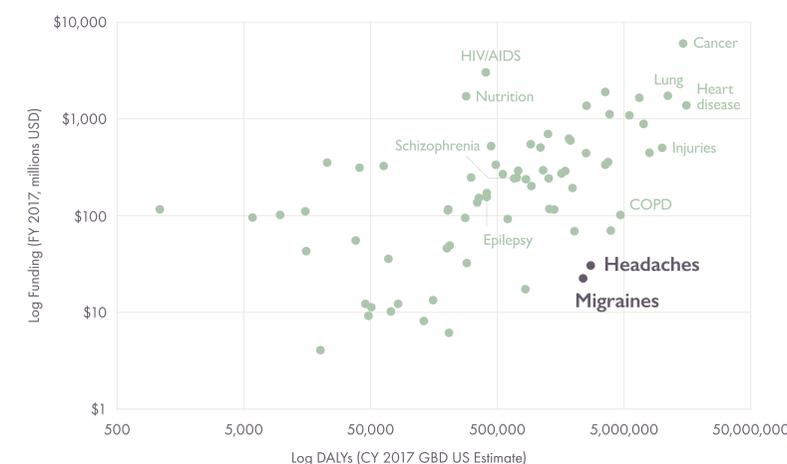
Influenced the issuance of the first-ever guidance by the **Social Security Administration** around headache disorders in the Blue Book policies that determines who is eligible for Social Security Disability Insurance.

## WHAT ARE HEADACHE DISORDERS?

Headache disorders are an invisible epidemic. Ranging from migraine, cluster headache, and spinal CSF leak to new daily persistent headache and tension-type headache, headache disorders are common, affecting up to 46% of the worldwide adult population.

Migraine is the second leading cause of global disability,<sup>1</sup> and the leading cause of disability among young women.<sup>2</sup> Yet those with these frequently disabling conditions do not have access to the equitable care and rights they deserve. Quality medical care can be hard to find due to a shortage of certified headache specialists in our country, and research funding from the National Institutes of Health (NIH) for migraine and headache disorders has the lowest allocation relative to the prevalence and economic burden of these conditions.<sup>3</sup>

## RCDC FUNDING VS. US DALYS



## IMPACT OF HEADACHE DISORDERS

### INDIGENOUS COMMUNITIES

have the highest prevalence of disabling headache.<sup>4</sup>

Migraine is 3 to 4× more prevalent in **WOMEN**<sup>5</sup>

### AFRICAN AMERICAN AND HISPANIC

patients are respectively 25% and 50% less likely to be diagnosed with migraine compared to white patients, even though their prevalence of migraine is roughly equivalent.<sup>6</sup>

## HEADACHE DISORDERS ARE AN ECONOMIC ISSUE

# 3.5 MILLION

Emergency department visits per year in the US.<sup>7</sup>

# 78B

Annual direct and indirect cost of migraine to US companies<sup>8</sup>

<sup>1</sup> <http://www.who.org>  
<sup>2</sup> <https://doi.org/10.1186/s12916-020-01208-0>  
<sup>3</sup> <https://doi.org/10.1186/s12916-020-01208-0>  
<sup>4</sup> <https://doi.org/10.1186/s12916-020-01208-0>  
<sup>5</sup> <https://doi.org/10.1186/s12916-020-01208-0>  
<sup>6</sup> <https://doi.org/10.1186/s12916-020-01208-0>  
<sup>7</sup> <https://doi.org/10.1186/s12916-020-01208-0>  
<sup>8</sup> <https://doi.org/10.1186/s12916-020-01208-0>