January 8, 2023

The Honorable Joe Biden & Dr. Jill Biden
President & First Lady of the United States of America
Dr. Carolyn Mazure
White House Gender Policy Council
The White House
1600 Pennsylvania Avenue, N.W.
Washington, DC 20500

Dear Mr. President, Dr. Biden, and Dr. Mazure,

The Alliance for Headache Disorders Advocacy (AHDA) was thrilled to see the announcement regarding the creation of the White House Women's Health Research Initiative. We thank you for taking this important step forward in addressing the disparate health experiences of women in America by addressing and providing concrete recommendations on the lack of research for conditions that disproportionately impact women. In line with this vital mission, we recommend that the Initiative keep at the forefront of its mind the tens of millions of American women who live with migraine and other headache disorders, including neuropathic facial pain. The AHDA is a non-profit umbrella of fifteen organizations, uniting headache advocates nationwide to secure equitable policies for those impacted by headache disorders. Along with the undersigned organizations, we describe below some of the many ways in which the issues facing headache disorders patients and researchers dovetail and align with the Initiative's critical mission and provide our recommendations to address these issues. We also humbly ask that the AHDA be invited and included in future meetings and activities of the Women's Health Research Initiative so that we may lend our expertise in the area of the impact of migraine and other headache disorders for women to the Initiative's important work.

The Initiative's report and recommendations should reflect the gaps in current research, the immense funding shortfall for headache disorders, including neuropathic facial pain, when evaluating the disease burden and economic impact of these conditions, and the experiences of women who are encumbered by stigma, lack of access to certified headache specialists, and inequitable provider protocols. Increased funding for migraine and other headache disorders would increase capacity to conduct research with a gendered lens to address the unique experiences of women living with these often disabling conditions.

1) Deficiencies in Current Research

We urge the Initiative to address the massive shortfall in research spending on headache disorders, in line with its mission to identify research gaps in women's health. The Initiative should evaluate its research recommendations based on each condition's impact relative to its current levels of funding. Women make up 52% of the population, yet the NIH investment into Women's health research in 2022 was only 10.8% of its budget.[1] The research gap for headache disorders, conditions which affect women at nearly twice the rate of men, is even more shocking. Headache and migraine disorders affect roughly one out of five women in the U.S. and account for roughly three percent of all emergency department visits annually.[2] Furthermore, migraine is the leading cause of disability for young women, accounting for almost five percent of total lost healthy life years.[3]

And yet, despite the drastic impact of headache disorders, the NIH has provided only $104 million funding for migraine and headache disorders, roughly 0.2% of its total budget.[4] This discrepancy is a striking example of the pattern of neglect and minimization of diseases which primarily affect women. Women are twice as likely as men to be diagnosed with a migraine or headache disorder.[5] The Initiative could make an impressive stride towards its goal of promoting research into women's chronic health conditions by addressing this funding gap.

Headache disorders researchers acutely feel the effects of this shortage; the current paradigm impedes efforts to develop new treatments and leaves pressing questions unresolved. The consequences stretch to tens of millions of women and encompass a vast range of disease states. For example, while some risk factors for migraine are understood, further research into the role of hormones, genetic factors, metabolic disorders, and psychological factors are needed

---

[1] Kerry Smith, *Women's Health Research Lacks The Funding - These Charts Show How*, Nature (2023) https://www.nature.com/immersive/d41586-023-01475-2/index.html.

[2] Rebecca Burch et. al., *The Prevalence and Impact of Migraine and Severe Headache in the United States: Figures and Trends From Government Health Studies.*

[3] T.J. Steiner et al., *Migraine Remains Second Among the World's Causes of Global Disability, and First Among Young Women,* 21, The J. of Headache and Pain, 137 (2020) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7708887/pdf/10194_2020_Article_1208.pdf.

[4] NIH REPORT, *Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)*, (Mar. 31, 2023), https://report.nih.gov/funding/categorical-spending#/.

[5] *Headache Diseases Statistics Guide*, CHAMP.

to open new insights into prevention and develop new strategies for management.[6] Studies have found that patients of cluster headaches, particularly women, have higher rates of multimorbidity, especially for mental health and cardiovascular conditions.[7] More research into the causes of this incongruity could help clinicians develop particularized treatment plans for such high risk patients. Posttraumatic headache, the most common secondary headache disorder, remains poorly understood and studies are needed to find specific treatments.[8] More recently, headaches have emerged as one of the most common symptoms of Long COVID, affecting millions of people, yet receiving little attention. Currently, headaches in Long COVID patients are treated based only on recommendations for other headache disorders and specialized research is urgently needed to develop best treatment practices.[9] These and other unanswered questions lead to suboptimal treatment for far too many women in the United States. The Initiative has the opportunity to help close these glaring gaps, aid in advancing new treatments and diagnostic protocols, and address the pain and disability that these women experience. **We therefore ask the Initiative to recommend increased research funding for migraine and headache disorders to further its goal of addressing evidence gaps in chronic debilitating conditions in women.**

2) Burden of Disease and Economic Impact

We further ask the Initiative to give appropriate weight to the substantial disease burden and economic impact which headache disorders impose, relative to their current levels of funding. Healthcare research does not only alleviate patients' pain and improve their quality of life; it contributes to economic savings which benefit patients, employers, and the United States as a whole. Headache and migraine disorders most commonly affect working age people, contributing to days of missed work and low employee productivity. Studies show that access to education on these issues, coupled with initiatives designed to raise awareness, decreases the

---

[6] Parastoo Amiri et al., *Migraine: A Review on Its History, Global Epidemiology, Risk Factors, and Comorbidities*, 12, Frontiers in Neurology, Feb. 2022, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8904749/pdf/fneur-12-800605.pdf.

[7] Caroline Rans et al., *Multimorbidity and Sickness Absence/Disability Pension in Patients With Cluster Headaches*, 100, Neurology, e1083 (2023), https://n.neurology.org/content/neurology/100/10/e1083.full.pdf.

[8] Morgan Heinzelmann et al., *Posttraumatic Headache*, 42, Seminars in Neurology, 428 (2022), https://pubmed.ncbi.nlm.nih.gov/36041477/.

[9] Claudio Tana et al., *Long COVID Headache*, 23, The J. of Headache and Pain, 93 (2022), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9340759/pdf/10194_2022_Article_1450.pdf.

number of workdays missed due to migraine, and improves productivity.[10] Migraine alone accounts for the second most years lived with disability and the WHO considers it as disabling as quadriplegia.[11] This condition alone drains the U.S. economy of more than $20 billion annually.[12] Clearly, the impact of migraine and other headache disorders does not stop at the pain and disability which patients experience; It balloons into far-reaching economic consequences, forcing employees away from work and limiting business productivity.

The gap in headache disorders funding not only impairs the health of patients, but the wellbeing of the economy as a whole. As previously discussed, the NIH projects to allocate only 0.2% of its 2023 budget to headache disorders research. The numbers are even more concerning upon closer examination. According to the Report on NIH Funding vs. Global Burden of Disease, migraine research consistently receives the least funding relative to burden amongst all the nation's highest burden diseases.[13] In 2016, migraine contributed 21.6% of the total U.S. burden attributable to the diseases that comprise the NINDS portfolio, but migraine research constituted just 0.6% of the NINDS extramural research funding.[14] The results of this imbalance are predictable; headache disorders continue to force employees out of work. Moreover, faced with the prospect of losing their jobs due to absenteeism, employees are forced to hide their symptoms, attend work while unwell, and consequently work less productively. This "presenteeism" contributes the most to lost productivity from headache disorders. Migraine, the second-leading cause of workplace presenteeism at 16.2% of the total productivity loss, accounts for as much as 4% of the total economic loss due to presenteeism in the United States.[15]

Women between the ages of eighteen and forty-four are most impacted by migraine, with 18.7% of Americans reporting migraine, the largest percentage of any age group.[16] Because those ages are the prime work and childbearing years, the lack of treatment options and efficacy can be catastrophic. Women with migraine may be effectively disabled by their condition, holding them

---

[10] Olivia Begasse de Dhaem, *Migraines Are a Serious Problem. Employers Can Help.,* Harvard Business Review, (Feb. 24, 2021), https://hbr.org/2021/02/migraines-are-a-serious-problem-employers-can-help.

[11] GBD 2017 Disease and Injury Incidence and Prevalence Collaborators, *Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017,* 392, Lancet, 1789, 1816 (2017)

[12] Goldfarb, *Economic Impact of Migraines*, Am. J. of Managed Care, (Mar. 31, 2020), https://www.ajmc.com/view/economic-impact-of-migraines.

[13] Robert E. Shapiro, *What Will it Take to Move the Needle for Headache Disorders*, 60, Headache, 2059, 2068 (2020).

[14] *Id.* at 2069.

[15] *Id.* at 2064.

[16] *Headache Diseases Statistics Guide*, CHAMP

back from advancement in their careers, or even completely removing them from the workforce.[17] This forced removal from the workforce and the reduced chance of advancement and promotion contribute to a lack of women in leadership positions, and increases the gender wage gap.[18] Further, some women who have their condition effectively managed by medication may still find themselves disabled if they choose to have children, as they may be unable to take their medication safely due to the lack of research around the safety and efficacy of migraine medications during childbirth and lactation and are likely to experience a return of severe symptoms.

These numbers indicate a large-scale problem which has yet to be addressed, but also present an opportunity for the Initiative to maximize its impact. By appropriately factoring the burden of disease and the economic cost into its analysis, the Initiative can create recommendations which will benefit not just patients, researchers, and providers, but the economy of the United States.

3) Increased Funding for Headache Disorders Would Increase Capacity to Conduct Research With A Gender/Sex Lens

By addressing the aforementioned gap in burden of disease and overall research funding, we could greatly increase capacity and focus to conduct more specific research on migraine and other headache disorders with a gender/sex lens, as well as, improve overall research by ensuring all research by including more diversity in studies and trials.

Researchers have already identified gaps that should be addressed when looking at the impact of headache disorders for women.[19] Their recommendations have determined that we must first address that female animals are not often included at equal levels as male animals in basic science studies. We must also incorporate different age groups to better reflect migraine

---

[17] *Impact of Migraine on Women*, MIGRAINE AT WORK, https://migraineatwork.org/infographics_migrain/the-migraine-truth-impact-of-migraine-on-women/

[18] *Why is Migraine a Diversity, Equity, and Inclusion (DEI) Issue?*, MIGRAINE AT WORK, https://migraineatwork.org/articles_migraine/why-is-migraine-a-diversity-equity-and-inclusion-dei-issue/#:~:text=disabilities%2C%20and%20veterans.-,Women,or%20more%20days%20per%20month

[19] See Schroeder RA, Brandes J, Buse DC, Calhoun A, Eikermann-Haerter K, Golden K, Halker R, Kempner J, Maleki N, Moriarty M, Pavlovic J, Shapiro RE, Starling A, Young WB, Nebel RA. Sex and Gender Differences in Migraine-Evaluating Knowledge Gaps. J Womens Health (Larchmt). 2018 Aug;27(8):965-973. doi: 10.1089/jwh.2018.7274. PMID: 30129895 and Al-Hassany L, Haas J, Piccininni M, Kurth T, Maassen Van Den Brink A, Rohmann JL. Giving Researchers a Headache - Sex and Gender Differences in Migraine. Front Neurol. 2020 Oct 22;11:549038. doi: 10.3389/fneur.2020.549038. PMID: 33192977; PMCID: PMC7642465.

phenotypes and consider hormonal effects throughout the lifespan.[20] A recent New York Times article highlighted the very issue of hormones as a possible cause of migraine's increased prevalence for women. More research to broaden understanding of the etiology, presentation, treatment, and care for migraine, emphasizing the role of sex hormones in the brain is critical.

Other recommendations include addressing deficiencies in understanding sex differences in response to current interventions, especially in pregnant or lactating women, and exploring treatment options for specific age groups and comorbidities. We can and should also investigate gender differences in migraine by considering dimensions of violence, trauma, precarity, obesity, and education, aiming to understand diverse contributors to migraine for more robust treatment options. Finally we must also evaluate stigma by gathering more data on employer and general population views on migraine, developing social frames to improve support, enhancing patient-reported outcomes, and increasing studies on societal views of migraine to design evidence-based initiatives addressing knowledge gaps and overcoming stigma.

4) Patient Perspective

We must address the multitude of significant barriers to care that women endure to ensure adequate treatments for conditions which disproportionately, exclusively, or differently affect women. These hurdles include the costs of treatment, the difficulty in reaching a diagnosis, and inequitable policies and practices. They are especially large for those who experience migraine and other headache disorders, conditions more underfunded than even most others that disparately affect women.[21]

Costs

Medication and treatment costs can be a significant barrier to satisfactory healthcare for patients experiencing chronic conditions. Barely regulated predatory insurance schemes like copay accumulators and step therapy mandates disrupt treatment plans and force patients to contend with high costs. Further, because of a lack of research and development, many chronic conditions do not have many effective or safe options for treatment. Until 2018, the most recent

---

[20] Why Do Women Get More Headaches Than Men? Dec. 5, 2023 Melinda Wenner Moyer. https://www.nytimes.com/2023/12/05/well/live/headaches-women-causes.html

[21] *Report on NIH Funding vs. Global Burden of Disease*, NIH Report, https://report.nih.gov/report-nih-funding-vs-global-burden-disease

development in the treatment of migraine attacks was a category of drugs called Triptans, a drug used to treat epilepsy which was applied to treat migraine attacks around 1990.[22] Triptans are effective at aborting migraine attacks in only 50%-60% of patients, and they may even have the adverse effect of increasing frequency and severity of the attacks, even for those who find it effective.[23] Before Triptans were developed, the main treatment available was taking a family of drugs which contained microdoses of the active ingredient, ergotamine, which is a fungus known to cause constriction of the blood vessels.[24] Both ergotamines and triptans were used to treat migraine attacks because of their ability to constrict blood vessels.[25] Triptans were better at avoiding dangerous constriction, and replaced ergotamines for that reason. However, as early as 1990, studies showed that there is *no correlation* between the pain of a migraine attack and dilated blood vessels, and that constricting the blood vessels would then be mostly ineffective at treating the symptoms.[26] However, with a lack of alternative treatments, Triptans continued to be prescribed, and are still the leading prescription drug offered for migraine treatment.[27] In 2018, calcitonin gene-related peptide inhibitors were approved by the Food and Drug Administration (FDA) as a new type of treatment for those with migraine.[28] These drugs work entirely differently to the older drugs, thanks to a new-but still incomplete-understanding of how and why migraine occurs.[29] Despite this exciting milestone, there are still huge steps that must be taken before treatment can be considered effective or successful for those experiencing migraine. Firstly, the new drugs are more effective than previous preventative drugs, but they still only show signs of reducing migraine attacks by one to two a month.[30] While that is an incredible success rate compared to the results of other preventative drugs, it is still far from the relief that patients experiencing migraine need to see. In fact, there has been so little success in the prevention of migraine attacks that a reduction of 50% of the attacks is considered a good

---

[22] Emily Underwood, *FDA just approved the first drug to prevent migraines*, SCIENCE.ORG, https://www.science.org/content/article/will-antibodies-finally-put-end-migraines

[23] *id*

[24] *id*

[25] *id*

[26] *id*

[27] *id*

[28] *FDA approves novel preventive treatment for migraine*, US FOOD AND DRUG ADMINISTRATION, https://www.fda.gov/news-events/press-announcements/fda-approves-novel-preventive-treatment-migraine

[29] *id*

[30] *id*

outcome.[31] To further complicate the use of more effective drugs, many insurance companies are still not covering the costs of the new drugs unless a patient fails on a number of Triptans first, despite the fact that their efficacy is low and their risks are high, because they are more expensive than Triptans.[32]

The research shortage keeps drug and treatment costs high when alternatives are not produced, and step therapy mandates ensure that getting to a newer, more effective drug, requires attempting the older, less effective, yet still expensive, drug. Beyond the financial cost of forcing patients to attempt less effective treatments first, there is also a cost to their short and long-term health. Delaying effective treatment can turn an acute problem into a lifelong struggle. Patients who do not receive effective treatment for episodic migraine can develop chronic migraine, which is less likely to respond to treatment.[33] Repeated and untreated migraine and cluster attacks can also cause other health issues "like photophobia and psychology-related health ailments such as depression, anxiety, and panic disorders" among other conditions like stroke and cardiovascular diseases.[34] The Initiative, then, must focus on reducing prescription drug costs for chronic conditions that have limited and expensive treatment options, and which have the potential to worsen and develop comorbidities when left untreated, like migraine and many other headache conditions. The Initiative could achieve this goal by pushing for more research funding for headache conditions in order to decrease the scarcity and cost of effective treatments.

Difficulty in Reaching a Diagnosis

Women often have difficulty even getting a diagnosis for chronic conditions, in part due to social stigma minimizing women's pain, lack of funding, and overall scarcity of educational resources. These deficiencies bar access to effective, non-invasive diagnostic procedures. Migraine and other headache disorders are not well-understood, and may present differently in

---

[31] Marianna Delussi, et. all, *Failure of preventive treatments in migraine: an observational retrospective study in a tertiary headache center*, BMC NEUROLOGY, https://bmcneurol.biomedcentral.com/articles/10.1186/s12883-020-01839-5

[32] Samantha DiGrande, *The Current Landscape of CGRP Inhibitor Coverage*, AJMC, https://www.ajmc.com/view/the-current-landscape-of-cgrp-inhibitor-coverage

[33] https://pubmed.ncbi.nlm.nih.gov/25672691/#:~:text=Migraine%20is%2C%20essentially%2C%20an%20episodic,result%2C%20develop%20into%20chronic%20migraine

[34] https://www.headpaininstitute.com/the-effects-of-untreated-chronic-migraines/#:~:text=Long%20Term%20Effects%20of%20Untreated%20Chronic%20Migraine&text=Symptoms%20include%20sensory%20problems%20like,coronary%20heart%20disease%20and%20hypertension

different patients, and even in the same patient over different life stages. Thus, recognition and diagnosis prove difficult, and effective treatment inevitably becomes delayed.

The lack of education affects both patients and providers. Neither has appropriate access to public information about conditions which manifest differently, or are more prevalent in women than men. Women of color confront an even more extreme information shortage when it comes to how conditions present for them. These disparities call for ardent advocacy and intersectional representation to effectively integrate symptoms and diagnostic information for women. We ask that the Initiative remain focused on these principles of intersectionality, purpose, and representation by prioritizing funding and research into migraine and other headache conditions, which occur at nearly equal rates in Black, White, and Hispanic women, and at a remarkably higher rate in populations of American Indian descent.[35] In order to ensure that these conditions are given the consideration they need in order for them to be visible to patients and providers of all genders, races, and ethnicities.

Poor education and social stigma around conditions that more commonly, or differently, affect women are cyclical causes and results of each other. Patients and providers alike have inadequate knowledge or experience with many of these conditions. Often, they only know a shadow of the realities of the condition, resulting in minimization of the severity and impact. This mentality leads to a migraine condition being written off as "just a headache", as many are unaware of the symptoms that accompany the severe head pain of a migraine. There are a number of other symptoms which any migraine patient may experience, although they do not necessarily experience all of them. Migraine attacks often occur in stages, with symptoms beginning between a few hours and a few days before the pain starts, and not fully dissipating for one to two days after it ends.[36] Some of the symptoms which may occur within any of the three to four stages someone experiencing a migraine attack may go through include increased sensitivity to physical stimuli like light, sound, and smells; cognitive impairments and difficulty focusing; irregular or amplified mood changes; vision or hearing changes, including loss of vision; nausea and vomiting; physical impairment like weakness and tingling, or even temporary

---

[35] *Headache Diseases Statistics Guide*, CHAMP

[36] *Migraine Signs and Symptoms*, AMERICAN MIGRAINE FOUNDATION, https://americanmigrainefoundation.org/migraine-signs-symptoms/

paralysis, of various parts of the body; and loss of consciousness.[37] Despite these serious effects, the stigma, lack of perceived seriousness of these conditions, and lack of available funding discourages physician specialization in headache medicine.[38] The lack of specialists in turn leads to missed diagnoses, a shortage of well-informed providers, lack of research into prevention, causation and treatment for these often disabling conditions and poor patient outcomes.

The absence of funding for research, equipment, testing, and treatment, as discussed above, all contribute to poor education, meaning that both providers and patients are unaware of the true symptoms of migraine and headache conditions, as they have learned incorrect or incomplete information from a variety of public and private sources. This causes difficulty in diagnosing or recognizing migraine, among other serious conditions. Poor education is likely both the cause and effect of a social stigma based on the perception of women's pain and illness. Migraine and headache conditions affect women at twice the rate of men, and tired stereotypes depicting women as sensitive, emotional, and unable to withstand pain factor into the discrepancies in treatment quality.[39] The stigma affects the quality of care as well as the quality of patients' lives and mental health. Providers who believe in or rely on this stigma often fail to recognize important symptoms in a patient as being related to migraine. For example, the fact that migraine attacks tend to cluster around a patient's menstrual cycle may lead a provider to believe that the head pain and associated symptoms are in some way caused by the period itself and the hormonal changes, rather than the root cause of a neurological condition (*id*). This can result in unnecessary and unproductive testing, wasting money, time, and delaying necessary diagnosis and treatment. The patient's mental health is also impacted, as they may believe that what they are experiencing is normal, and they may be ashamed or embarrassed that they cannot just 'push through' the pain. They may stop seeking out care, or may never seek it out in the first place. The result of this stigma is represented by the 40-50% of those who experience migraine who are undiagnosed.[40]

---

[37] *Safeguard Access to Special Education Services for Children with Headache Disorders*, ALLIANCE FOR HEADACHE DISORDERS ADVOCACY, https://allianceforheadacheadvocacy.org/wp-content/uploads/FINAL-Headache-Disorders-_-Children-.pdf

[38] Lauren Sharkey, *Why Don't We Know More About Migraines?*, FUTURE, https://www.bbc.com/future/article/20180702-the-sexist-history-of-migraine-may-affect-research-today

[39] Jennifer Billock, *Pain Bias: The Health Inequality Rarely Discussed*, BBC, https://www.bbc.com/future/article/20180518-the-inequality-in-how-women-are-treated-for-pain

[40] *Headache Diseases Statistics Guide*, CHAMP

Because of the harm that delayed or absent diagnoses can have on patients, and the implicit gender/sex bias in the lack of education available, we urge the Initiative to focus efforts on prioritizing and funding education for both the public and medical providers in an intersectional and inclusive way, by focusing a portion of research on migraine and other headache disorders.

Inequitable Policies and Practices

Inequitable policies and practices result in inequitable treatments. The Initiative must focus on policies that impede its goal of providing equitable treatment, and must look for alternatives and optimal resolutions for each and every patient. Equitable treatment involves equal funding and access in research, prevention, and treatment of conditions which affect underrepresented communities, and which have been previously underfunded despite the serious burden they put on patients' lives and the economy alike. Inequitable practices affect the access and quality of treatments, exacerbating all of the aforementioned problems. The Initiative should empower women whose experiences with chronic conditions have been ignored or minimized, and give them a chance to finally be included in research and education.

Inequitable policies include a lack of research into medication and treatments for patients who are pregnant and lactating, motivated by a desire to protect those patients and their unborn children. As a cautionary measure, patients who are pregnant or lactating have been excluded from research studies to avoid the possibility of unknown harm.[41] However, this exclusion has resulted in the unintended consequence of a near-complete absence of research on the dosing and effects of various medications on pregnant and lactating patients (*id*). Many patients either stop taking their medications entirely while pregnant and lactating, or choose to continue taking it, with no idea whether they are using the correct dosage and whether such medication is safe to take (*id*). Often, they could be taking the normal dose, but doctors advise against it in an abundance of caution.[42] In fact, some physicians will tell patients that medications are unsafe to take during pregnancy or lactation, despite research supporting safety, because of either personal bias or a refusal to take any risk in prescribing medication which they're not familiar enough

---

[41] *About the InfantRisk Center*, INFANT RISK CENTER, https://infantrisk.com/about-infantrisk-center

[42] Emily Anthes, *Is There a Case for Testing Drugs on Pregnant Women?,* THE WIRE, https://thewire.in/gender/is-there-a-case-for-testing-drugs-on-pregnant-women

with.[43] This issue is especially harmful for those experiencing conditions which are affected by hormone cycles, which are altered dramatically during pregnancy and lactation. Migraine conditions in women are affected by hormonal cycles and changes, with symptoms and frequency of attacks changing and attacks becoming more frequent during hormonal changes. As a result, many patients experience increased symptoms and attacks during pregnancy[44] and they experience it while being unable to take their medications safely to manage their symptoms[45]. For a significant portion of time, patients are unable to treat their conditions, all while dealing with the general stress a pregnancy puts on a patient's body.

Another life stage that is under-researched is children and adolescents with migraine and headache conditions.[46] Migraine and headache conditions are experienced less frequently by youth than adults, at a rate of 3% in young children and 20% in adolescents, and research into treating children with these conditions is even less thorough than research for adults (*id*). This leaves children experiencing these symptoms in the dark when it comes to medication and treatment options, and how to manage their conditions (*id*). There is also little integration of migraine and headache conditions into disability statutes in relation to education, leaving children with a variety of difficulties in accessing a normal educational experience while experiencing their symptoms and attacks.[47]

Due to the burden of migraine and headache disorders and the effect that various life stages affect the severity of these conditions, there must be an effort to increase research into these conditions, especially during their various life stages.

Conclusion

Migraine and headache disorders are underfunded and overlooked; costly and pervasive; stigmatized and ignored. They impact one in five women, occur at various life stages, and disproportionately affect the most vulnerable. More research in this area can ensure more

---

[43] Adrienne Einarson and Gideon Koren, *Prescribing Antidepressants to Pregnant Women*, NATIONAL LIBRARY OF MEDICINE, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2234608/

[44] Punam Sachdeva et. al, *Drug Use in Pregnancy; A Point to Ponder*, NATIONAL LIBRARY OF MEDICINE, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2810038/

[45] *About the InfantRisk Center*, INFANT RISK CENTER, https://infantrisk.com/about-infantrisk-center

[46] Laura Papetti, *Migraine treatment in developmental age: guidelines update*, BMC, https://thejournalofheadacheandpain.biomedcentral.com/articles/10.1007/s10194-010-0205-4

[47] *Safeguard Access to Special Education Services for Children with Headache Disorders*, ALLIANCE FOR HEADACHE DISORDERS ADVOCACY, https://allianceforheadacheadvocacy.org/wp-content/uploads/FINAL-Headache-Disorders-_-Children-.pdf

efficient, effective, and affordable avenues of treatment for women of all races, ages, income levels, and medical statuses. As the Initiative deliberates on a framework to approach research gaps for women's health, we urge it to include the millions who experience the pain and disability of headache disorders.

As an organization, the AHDA commits to working to ensure our own work and advocacy remains focused on the disparate impact of headache disorders on women. We welcome the opportunity to provide any additional help or support to the Initiative in the fulfillment of its vital mission. Thank you for your commitment to this important issue and for the opportunity to provide recommendations.

With Appreciation and Enthusiasm,

Alliance for Headache Disorders Advocacy
American Academy of Neurology
American Migraine Foundation
Association of Migraine Disorders
Chronic Migraine Awareness, Inc.
Cyclical Vomiting Syndrome Association
ClusterBusters
Coalition for Headache and Migraine Patients
Danielle Byron Henry Migraine Foundation
Facial Pain Association
Global Healthy Living Foundation
Headache Cooperative of the Northeast (HCNE)
Headache Cooperative of the Pacific
Migraine at School
Migraine World Summit
Miles for Migraine
National Headache Foundation
Southern Headache Society
Spinal CSF Leak Foundation
U.S. Pain Foundation