April 10, 2025

The Honorable Donald J. Trump
President of the United States
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

The Honorable Robert F. Kennedy Jr.
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Dear President Trump and Secretary Kennedy**,**

On behalf of the undersigned organizations, we commend the *Make America Healthy Again* Commission's focus on chronic health conditions in children, a critical area that has long been overlooked in public health policy. In alignment with the Commission's mission, we urge a focused examination of migraine and other headache disorders, which profoundly impact the pediatric population and represent some of the most disabling and under-resourced chronic conditions affecting children and adolescents.

The Alliance for Headache Disorders Advocacy (AHDA) is a national nonprofit umbrella organization composed of 16 leading headache and migraine advocacy groups. We work together to advance public policies and research investments for those Americans impacted by headache disorders, a major neglected public health concern.

Pediatric Headache Disorders: A Silent Public Health Crisis

Headache disorders are among the most common chronic neurological conditions in children and adolescents, yet they remain largely underdiagnosed, undertreated, and under-researched. An estimated 14 million (17%) of American children and adolescents experience headache disorders, including migraine, tension-type headache, cluster headache, New Daily Persistent Headache (i.e., sudden onset unremitting headache), and post-traumatic

headache highlighting the urgent need for increased research and intervention.[1] [2] Migraine is a childhood-onset disorder with an average age of onset between 8-9 years old with the peak of incident cases of migraine being 10-14 years old.[3] Moreover, childhood migraine can present with unexpected symptoms, such as inconsolable crying in infants (infantile colic), or recurrent abdominal pain without headache in early childhood.

Chronic Migraine in Children

Chronic migraine is the most prevalent disabling form of this disorder, including 15 days with headache per month extending for more than three months. Nearly a million school-age children and adolescents currently live with chronic migraine.

Children with chronic migraine may experience recurrent attacks of pain, sensory disturbances, nausea, dizziness, and cognitive dysfunction, including impairments of memory, concentration, and language.[4] They are twice as likely to be absent from school as their peers without migraine[5], and they are at risk for lower educational attainment and reduced future workforce participation.[6] Persistent pain disrupts sleep and overall quality of life. Children with severe headache disorders frequently report feelings of isolation, frustration, and depression as they struggle to participate in school, social activities, and even routine family life. The unpredictability of attacks and the lack of effective treatment options may lead to intractable alterations in pain processing, long-term morbidity, and greater health care costs.[7,8] After puberty, migraine becomes 2-3 times more prevalent in women than in men. The high prevalence and protracted course of the disease makes it the [first] most disabling condition (measured in years lived with disability or YLD) in the world for women between the ages of 15-49 years old. Migraine is the second most disabling condition across all age groups and genders.[9]

Moreover, chronic migraine often persists into adulthood and may become a lifelong challenge with increased risk for profound despair and suicidality. [5] Migraine is the 7th leading cause of years lived with disability in the US.[10]

Given the diverse spectrum of childhood headache disorders, we urge the Commission to adopt a comprehensive approach to addressing pediatric headache disorders.

Risk of Chronification, Long-Term Disability and Mental Health Concerns

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[1] Onofri A, Pensato U, Rosignoli C, et al. Primary headache epidemiology in children and adolescents: a systematic review and meta-analysis. *J Headache Pain*. 2023;24(8). doi:10.1186/s10194-023-01541-0.

[2] Lateef TM, Merikangas KR, He J, Kalaydjian A, Khoromi S, Knight E, Nelson KB. Headache in a national sample of American children: prevalence and comorbidity. *J Child Neurol*. 2009;24(5):536-543. doi:10.1177/0883073808327831.

[3] (Safiri et al, 2022) https://pubmed.ncbi.nlm.nih.gov/34001771/

[4] Juang KD, Wang SJ, Fuh JL. Comorbidity of depressive and anxiety disorders in chronic daily headache and its subtypes. *Headache*. 2000;40(10):818-823. doi:10.1046/j.1526-4610.2000.00148.x.

[5] Martin, V.T., Fassler, C.S., Brunst, K.J. *et al.* Migraine and its association with pubertal maturation and behavioral traits among adolescent girls. *Acta Neurol Belg* **123**, 1279–1289 (2023). https://doi.org/10.1007/s13760-022-02161-2

[6] ikorski C, Mavromanoli AC, Manji K, Behzad D, Kreatsoulas C. Adverse Childhood Experiences and Primary Headache Disorders: A Systematic Review, Meta-analysis, and Application of a Biological Theory. Neurology. 2023 Nov 21;101(21):e2151-e2161. doi: 10.1212/WNL.0000000000207910.

7 Juang KD, Wang SJ, Fuh JL. Comorbidity of depressive and anxiety disorders in chronic daily headache and its subtypes. *Headache*. 2000;40(10):818-823. doi:10.1046/j.1526-4610.2000.00148.x.

8 zge A, Yalin OÖ. Chronic Migraine in Children and Adolescents. Curr Pain Headache Rep. 2016 Feb;20(2):14. doi: 10.1007/s11916-016-0538-z. PMID: 26875191.

[9] (Steiner et al, 2020).
https://thejournalofheadacheandpain.biomedcentral.com/articles/10.1186/s10194-020-01208-0

[10] http://ihmeuw.org/6uvs

Migraine and other headache disorders are leading contributors to chronic absenteeism in schools, defined as missing 10% or more school days in a year.[11] Children with migraine:

- Are twice as likely to miss school compared to their peers.[12]
- Experience impaired cognitive function, including difficulties with memory, concentration, and language processing.[13]
- Face disruptions to their academic trajectory, increasing their risk of lower educational attainment and future employment instability.[14]
- Youth with migraine experience lower quality of life scores.[15]

Children with frequent headache attacks are at a heightened risk of these conditions persisting into adulthood, leading to significant disability, reduced workforce participation, and increased healthcare costs. There are a reduced number of treatment options for children as compared to the adult population and without adequate treatment and intervention, headache disorders in children can worsen over time, resulting in permanent alterations in pain processing, increased central sensitization, and greater long-term morbidity.[16]

Studies indicate that the overall prevalence of migraine is influenced approximately equally by genetic and environmental factors, but the *progression* of monthly headache frequency from episodic to chronic migraine (i.e. “chronification”), is almost entirely mediated by non-genetic factors.[17] In other words, the experiences of children are the major causes of chronic migraine and therefore opportunities must exist to intervene to prevent this disease.

Reported risk factors for migraine chronification include age[18], sex[19] and puberty, adverse childhood experiences[20] (encompassing a spectrum from neglect to head trauma), and use of pain-relieving medications 15 or more days per month, a condition termed rebound headache or medication overuse headache. Approximately a million (3.5%) American adolescents experience 15 or more headache days per month (including chronic migraine), and a quarter of these adolescents have rebound headache.

Children and adolescents living with chronic headache disorders, including migraine, experience profound mental and emotional distress due to the relentless nature of their pain.

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[11] U.S. Department of Education. *Chronic Absenteeism.* Accessed February 19, 2025. https://www.ed.gov/teaching-and-administration/supporting-students/chronic-absenteeism

[12] Turner SB, Szperka CL, Hershey AD, Law EF, Palermo TM, Groenewald CB. Association of Headache With School Functioning Among Children and Adolescents in the United States. JAMA Pediatr. 2021 May 1;175(5):522-524. doi: 10.1001/jamapediatrics.2020.5680. PMID: 33523093; PMCID: PMC7851753.

[13] Costa-Silva MA, Prado ACA, de Souza LC, Gomez RS, Teixeira AL. Cognitive functioning in adolescents with migraine. Dement Neuropsychol. 2016 Jan-Mar;10(1):47-51. doi: 10.1590/S1980-57642016DN10100009. PMID: 29213431; PMCID: PMC5674914.

[14] Rocha-Filho PA, Santos PV. Headaches, quality of life, and academic performance in schoolchildren and adolescents. Headache. 2014 Jul-Aug;54(7):1194-202. doi: 10.1111/head.12394. Epub 2014 Jun 4. PMID: 24898739.

[15] (Powers et al, 2003) https://pubmed.ncbi.nlm.nih.gov/12837897/

[16] Arruda MA, Bigal ME. Behavioral and emotional symptoms and primary headaches in children: a population-based study. *Cephalalgia*. 2012;32(14):1093-1100. doi:10.1177/0333102412454226.

[17] Chalmer, M.A., Rasmussen, A.H., , , Kogelman, L.J.A., Olesen, J. and Hansen, T.F. (2021), Chronic migraine: Genetics or environment?. Eur J Neurol, 28: 1726-1736. https://doi.org/10.1111/ene.14724

[18] Özge A, Yalin OÖ. Chronic Migraine in Children and Adolescents. Curr Pain Headache Rep. 2016 Feb;20(2):14. doi: 10.1007/s11916-016-0538-z. PMID: 26875191.

[19] Martin, V.T., Fassler, C.S., Brunst, K.J. *et al.* Migraine and its association with pubertal maturation and behavioral traits among adolescent girls. *Acta Neurol Belg* **123**, 1279–1289 (2023). https://doi.org/10.1007/s13760-022-02161-2

[20] Sikorski C, Mavromanoli AC, Manji K, Behzad D, Kreatsoulas C. Adverse Childhood Experiences and Primary Headache Disorders: A Systematic Review, Meta-analysis, and Application of a Biological Theory. Neurology. 2023 Nov 21;101(21):e2151-e2161. doi: 10.1212/WNL.0000000000207910.

Unlike acute illnesses, which resolve with time, chronic headache disorders often persist **f**or years, if not a lifetime, creating a sense of hopelessness, isolation, and despair. Research indicates that children with chronic migraine or frequent headache disorders are at a significantly increased risk of suicidal ideation and suicide attempts.[21] This risk increases with chronicity and pain severity, underscoring the urgent need for better pain management strategies and expanded treatment options for children.[22]

The impact of untreated or poorly managed chronic pain in children extends far beyond physical suffering. Persistent pain disrupts sleep, cognitive function, social interactions, and overall quality of life, leading to increased psychological distress. Children with severe headache disorders frequently report feelings of isolation, frustration, and depression as they struggle to participate in school, social activities, and even routine family life. The unpredictability of attacks and the lack of effective treatment options further exacerbate this distress.

Given these findings, it is critical that the Commission prioritize investment in pediatric headache research, expanding both pharmacological and non-pharmacological treatment options to reduce the burden of chronic pain in children. Without adequate intervention, these disorders will continue to contribute to preventable suffering and increased suicide risk in young people.

Call for Increased Investment and Policy Action

To address the significant burden of pediatric headache disorders, we urge the Commission to:

1. **Prioritize federal funding of translational research into pediatric migraine and headache disorders.**
    a. In FY2023, only ~$4 million of NIH research was focused on pediatric migraine.[23] Research is urgently needed to investigate genetic, hormonal, environmental, medication-related, psychosocial, and neurobiological mechanisms underlying the pathophysiology and chronification of headache disorders in children, including menstrual migraine, a highly prevalent yet under-researched condition requires focused studies on hormonal and non-hormonal treatment options. For example, new NIH Funding Opportunities dedicated to these questions should be issued within the NIH Helping End Addiction Long-Term (HEAL) Initiative.
2. **Develop pediatric-specific clinical trials and treatment guidelines and prioritize the funding of pre-clinical and clinical research directed toward discovery and development of novel therapies.**

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[21] Juang KD, Wang SJ, Fuh JL. Comorbidity of depressive and anxiety disorders in chronic daily headache and its subtypes. *Headache*. 2000;40(10):818-823. doi:10.1046/j.1526-4610.2000.00148.x.
[22] Friedman LE, Zhong QY, Gelaye B, Williams MA, Peterlin BL. Association between migraine and suicidal behaviors: a nationwide study in the USA. *Headache*. 2018;58(3):371-380. doi:10.1111/head.13226.
[23] **https://report.nih.gov/funding/categorical-spending#/**

    a. Current FDA-approved treatments are largely designed for adults, necessitating new research into pediatric-specific medications, and the safety and dosing of existing adult treatment options for the pediatric population.

3. **Ensure inclusion of migraine in all future discussions on pediatric chronic disease.**
4. **Expand research into, and access to, evidence-based non-pharmacological and device-based treatments**.
    a. More research is needed into other non-pharmacological treatment options for children including neuromodulation devices and behavioral therapies, alongside improved insurance coverage for these treatment options.
5. **Safeguard and reinforce statutory protections for students living and learning with the impairments of headache disorders.**
    a. Despite these challenges, headache disorders are not explicitly included under the Individuals with Disabilities Education Act (IDEA), which may leave children without the educational accommodations they need due to school district misinterpretations of the law.[24] Encouragingly, the Department of Education issued guidance affirming that students with migraine are entitled to Section 504 Plan accommodations and potentially under IDEA, a critical step in ensuring educational opportunities and supports for children living with migraine.[25] However, in light of recent legal challenges [RS1] to Section 504, it is imperative to safeguard and reinforce the rights of students living with headache disorders, and to secure the support necessary for their educational success.

By taking these steps, we can improve educational outcomes, prevent lifelong disability, and reduce the significant personal and economic burdens of these conditions.

The President's Executive Order of February 13, 2025 calls for focused measures to mitigate the crisis of childhood chronic diseases, particularly as these diseases may be associated with the "*over-reliance on medication*". Therefore, disabling childhood chronic headache disorders, particularly including rebound headache, are indisputably within the Commission's ambit and we strongly urge the Commission to prioritize resources for these diseases within the *Make our Children Healthy Again Strategy*.

We appreciate your leadership and stand ready to collaborate to advance the health and well-being of children living with debilitating headache disorders. Given our extensive expertise in this area, we respectfully request that AHDA be included in the *Make America Healthy Again Commission*'s work and future discussions to ensure that migraine and headache disorders are appropriately addressed within pediatric health policy.

With Appreciation,

Alliance for Headache Disorders Advocacy

Alliance for Women's Health and Prevention

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[24] S.P. v. Fairview Sch. Dist., Civil Action No. 13-96E (W.D. Pa. Sep. 30, 2014)

[25] U.S. Department of Education, Office for Civil Rights**.** *Fact Sheet: Migraine and Section 504 of the Rehabilitation Act of 1973.* December 2024. Accessed February 19, 2025.. https://www.ed.gov/media/document/ocr-factsheet-migraine-108821.pdf

American Academy of Neurology

American Headache Society

Chronic Migraine Awareness, Inc.

Cyclic Vomiting Syndrome Association

Danielle Byron Henry Migraine Foundation

Headache Cooperative of the Pacific

Migraine at School

Miles for Migraine

MigraineNation

National Headache Foundation

NDPHaware, Inc

The Headache & Migraine Policy Forum

US Pain Foundation