



# Advocacy for Migraine Relief: Strategic Planning to Eliminate the Burden

Teshamae S. Monteith<sup>1</sup>

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## Abstract

**Purpose of Review** The goal of this article is to describe migraine advocacy as an essential means to advance the field of headache medicine. Special attention is spent outlining advocacy initiatives and priorities.

**Recent Findings** There is little written about “migraine advocacy” in the literature. However, organizational and expert priorities include advocating for policies that improve systems of care, telemedicine, education, research, and public initiatives that reduce health disparities and the stigma of migraine.

**Summary** This summary includes the latest advocacy efforts to support policies that may improve migraine care, strengthen the field of headache medicine, and eliminate the burden of migraine.

**Keywords** Migraine · Advocacy · Headache · Telemedicine · Health equity · COVID-19 pandemic

## Introduction

Migraine is a chronic neurological illness with recurrent episodes of moderate to severe headaches, sensory disturbances, gastrointestinal symptoms, and transient neurological symptoms [1]. Migraine is one of the most common brain disorders in the world, occurring in one billion people worldwide. Yet, the condition is often under-recognized, under-diagnosed, and under-treated [2, 3]. As a major public health problem, migraine requires advocacy on multiple levels to ensure optimal standards of care, to enhance quality of life, and to reduce the societal burden (Fig. 1).

Advocacy is the act or process of supporting a cause or proposal to effect change and influence decisions. According to Hubinette et al., “in the medical profession, activities related to ensuring access to care, navigating the system, mobilizing resources, addressing health inequities, influencing health policy and creating system change are known as health advocacy [4]”. There is a tremendous need

for migraine advocacy to advance the field of headache medicine.

## Migraine Stigma and Awareness

### Reframing Migraine

Migraine is a highly stigmatized disorder, perpetuated by many cultural stereotypes and biases [5]. Migraine was once thought to be driven by psychiatric alterations and neurotic traits [6]. For example, migraine with visual aura was linked to hysteria, and termed migraine ophthalmique hystérique by Joseph François Felix Babinski in 1890 [7]. Historically, some interventions included advising women to have hysterectomies for hysteria or get married. By the 1990s, migraine was taken more seriously. This decade marked the development and widespread adoption of triptans, FDA-approved serotonin receptor agonists, to treat migraine attacks. The emergence of triptans led to a fundamental shift in the recognition of migraine as a legitimate neurological disorder. The knowledge that migraine is more than just a headache is important from a diagnostic and treatment perspective as well as to reduce stigma.

According to Young, migraine can be de-stigmatized with words [5]. Even the diagnostic distinction for defining migraine and chronic migraine has important implications

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✉ Teshamae S. Monteith  
Tmonteith@med.miami.edu

<sup>1</sup> University of Miami, Miller School of Medicine, Miami, FL 33132, USA

**Figure 1. Strategic Planning for Migraine Advocacy**

Stigma and Awareness	Public Health	Access to Care	Research	Social Determinants of Health	Education and Workforce
<ul style="list-style-type: none"> <li>Educate patient and public on migraine diagnosis, prevention and treatment</li> <li>Educate to reduce disease progression</li> <li>Reframe with language choice and messaging</li> <li>Increase awareness of diversity including BIPOC and LGBTQ communities</li> <li>Reduce stigma of migraine and associated comorbidities</li> <li>Eliminate migraine stereotypes and bias</li> <li>Form coalitions with advocacy groups</li> </ul>	<ul style="list-style-type: none"> <li>Improve CDC reporting</li> <li>Track indirect and direct costs</li> <li>Target opiate epidemic by preventing inappropriate use of opiates and increasing education of migraine specific treatments and prevention</li> <li>Address headache disorders linked to the COVID19 Pandemic and Long-COVID</li> <li>Expand access to migraine care for veterans with migraine and posttraumatic headache</li> </ul>	<ul style="list-style-type: none"> <li>Improve clinical access and quality</li> <li>Eliminate arbitrary limits on personalized medicine</li> <li>Address rising costs</li> <li>Reform prior authorization and eliminate step care</li> <li>Eliminate non-medical switching</li> <li>Support widespread of telemedicine adoption</li> <li>Assure transitions from pediatric to adult clinics</li> <li>Improve access to affordable behavioral health services</li> </ul>	<ul style="list-style-type: none"> <li>Fund translational studies including biomarker programs</li> <li>Fund accelerated therapeutic development</li> <li>Increase health disparities and inequities research</li> <li>Develop coordinated multidisciplinary centers and networks</li> <li>Increase recruitment and retention of underrepresented minorities in trials and as investigators</li> <li>Engage patients and stakeholders for patient centered outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Support policies resulting in affordable care</li> <li>Accommodations and workplace outreach</li> <li>Reduce discrimination</li> <li>Increase collaborations with social workers and other allied services</li> <li>Increase studies that identify the impact of social determinants of health and interventions for migraine</li> <li>Address the impact of environmental factors and structural barriers that may be linked to migraine</li> </ul>	<ul style="list-style-type: none"> <li>Increase headache education in residency and medical schools</li> <li>Train more headache specialists</li> <li>Increase continuing medical education opportunities for frontline providers</li> <li>Increase diversity and inclusion efforts</li> <li>Incorporate advocacy training as a part of professional development</li> <li>Reduce burnout</li> <li>Support global collaborations for shared resources</li> </ul>

**Fig. 1** Strategic planning for migraine

for healthcare access. Whereas an individual with migraine might have, in the past, been described as “difficult,” medical language can instead recognize that migraine is a complex brain disorder, for which the mechanisms of disease have not been fully unraveled. Similarly, such rephrasing as *the individual with migraine “failed” the medication trial to the medication trial “failed” the person* may be simple but could result in powerful shifts [8]. Taken together, the language that is used to describe migraine has an important impact in the way the disorder and affected individuals are treated.

### Advocacy Campaigns for Awareness

There have been several patient and professional advocacy campaigns to reduce stigma and give migraine the attention it deserves. According to the National Headache Foundation, the drive for National Headache Week began in the Fall of 1989, attempting to gain political and public support for the recognition of these significant disorders but failed attempts to pass congressional legislation [9]. In 2011, Awareness Week became Awareness Month, and by 2013, the observance was renamed to “National Migraine and Headache Awareness Month” to support all headache types. On June 11, 2021, H. Res 469 was introduced to the House to express support for the designation of June 2021 as “Migraine and Headache Awareness Month.” Once introduced, this legislation resolved that the House of Representatives expresses support for the designation to highlight invisible diseases like migraine that disproportionately impact women and support for public education and efforts to reduce stigma.

In addition, the legislation increased federal funding, for research, to improve access to treatment options and diagnostic methods including telemedicine, and to provide economic incentives for additional employer accommodations. Another example of successful advocacy is work from the World Federation of Neurology and the International Headache Society. They partnered to spread five key messages for the World Brain Day campaign called Migraine: The Painful Truth, which included media activity, webinars, and public education to advocate for early diagnosis and treatment. These advocacy efforts are especially essential as the migraine-associated economic costs result in large medical and lost labor costs due to presenteeism and absenteeism [10].

### Advocacy for Public Health

#### Migraine as a Major Debilitating Disorder

Migraine is a major public health problem. It is estimated that the prevalence of migraine in the USA is approximately 40 million [3]. The peak prevalence is between the ages of 25 and 55, during the most productive time of life personally and professionally [11]. Due to the prevalence and loss of function, migraine is a leading cause of disability worldwide for individuals younger than 50 and the second cause of disability overall in terms of disability-adjusted years lived (DALYs) [12]. One in four people may benefit from migraine prevention, yet a substantial portion of persons with migraine do not use it [3]. To reduce disability,

educational outreach programs that target primary care and the public are needed to enhance quality care. With advances in virtual programming and video, the potential to advocate through education is enormous.

### Migraine in the Context of the COVID-19 Pandemic

As of June 15, 2022, 537 million individuals have been infected with COVID-19, and more than 6.3 million individuals have died worldwide [13]. The impact of the COVID-19 pandemic and the effects of lockdown are massive, and individuals living with migraine may be adversely impacted due to persistent stress and personal loss. In addition, headache is a common symptom of COVID-19 infection; headaches may be a systemic symptom, a manifestation of nervous system involvement, or a triggering of pre-existing primary headache such as migraine.

The development of the COVID-19 vaccines has been one of the most successful public health interventions in modern history. Yet in industrialized countries such as the USA, vaccine hesitancy has limited the path towards herd immunity. During clinical encounters, patients with migraine express concerns about vaccines causing a worsening of pre-existing conditions, such as triggering migraine attacks. In fact, headache is a common side effect of the COVID-19 vaccines, occurring significantly higher than placebo in the active groups that received the novel mRNA COVID-19 vaccines [14, 15] and the single-dose adenovirus vaccine [16]. However, the risk vs benefit for individuals with migraine is favorable, so advocacy may have a huge impact to reduce vaccine hesitancy and prevent COVID-19 infection.

Many studies show that COVID-19 infection is associated with long-term symptomatology, also known as the COVID long-hauler syndrome or Long COVID-19 [17]. Although deep phenotyping has its challenges, common symptoms of Long COVID include fatigue, neurological sequelae such as cognitive disturbances, palpitations, and headaches [18]. H.R. 2754: The COVID-19 Long Haulers Act was introduced to provide support for research, improve health systems, and provide education on common symptoms, treatments, and other post-viral illnesses. Ultimately, due to the continuing prevalence of COVID-19 infection, the potential for headache persistence is unknown but of concern. Ongoing advocacy is needed to address health concerns and headache medicine should play a significant role.

### Migraine in the Context of the Opioid Epidemic

The opioid epidemic is associated with addiction and overdose and has been driven in part due to inadequate pain education, research, and care. Fifty million Americans alone receive opioids for chronic pain [19]. In a claims database study of over 5 million Medicaid beneficiaries,

18.8% had had an opioid prescription filled within 14 days of diagnosis [20]. In the study, 12.9% of opioid prescriptions were for headaches, including migraine and cluster headaches. In another study of 1,222 visits for migraine, opioids were ordered 35.8% of the time. Moreover, in a study of adults hospitalized for primary headache disorders from 2013 to 2014, opioid abusers with primary headache disorders had higher odds of morbidity, severe disability, and discharge to non-home location as compared to non-abusers. Overall, the common prescription of opioids for headache belies the research showing opioids have limited efficacy in migraine management [21]; in fact, the inappropriate use of opioids has been associated with not only addiction but other complications such as migraine overuse headache [22].

There have been several local, state, and federal interventions such as prescribing drug monitoring programs and caps on pain pill quantity and duration. Opioid-free treatment algorithms in Emergency Departments have been developed and shown to reduce revisit rates [23]. However, novel non-addictive treatment options are needed that allow for dignified and evidence-based treatment as outlined in the Department of Health and Human Services Opioid Strategy [24]. In the NIH Helping to End Addiction Long-term (HEAL) Research Plan, initiatives to develop preclinical, translational, and clinical research to enhance pain management are outlined after consultations with patients with migraine, academic experts, and federal and private sector as well as advocates [25]. Short-term goals include biological signatures to predict which patients with migraine are at risk for developing chronic pain and precision medicine approaches to reduce transition to chronic pain. Long-term goals include a pipeline of novel non-opioid therapies for the treatment of acute and chronic pain. A commitment to advocacy will be needed for accountability and to determine progress.

### Migraine With and Without Traumatic Brain Injury in Veterans

Compared to civilians, veterans are more likely to develop migraine or other persistent headache disorders. For example, one study showed that 36% of veterans who had completed a 12-month deployment to Iraq were diagnosed with migraine or symptoms of migraine [26]. The designations of Headache Center of Excellence (CoE) by the Department of Veterans Affairs are an example of successful advocacy by the Alliance for Headache Disorders Advocacy (AHDA). Further advocacy has resulted in regional expansion of more centers and the funding that will allow support for headache fellowship training, infrastructure for research innovation, and service quality to improve clinical efforts, and reduce migraine disability.

## Advocacy for Access to Care

### Access to Care and Rising Costs

Over the past several years, major advances have occurred for the treatment of migraine; however, several barriers to widespread adoption still exist [27]. Access to effective migraine therapies, especially non-pharmacological devices such as the five FDA-cleared neuromodulatory devices, remains a barrier due to costs and coverage. While high drug costs remain a critical issue, cost containment should not limit access to appropriate quality treatments or providers. According to the American Academy of Neurology Position on Prescription Drug Prices, the solution should include transparency, price negotiation, and importation as viable solutions. To date, there is no accountability for drug pricing; even patients that are covered by insurance may be negatively impacted economically in the current profit-based health insurance system. The position statement of the International Headache Society for *Health Technology Assessment for the Acute and Preventive Treatment of Migraine* was developed to inform decision makers about access and reimbursement for medications and devices [28]. According to the position statement, both direct and indirect costs should be considered.

### Prior Authorization

The Timely Access to Care Act of 2021 (H.R.3173) was designed to streamline the prior authorizations process that often delays or denies migraine therapeutics. There are many examples of how insurance denials result in harm for migraine. For example, insurance arbitrarily sets limits on when certain migraine medications can be started or continued; insurance practices for other conditions such as hypertension or depression and maintenance therapy are not challenged in a similar way. Under the prior authorization bill, plans will be required to adopt transparent prior authorization programs that adhere to evidence-based guidelines and include continuity of care for patients transitioning between coverage policies to minimize any disruption in care from discontinuation of acute and preventive therapies.

### Step Therapy

Step therapy is a first-fail protocol designed by managed care to control costs. Unfortunately, some of these protocols include requirements for non-specific treatments or drugs that are not FDA approved for migraine. This practice may have important cost considerations, according to one study of 24,282 individuals with incident migraine who

did not respond to at least one preventive treatment [29]. In the study, treatment failure in individuals with migraine was associated with a substantial resource and cost burden. This is especially concerning as insurance companies are denying access to highly effective, new-generation migraine-specific treatments such as the monoclonal antibodies to the calcitonin gene related peptide or its receptor for migraine prevention.

Patients with migraine may be forced to first try insurance preferred triptans based on cost. In clinic, common complaints include “why should I have to try this triptan when I know this one works?” Today, a person with migraine told me she is only allowed to have 6 migraine attacks per month because that is all the triptans that are approved. There may be legitimate safety considerations in play with this limitation, as triptan therapies are contraindicated in patients with vascular complications. Due to the lack of vasoconstriction, calcitonin gene related peptide antagonists and lasmiditan, the only serotonin agonist targeting the 5HT<sub>1F</sub> receptor agonist, may be safer to use in individuals with a high burden of vascular risk factors, but access remains limited [30, 31]. As a remedy, the Safe Step Act (S. 464/H.R. 2163) seeks exemptions for contraindications, stable medication regimens, or the likelihood that the treatment will be ineffective, cause adverse events, or reduce daily function.

### Non-medical Switching

The Alliance for Patient Access (AfPA) has a Headache and Migraine Disease Working Group that consists of a network of policy-minded health care providers who advocate for patient-centered care. The group has drafted several position statements including one regarding the issue of non-medical switching.

Non-medical switching is a practice in which insurance companies force patients with migraine on stable medication to change to an alternative, driven purely by cost considerations or agreements with pharmaceutical companies, and without considering clinical benefit vs harm.

One retrospective claims study of patients with chronic migraine showed that switching between oral migraine preventive medications is common overall, but persistence worsens as patients with migraine cycle through various oral migraine preventive medications [32]. Generally, non-medical switching may increase the risk of harm, and increase the risk of emergency room visits and costs long term.

### Telemedicine

The rapid widespread expansion and adoption of telemedicine is not something that could have been appreciated prior to the COVID-19 pandemic. An advocacy priority is the passage of federal and state policies that support the permanent

and widespread adoption of telemedicine that is high quality, convenient, and accessible [33]. Congress is currently examining regulatory, legislative, and private-sector perspectives to facilitate the use of the technology. Several bills have been developed to ensure that telemedicine becomes permanent and includes payment parity with evaluation and management (E/M), and removal of originating site requirements.

There have been several studies supporting the safety and effectiveness of telemedicine in the management of migraine. Telemedicine may be especially helpful for patients with migraine who may be too sick to travel to the doctor's office or for those that do not have access to headache specialists locally. In a survey study, 89% of individuals with migraine said they would prefer to continue to use telemedicine for their headache care [34]. To be more effective, telemedicine needs to be a part a solution that reduces health disparities and inequities, such as with universal broadband and reimbursements for audio-only visits.

## **Advocating for Inclusion, Diversity, Equity, Anti-racism, and Social Justice**

### **Structural Barriers and Social Justice**

The COVID-19 pandemic has resulted in economic turmoil and has brought to light the importance of structural barriers. Social determinants of health are the economic and social conditions that influence individual and group differences in health status. Migraine is associated with a lower socio-economic state and a higher prevalence of food insecurity compared to healthy controls [35, 36]. Migraine is highly associated with unemployment, presenteeism, and absenteeism, partly due to emergency room visits and frequent office visits to care providers [10, 37]. Advocacy initiatives should include the right for reasonable accommodations, such as work from home, and incentives for employers. A focus of the International Headache Society Global Patient Advocacy Coalition (IHS-GPAC) is to encourage support from employers and to implement employee support programs for people with migraine. Advocacy programs such as this may improve social justice by reducing the disparate economic and social impacts of migraine.

### **Inclusion, Diversity, Equity, and Anti-racism**

The pandemic has uncovered serious and long-standing racial and ethnic health inequities. Marginalized communities experience greater structural barriers, which has resulted in a widened economic gap and limitations in access to care. Racism and other forms of bias and discrimination must be eliminated to reduce the overall burden of migraine. Both the American Academy of Neurology (AAN) and the American

Neurological Association have put out detailed plans to target these issues, developed virtual programming, and created the Inclusion, Diversity, Equity, Anti-Racism, and Social Justice (IDEAS) taskforce. In the joint American Headache Society (AHS) and American Migraine Foundation statement led by the AHS Advocacy Committee, solidarity was announced with Black physicians, healthcare professionals, individuals with migraine, and communities as “racism is a public health issue” and there is a need to take an active role [38]. A similar statement was released by the American Migraine Foundation to denounce the rise in anti-Asian sentiment and the acts of violence targeting people of Asian heritage [39]. As an advocacy and scientific health organization, they committed to standing up to “negative stereotypes, inappropriate labels, unconscious biases, and discrimination.” Several action items were reported to eliminate racism, bias, and barriers to healthcare access. This included fostering an environment of inclusiveness, increasing racial and ethnic diversity at all levels, supporting mentorship and sponsorship of health professionals from underrepresented groups of color, and supporting health disparities research.

## **Advocating for Migraine Research**

### **Migraine Is a Complex Brain Disorder**

There have been many important events in the history of migraine research, leading us to realize that migraine is a complicated disorder of the brain with dysregulation of sensory processing driven by environmental and genetic factors [40–42]. Although advances in technologies and methodologies have greatly contributed to our understanding, there are as yet no available biomarkers for validation studies. Funding for migraine has been woefully low and disproportionate for addressing the disease burden. Therefore, advocacy for migraine research must be a major priority.

Clinical and imaging investigations suggest that the earliest part a migraine attack, known as the premonitory phase, begins with brain activation, notably in the hypothalamus [43]. Still, the basic mechanisms in which migraine is turned on and off remain unknown. Even the predictability and validation of widely accepted migraine triggers has come into question with research studies suggesting perceived triggers such as sensitivity to bright light, odors, sleep deprivation, or certain food may be misinterpreted during the premonitory phase [44]. This is but one of many examples supporting the need to unravel basic mechanisms and to enact the paradigm shifts necessary to change not only how migraine is perceived, but also how it is managed. A multipronged approach is needed which includes collaborations with patient advocacy groups [45].

## Programmatic Support for Therapeutic Development

Programmatic support is needed to fund research designed to develop innovative technologies, identify biomarkers, elucidate the pathophysiology, determine imaging characteristics, and define the risk factors. Because so many are suffering from migraine disorders, it is also important to focus on the identification and development of effective pharmacological or other therapies. Unique strategies will be needed for high-throughput screening and identification of potential targets for drug discovery. In addition to research funding, infrastructure support for multidisciplinary research networks is needed in addition to coordination and dissemination centers. While there have been some advances in personalized medicine, accelerated and coordinated NIH programs could provide relief for this major public health problem.

## Increasing the Workforce of Physician and Biomedical Scientists

The New Investigator and Trainee Section of the American Headache Society was created to advocate for the needs of members in early career stages. On June 18, 2015 in Washington DC, the NIH forum, *the Future of Headache Research*, convened for the first time. The forum included an expert panel of leadership from the National Institute of Neurological Disorders and Stroke (NINDS), new investigators, and senior scientists who came together to exchange ideas with clinicians, scientists, individuals with migraine, and pharmaceutical companies to discuss the pathway forward. The major focus was increasing NIH funding, identifying gaps, and encouraging dialogue, research initiatives, and collaborations. The key themes that emerged included the need for more collaborations with the NIH and the migraine community, increases in migraine-specific extramural funding at all levels, and expert representation in study sections.

## Health Disparities and Equity Research

The NINDS issued a request for information, RFI-NOT-NS 20–026, for known or perceived areas of health disparities and inequities as well as determinants for such disparities and inequities [46]. Health disparities are defined as health differences that are closely linked with economic, social, or environmental advantages. Disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial/ethnic group, gender, age, sexual orientation or gender identity, geographic location, or other characteristics linked to exclusion or discrimination. Recommendations for clinical trials should also include efforts to recruit and report outcomes in racial/ethnically diverse groups. In addition,

community engagement and commitment to public education facilitated by advocacy groups may be effective strategies. Advocacy efforts are needed to specifically address these knowledge gaps and to provide a more equitable health system for all individuals with migraine [47].

## Expanding the Workforce and Professional Development

### Encouraging Growth as a Subspecialty

While most patients that seek care present to primary care, they are often referred to specialists; however, there are only just over 600 UCNS-certified headache specialists in the USA. To increase the number of headache specialists, advocacy initiatives should target the medical school curriculum. Some barriers to consistent headache education have been identified and can be remedied with online case-based learning modules and training [48]. Advocacy for educational programs may result in greater exposure and a more diverse and inclusive workforce, which could increase patient satisfaction [49]. During teaching rounds, basic advocacy skills are needed to influence the trainee's appreciation of headache medicine as a career as well as their decision to continue learning about best practices in headache medicine. There are several national and global headache education initiatives, some of which have utilized virtual symposiums and telementoring.

### Advocacy Training for Professional Development

In addition to developing innovative educational migraine programs, there is also a need to teach advocacy skills for leadership development and membership engagement. Advocacy skills may be acquired through a dedicated curriculum or through organized activities on social media or other measures to influence policy and goals [50]. Advocacy skills training is needed to assure growth, stability, and longevity of the field of headache medicine [51].

Formal training through the AAN's Palatucci Advocacy Leadership Program and similar opportunities may increase leadership potential and networking to transform innovative ideas into advocacy solutions. The organization Miles for Migraine has an extensive advocacy training program, ACT NOW, designed for headache fellows and patients. The AHDA provides advocacy training in preparation for Headache on the Hill events. Lastly, participation in AfPA's initiatives ensures that the clinicians' perspective informs healthcare policy discussions, rather than the insurer, for people living with migraine.

## Conclusion

Migraine advocacy is needed to transform patient care, to reduce stigma, and to strengthen the field of headache medicine. Both large-scale and smaller acts of migraine advocacy are important. Successful advocacy starts with identifying the problem, developing objectives, knowing your audience, setting goals, and identifying adequate resources. Taken together, fundamental skills such as the ability to form collaborations and coalitions, inspire, utilize media outlets for messaging, and influence policies are all required. The ability to engage patient advocacy groups and to form coalitions may be useful for larger scope initiatives.

Whether migraine advocacy is conscious or not, advocating should be done routinely as a part of an ongoing strategic mindset. With persistence, physicians, healthcare providers, persons with migraine, and their families are naturally positioned for advocacy as disease experts or through personal experiences. Specialized advocacy training may accelerate the path to success as a personal effort or through collaboration. Through migraine advocacy, the promise to transform the lives of millions may be realized on many levels.

The migraine priority areas outlined in this manuscript require dire attention both nationally and globally. As summarized, major gains can be made by an individual advocate and through coalitions or advocacy partnerships. Taken together, creative and innovative approaches to finding solutions for education, research, clinical care, health equity, and social justice have enormous potential to meet the needs of those living with migraine.

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