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EXECUTIVE SUMMARY

The healthcare system in the United States is fraught with issues, and the area of headache medicine is no exception. The systemic racism that continues to exist has shed a needed light on the racial and health disparities in headache diagnosis and patient care. Many studies have shown that migraine diagnosis rates and treatments are vastly different among Blacks and African Americans and Hispanics and Latinx* compared to Whites.

Research has revealed that people exposed to racism and racial trauma experience stress and adverse health outcomes, including migraine. This phenomenon is known as race-based traumatic stress, a theory that suggests some people may experience racial discrimination as a psychological trauma, prompting a response similar to posttraumatic stress.

Historically excluded groups remain underrepresented in clinical research trials across disease states and conditions. In the U.S. Food and Drug Administration’s 2015-2019 Drug Trials Snapshot Report,1 an imbalance in the representation of minorities in clinical research can be noted. From 2015 to 2019, there were 34,209 trial participants. As of 2019,2 Whites make up 76% of the U.S. population and comprised 70% of clinical trial participants from 2015 to 2019. Blacks and African Americans make up 13% of the U.S. population but comprised only 9% of clinical trial participants from 2015 to 2019. Hispanics and Latinx represent 18.5% of the U.S. population but only 6% of clinical trial participants. Because Whites are projected to be the minority in the U.S. population by 2045, increased diversity should be prioritized in future clinical trials, and studies should investigate race-based differences in migraine disease and treatment.

The Coalition for Headache and Migraine Patients (CHAMP) and its diverse group of partners recognized an inherent need to effect real change. Through its Disparities in Headache Advisory Council (DiHAC), it has provided meaningful educational sessions for members as well as a seed-funding opportunity for new programmatic initiatives that promote diversity and equity and reduce disparities in headache medicine. A total of $100,000 was approved to help fund six new programs and initiatives.

Another program by CHAMP and DiHAC, Heralding Excellence in Access to Diverse & Affordable Care for Headache Disorders Equity (headACHE), will aim to provide access to adequate and affordable healthcare to underserved populations living with migraine, cluster, and other headache diseases and mental illness. It will achieve its mission through education, support groups, and strategic partnerships. headACHE will fall under the leadership of Jaime Sanders.

We use the terms ‘Black’, ‘African American’, ‘Hispanic’ and ‘Latinx’ to include people who identify as Black, African American, Afro-Caribbean, Afro-Latinx, Hispanic, Latino/a/x, Xicanx, et al.
HEADACHE MEDICINE: INTRODUCTION & BACKGROUND

The field of headache medicine is moving and changing fast, with new advances in research, therapies, and technology over the last decade, and more coming down the pipeline. One area of headache medicine continues to lag behind other disease states in modern medicine: racial and health disparity in headache diagnosis and patient care.

In this unprecedented time in our country and history, the brutality of police violence against brown bodies amidst the coronavirus, or COVID-19, pandemic has brought to light the very real issue that systemic racism has created a public health crisis. This is documented through the health disparities, implicit biases, and inadequate care that Black, Indigenous, and People Of Color (BIPOC) experience and receive in the current healthcare system, even in headache medicine.

Although the prevalence of migraine is similar among BIPOC and Whites, differences in migraine diagnosis and treatment indicate that the level of care BIPOC are receiving is less adequate compared with the care Whites are receiving. BIPOC utilize healthcare at a disproportionate rate compared to Whites in terms of outpatient medical visits, despite similar rates of prevalence. When treatment is sought, the total number of visits resulting in a migraine diagnosis is much lower for Hispanics and Latinx, whereas Blacks and African Americans who report having severe headache are more likely to be diagnosed with probable migraine than Whites (7.4% female vs. 4.8%; 4.8% male vs. 3.7%).

The reasons for these differences are not entirely clear. Racial disparity and resulting health outcomes in regard to headache disorders are poorly understood and underresearched. Obstacles presented to BIPOC are often structural, institutional, social, and economical. Language barriers, undocumented immigration status, socioeconomic status, and insurance status can all play a significant role in why these groups have disproportionate effects of stress, poor diets, and less access to equitable healthcare. All of these factors may contribute to the greater frequency and severity of migraine among marginalized groups.

We should also note that pain itself is widely misunderstood in the United States; the education on pain assessment and pain management is severely deficient in medical schools. Only 9 teaching hours are allotted to pain and its management in the United States, comprising 0.3% of the total curriculum hours, compared to 19.5 hours in Canada, according to a 2011 study on pain education programs in the United States and Canada. In contrast, veterinary students spend five times more education hours on pain management than do medical students.

This Issue Brief focuses on the overall issue of disparities in headache medicine for all marginalized groups. We have chosen to concentrate on these groups because of (a) the historical disenfranchisement of BIPOC, (b) four centuries of systemic oppression and racism, and (c) the abuse and exploitation of black and brown bodies in the name of medical advancement. These issues pertaining to BIPOC matter because institutional racism can result in chronic stress and increase inflammatory responses, both of which increase the likelihood of other chronic conditions developing and contributing to poor health outcomes.
Incidence and Prevalence

Migraine and severe headache have an estimated prevalence of 15.3% overall in the United States, with 9.7% of men affected and 20.7% of women affected. Headache has been shown to be a leading reason for medical consultation, especially for neurological evaluation. Worldwide, migraine is the seventh highest specific cause of disability, and in evaluating the global prevalence of the 50 most common sequelae, tension-type headache and migraine are ranked second and third. Additionally, individuals from underrepresented backgrounds and those with poor health insurance coverage tend to have lower diagnostic rates and worse outcomes. Evidence continues to show that historically, socially, and economically marginalized people are disproportionately disabled by migraine. The attitudes and behaviors of healthcare providers have been identified as one of many factors that contribute to health disparities. A report by Loder et al. examined diagnosis and treatment among U.S. racial and ethnic minorities by evaluating prevalence data from the National Health Interview Survey (NHIS). The review identified the average prevalence of severe headache or migraine was 17.7% for Native Americans, 15.5% for Whites, 14.5% for Hispanics and Latinx, 14.45% for Blacks and African Americans, and 9.2% for Asians. While this report shows a higher prevalence of severe headache or migraine among Native Americans and a lower prevalence among Asians, we believe more research is needed to support these numbers. Additionally, the American Migraine Prevalence and Prevention study showed that among those with chronic migraine, the prevalence of chronic migraine was highest in Hispanic and Latinx women (2.26% compared to 1.2% for White females) and lowest in White males (0.46%).

Access to Care

Historically, persons of color have faced disparities in health outcomes, access to healthcare, and the quality of care received in the United States. The Report of the Secretary’s Task Force on Black and Minority Health,
also known as “The Heckler Report,” emphasized that compared to Whites, there were compelling disparities in mortality and illness burden among minority communities.\(^1\) Although there have been studies showing evidence of Whites having higher rates of migraine than Blacks and African Americans, Blacks and African Americans are less likely to be diagnosed with and meet the full criteria for migraine. Consequently, they are more likely to be diagnosed with probable migraine.\(^2\) In a study by Silberstein et al.,\(^3\) the prevalence of probable migraine was found to be significantly higher in Blacks and African Americans than Whites and was inversely associated with household income.

According to Stewart and Lipton\(^4\) and data from a national survey of the U.S. population, migraine prevalence and the frequency of attacks increase as household income decreases. However, a physician diagnosis of migraine is more likely to occur as household income increases. There remains a compelling number of people with severely disabling migraine disease who do not receive medical diagnosis and treatment, and current therapy appears to be insufficient.\(^5\)

Compared to Whites, Blacks and African Americans may not receive adequate medical care, according to a study by Loder et al.\(^6\) However, studies have shown that among Blacks and African Americans, migraine is more frequent, more severe, and more likely to become chronic and associated with depression and poorer quality of life.\(^7\) Further, Blacks and African Americans are less likely to seek medical care, receive an accurate diagnosis, or receive treatment for migraine or headache.\(^8\) However, in a research study by the National Headache Foundation and Sam Brown Inc (2021), when asked about treating their disease overall, 77% of Blacks and African Americans and 73% of Hispanics and Latinx said they wish they had sought care sooner.\(^9\)

When it comes to treatment for migraine, BIPOC were more likely to feel worry, fear, and anxiety at the thought of taking a migraine preventive treatment. Additionally, they were less aware of preventive treatments prior to being prescribed one. They also felt surprised and scared after learning that their migraine attacks would be an indefinite part of their lives and that their disease was serious enough to require prevention.

Racial and ethnic disparities in the care of acute, chronic, cancer, and palliative pain persist, with minorities receiving poorer quality pain care, but are absent from public health and healthcare reform plans. Guaranteeing the best pain care for all is critical, and research on disparities in pain is needed to reduce and eliminate disparities in care.\(^10\)

**Race-Based Traumatic Stress (RBTS)**

RBTS is a valid and unique phenomenon, especially in the United States.\(^11\) The RBTS theory\(^12\) proposes that some racial and ethnic minorities may experience racial discrimination as psychological trauma, prompting a response analogous to posttraumatic stress.\(^13\) Injustice affects the physical well-being of individuals and groups in various ways, and racism and racial
discrimination have been shown to have long-term psychological and emotional effects. Research has shown that those exposed to racism and racial trauma experience stress and adverse health outcomes, including migraine. Therefore, an approach must be developed for understanding, assessing, measuring, and treating the health effects of RBTS.\textsuperscript{20}

adequate minority representation and inclusion reporting in migraine clinical trials is unknown, while Whites continue to be overrepresented. Future studies should aim to increase minority inclusion and examine race-based differences in migraine.\textsuperscript{14}

Research has shown that those exposed to racism and racial trauma experience stress and adverse health outcomes, including migraine.

MinORITY REPRESENTATION IN MIGRAINE

Clinical Research Studies

The majority of the gap in health outcomes can be attributed to wealth disparities, differences in insurance coverage, and access to care, but there is still a significant percentage of the gap yet to be explained.\textsuperscript{23} When it comes to clinical trials, minority groups have historically been underrepresented, even though they have comparatively poor health indicators. Due to the increased burden of disease and decreased participation in research, the National Institutes of Health (NIH) Revitalization Act of 1993 mandated the inclusion and reporting of women and minorities in NIH-funded research. Over the years there has been progress, yet the underrepresentation of minorities in research trials remains a problem. The extent of
The American healthcare system is burdened with inequalities and inequities that have a disproportionate impact on people of color and other marginalized groups. These inequalities contribute to gaps in health insurance coverage, uneven access to services, and poorer health outcomes among certain populations. Blacks and African Americans bear the brunt of these healthcare challenges, especially when related to headache diseases. In the summer of 2020, the Coalition for Headache and Migraine Patients (CHAMP), its coalition participants, and some of the nation’s leading headache specialists committed to taking immediate, tangible action to change this. CHAMP formed the DiHAC, a cross-functional group of patient advocacy organization leaders, BIPOC headache patients, and healthcare providers, to understand the scope of the issue. Working with Sheila Thorne, a leading expert in multicultural healthcare marketing, members of DiHAC have been working on identifying and supporting solutions to racial disparities in headache medicine and diversifying an engaged headache patient community.

In just 12 months since its inception, DiHAC has attended weekly sessions on cross-cultural competency training and learned from leaders of successful disparity reduction efforts in other disease areas. From these insights, DiHAC initiated a Request For Proposal process for Council members and guest speakers to submit funding proposals for programs that aim to increase diversity in the headache patient community and/or reduce disparities in headache medicine. Six proposals were received, reviewed, and evaluated by a volunteer grant review committee, which approved $100,000 in funding.

DiHAC has also partnered with CHAMP participant and blogger, Jaime Sanders, and Dr. Anikah Salim, epidemiologist and migraine patient, to create and distribute this Issue Brief on disparities in headache.
**Strengthening Headache Knowledge of Medical Students - Larry Charleston IV, MD MSc, FAHS**

The goal of this project is to introduce Student National Medical Association (SNMA) members to headache medicine (migraine diagnosis and disparities). A partnership will be formed with the members to create a community service headache awareness program that focuses on people of color and services the health needs of underserved communities. A new migraine diagnosis and disparities program will be developed for medical students that will be delivered within SNMA chapters.

**Utilizing Opportunities to Expand Diversity and Inclusion - Clusterbusters, Inc.**

This project seeks to diversify the population that receives resources offered and the population that participates in Clusterbusters events. This project also aims to educate a broader population about cluster headache and treatments available, prevent suicide and suffering by raising awareness for cluster headache and access to treatments, and increase access to diagnosis and treatments for those affected by cluster headache. This project will launch in Chicago, Illinois, as it has vibrant Latinx and Asian communities, the two demographics that will be the initial focus of Cluster Connections.

**Engaging the BIPOC Community in Migraine Disease Advocacy - Miles for Migraine (MFM)**

This project will engage BIPOC patients and their families in MFM live events by partnering with local headache centers and key funders to educate, engage and support these communities within targeted cities through the MFM walk/run/relax events. The pilot for this project will take place in Philadelphia, Pennsylvania, which is the fourth largest Black and African American market in the United States, with Blacks and African Americans comprising 42.2% of the total population in Philadelphia County.

**Migraine Education for Patients & Practitioners in Underserved Communities - Association of Migraine Disorders (AMD)**

This project will provide continuing education in migraine diagnosis and treatment to clinicians serving in Native American health facilities, inner city and rural community health clinics, and other free clinics. This project will further enhance patient and clinician understanding of migraine disease by providing tools (i.e., handouts and guidelines) to help manage migraine disease and educate patients on triggers, lifestyle changes, medications, and disease management.
Developing Headache Medicine Providers for the Native American Communities - William B. Young, MD

This project will train one provider in 2021-2022 in the Native American community to become a headache expert to reduce the burden of illness in this group, since there are no United Council for Neurologic Subspecialties or other certified headache providers for the Native American community. The provider (i.e., neurologist, primary care provider, nurse practitioner, physician assistant) will be trained by Thomas Jefferson University's 1-year course in headache medicine. The training will include diagnosis, treatment, and first-line management of comorbidities.

Patient Professors - U.S. Pain Foundation, Inc.

This project aims to educate medical students using the lived experiences of individuals with chronic pain and to improve patient-centered care by reducing stigma, addressing disparities, and emphasizing the importance of the doctor/patient relationship. Patient advocates will be trained to effectively tell their medical story by sharing their diverse personal experiences while also discussing roadblocks to care. By visiting two of the four Historically Black Colleges and Universities that have medical programs (Howard University, Morehouse, Meharry Medical College, and Charles R. Drew University of Medicine and Science), the goal is to capture healthcare providers who are more willing to treat people with pain or know when to give a referral to a doctor who can help.
ENSURING DIVERSITY, EQUITY, AND INCLUSION (DEI) EFFORTS THROUGH DiHAC

In addition to the work that will be accomplished through the funded programs, the Council will continue to educate its members on the importance of implementing and practicing DEI both internally and externally. In early 2021, DiHAC focused its sessions on providing the tools necessary for its members to put into practice the lessons learned throughout 2020. Through a mix of guest speakers and guidance from Ms. Thorne, members were equipped to incorporate DEI into their organizations through hiring practices, funding streams, and other internal actions. The group will also be assisted in the implementation of external strategies such as initiatives their organizations can undertake to address health disparities and increase diversity.

As members and grant recipients begin to enact initiatives and programs, the DiHAC sessions will provide support, serve as a sounding board, and hold individuals accountable throughout the process. Along with the reporting requirements of the grant recipients, other members will be asked to share systematic updates of their organizations’ plans. This open dialogue and transparency ensure better collaboration and cohesion across the community, while holding members accountable generates more robust, well-rounded DEI programs.

DiHAC believes its focus for 2021 will lead to a more diverse patient community and decrease racial disparities in headache medicine.

HERALDING EXCELLENCE IN ACCESS TO DIVERSE & AFFORDABLE CARE FOR HEADACHE DISORDERS EQUITY (headACHE) - JAIME SANDERS

headACHE will be a program under CHAMP and DiHAC whose mission is to provide access to adequate and affordable healthcare to underserved populations living with migraine, cluster, and headache diseases and mental illness. headACHE aims to fulfill this mission by:

1. Increasing education and training in headache medicine for healthcare professionals in community, rural, and federally qualified health centers (FQHCs) to treat residents;

2. Providing mental health resources, support groups, and trained clinicians for adversely affected populations;

3. Filling the unmet needs of the uninsured and underinsured through bolstering, supporting, and enriching medical deserts;

4. Creating partnerships with trusted local leadership and government, physicians, pharmacists, media outlets, places of worship, and community programs to increase health literacy and adherence; and

5. Encouraging other organizations to work alongside headACHE by creating and delivering resources, information, and technology in formats that will serve to better support all patients regardless of geographic location, access to the internet, or language barrier.
AMD Migraine Toolbox in FQHCs

Many people rely on receiving healthcare from an FQHC. Within these centers are preventative care services such as internal medicine, obstetrics and gynecology, pediatrics, and dentistry. There are not many specialty departments, such as neurology. If someone comes in complaining of severe headaches and needs to be referred to a specialist, they would most likely be sent to a participating hospital for services.

Utilizing the AMD Migraine Toolbox, a free comprehensive online course to engage healthcare professionals in the management of migraine, along with an engaging exam room poster, will help marginalized patients who live in underserved areas who are often underdiagnosed or misdiagnosed in the area of headache disorders.

This collaborative effort will ensure that the providers these patients see can recognize, diagnose, and treat migraine and headache disorders in populations that are often under- or undiagnosed or that underutilize care in terms of headache treatment. This also affords us an opportunity to increase patient education and awareness.

Diversity and Cultural/Patient Competency Training for Medical Professionals

The expression of pain is not linear. Cultures and ethnicities describe and approach pain differently. These nuances in culture-related pain experiences should be recognized and considered when treating patients of multiple backgrounds. Someone’s culture may determine how their pain is first treated. Many may fall back onto homemade remedies or religion to help manage and cope with their pain. There could be a cultural distrust of the medical community. Someone’s cultural relationship with food may be a contributing factor in how they cope with and manage their pain.

These aspects of a person’s identity are important in learning their pain story and should never be discounted, nor should the patient be made to feel stupid or shameful for relying on what they know to help them feel better. Medical professionals need to do a better job at listening to how someone talks about their pain. For example, a BIPOC patient may not use the same descriptive language as a patient of European descent.

Patients, regardless of their race, ethnicity or background, should be made to feel comfortable when talking about their pain experience. Training for continuing medical education credit could be offered at sessions during American Headache Society meetings and other professional meetings to address:

- Patient safety in communication;
- Cultural competency;
- Cultural proficiency; and
- DEI and Belonging in the examination room and beyond.
CONCLUSION

The time to act is now. We know the American healthcare system is rife with inequalities and inequities that result in poorer health outcomes among certain populations, with BIPOC communities bearing the brunt of the challenges. DiHAC is shining a light on this systemic problem and proactively addressing it within the headache medicine arena.

Already, in the organization’s short existence, under the leadership of an industry expert in multicultural healthcare marketing, Sheila Thorne, DiHAC has brought together a cross-functional group of patient advocacy organizations, BIPOC headache patients, and healthcare providers to understand the scope of the issue and work on solutions to racial disparities in headache medicine. DiHAC is now proud to support seven remarkable and proactive initiatives that aim to increase diversity in the headache patient community and/or reduce disparities in headache medicine with grant funding. We are confident these programs will help advance our mission and inspire others to do the same.

DiHAC is committed to leading the way to build a better future in headache medicine by continuing to offer cross-cultural training, supporting programs that make an impact, and acting on solutions that will create a just environment, so all patients have equal access to services and treatments they need to address their headache disease.

With the field of headache medicine advancing quickly in terms of research, therapies, and technology, it is critically important we also advance in our work to finally end racial and health disparities in headache diagnosis and patient care. We understand and recognize the limitations of our capabilities to accomplish these goals. We cannot do it alone and encourage all stakeholders and providers in headache medicine, and throughout the entire American healthcare system, to learn from DiHAC’s initial work and take measures to create a more equitable environment for access and care. We recommend creating partnerships with local community leaders and advocacy organizations in other disease states to help broaden the reach of our work. Further research is needed and additional work must be done. We must keep the momentum going. Together, as a community dedicated to ending inequalities and inequities that result in poorer health outcomes, we can make strides and improve healthcare.
The following organizations and individuals make up the members of DiHAC and commit to advancing its work to help increase diversity and eliminate inequalities and inequities that exist in headache medicine.

**Organizations**

Alliance for Headache Disorders Advocacy (AHDA)
Association of Migraine Disorders (AMD)
Chronic Migraine Awareness, Inc. (CMA)
Clusterbusters, Inc.
National Headache Foundation (NHF)
U.S. Pain Foundation

**Individuals**

Alexes Elizabeth Griffin - Health Advocate
Amaal J. Starling, MD, FAHS, FAAN - Associate Professor of Neurology; Program Director, Transitional Year Residency; Department of Neurology, Mayo Clinic
Anikah H. Salim, DrPH, CPH
Courtney S. White, MD - Assistant Professor, Department of Neurology, Thomas Jefferson University Hospitals
Isiah Lineberry - U.S. Pain Ambassador & Member of U.S. Pain's Disparities Solutions Advisory Council
Jenn Heater - Patient Advocate
Joanna Kempner, PhD - Associate Professor of Sociology, Rutgers University & Member-at-Large, Board of Directors, Alliance of Headache Disorders Advocacy
Katie Golden - Patient Opinion Leader
Katie MacDonald - Director of Federal Policy, AHDA
Katie Moran - Miles for Migraine, Volunteer Coordinator, Support Group Coordinator
Mary Franklin - CHAMP Emeritus Member
Ronetta Stokes - Patient Advocate
Sheila Lineberry - U.S. Pain Ambassador & Member of U.S. Pain’s Disparities Solutions Advisory Council
Yuri Cárdenas - PhD in Migraine Disease
THANK YOU TO DiHAC SPONSORS

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