The Coalition for Headache and Migraine Patients (CHAMP) is a non-profit that provides support to people with headache, migraine, and cluster diseases who are often stigmatized and under-served. CHAMP brings together 21 organizations and opinion leaders in this disease area to enhance communication, coordination, and collaboration to more effectively help people wherever they are on their patient journey. This guide was created to provide information on each CHAMP participant: who they are, how they contribute to the headache community, and how they can be contacted.

CHAMP has three pillars that guide the work of the coalition: Community, Education, and Advocacy. Some of the programs that make up these pillars are highlighted at the back of the guide.

CHAMP works closely with all participants and stakeholders to fight the stigma of migraine and headache diseases, and to ensure patients have access to innovative treatments that are creating a new era of improved outcomes for people living with headache diseases.

To learn more, visit: headachemigraine.org
Non-Profit Organizations

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05 Association of Migraine Disorders
06 Chronic Migraine Awareness
07 Clusterbusters
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Additional Information and Resources
Dedicated to the advancement of research and awareness surrounding migraine...

The American Migraine Foundation (AMF) is a non-profit organization dedicated to the advancement of research and awareness surrounding migraine, a disabling condition that impacts almost 40 million men, women, and children in the United States. AMF was founded in 2010 to provide global access to information and resources for individuals with migraine as well as their family and friends.

Working alongside the American Headache Society, the AMF mission is to mobilize a community for patient support and advocacy, drive and support impactful research that translates into treatment advances for patients with migraine and other disabling diseases that cause severe head pain.

What is Migraine?

Migraine is an inherited neurological disorder that is characterized by overexcitability of specific areas of the brain. Although it is not clear how a migraine brain is different or what happens in the brain to start a migraine attack, it is known that individuals with migraine are more susceptible to the influence of transient factors, termed “triggers,” that raise the risk for having a migraine attack. These triggers include hormonal fluctuations, environmental stimuli like weather or bright lights, certain smells, alcohol, certain foods, poor sleep, and high stress. However, not everyone has a clear trigger for migraine attacks.

Research

The goal of AMF is to advance migraine research and start vital conversations that empower those living with this disabling disease. From advocating for more research to building patient registries to sharing the latest findings on migraine treatment and more, AMF works every day to improve the lives of those living with migraine.

Get Involved

Through active online communities, educational resources and patient-first donation allocation, it’s easier than ever to get involved with the American Migraine Foundation.
The Association of Migraine Disorders (AMD) is devoted to expanding the understanding of migraine disease and its true scope through research, education, and awareness. It does so under the guidance of physicians from a broad range of medical specialties and with a focus on migraine symptoms beyond headache. AMD is committed to increasing the number of non-neurology medical specialists who can recognize and treat this disease. Therefore, AMD has created a comprehensive, practical online course on migraine management available on MyCME.com. The course is free and CME-accredited.

To educate patients, caregivers, and others, AMD presents lectures and interviews on a variety of topics with their audio and video podcast, Spotlight on Migraine. Another way they provide education is AMD’s annual Migraine Symposium, featuring more than 30 speakers from around the country. This event includes a dual series of lectures, one of which is geared toward medical professionals with CME credits available while the other is for people with migraine and the public. AMD also recognizes leading clinicians, researchers, and advocates with annual awards at this event.

AMD believes that migraine has yet to capture the support of the general public and therefore hosts Shades for Migraine, a playful, collaborative international awareness campaign centered around sunglasses. Shades for Migraine also includes a directory of partners, a photo contest, a volunteer registry, and Taking it to the Streets events (page 26).

Finally, AMD strives to connect and grow the migraine research community through the Migraine Science Collaborative (MSC), a membership-based, targeted resource hub and communication platform. The MSC strives to form an inter-institutional and multi-disciplinary network of migraine researchers and medical professionals in an effort to increase and enhance research in the fields of migraine, cluster, and headache disease.
Chronic Migraine Awareness, Inc. (CMA) is a 501(c)(3) non-profit founded in 2012 with the mission to be the voice of the chronic migraine community globally. Unique from other migraine programs, CMA is tailored to those with chronic migraine disease. Founder Catherine Charrett-Dykes says the reason she established CMA is, “I couldn’t leave this legacy of pain to my daughter, nor let the next generation suffer.”

CMA empowers individuals to advocate for their own health through online support groups and volunteer programs. With representation all over the world, CMA offers a diversity of support groups on Facebook. CMA also offers the Aware Care program, Triage Kits of comfort items and resources, and the Rally Against Chronic Migraine campaign.

The Aware Care “Support Squad” is devoted to helping people with chronic migraine disease feel less alone, surrounding each member with tenderness and empathy. One example is sending heartfelt cards or Triage Kits to people going through a difficult time. The Rally Against Chronic Migraine campaign reminds people that when they rally and persist against this disease, it empowers them to use their voice to combat stigma and fight for awareness, not only on Chronic Migraine Awareness Day (June 29th), but throughout the year.

Advocates Removing Migraine Stigma (ARMS) is the advocacy program of CMA. ARMS is simple: CMA provides advocates with an advocacy kit of resources to place at doctor’s offices and other areas approved for placement. These tools include CMA resources and other valuable information. ARMS offers advocacy tasks at every level, helping people do what they are capable of, despite their disease, to fight against stigma.

CMA also offers a robust Migraine & Headache Awareness Month campaign, which includes: Fact a Day, actionable challenges, Faces of Chronic Migraine, CMA Day, and a focus on the campaign “Rally Against Chronic Migraine” initiative.

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Clusterbusters supports research for better treatments and a cure while advocating to improve the lives of those struggling with cluster headache.

Medical professionals and patients consider cluster headache to be one of the most painful conditions known to man. They are an incurable form of trigeminal autonomic cephalgia.

One of Clusterbusters primary objectives is to promote research and share knowledge of psilocybin, LSD, and other related molecules that have been shown to be effective treatments for cluster headache. Clusterbusters has also partnered with many other researchers to design and publish studies, launch new medications and devices, and discover new treatments for this debilitating disease.

Clusterbusters hosts an annual patient conference to educate and offer community to those living with cluster headache and their caregivers. They also provide free information about best practices for treatment through printed materials, their website, social media, and speaking engagements.

Clusterbusters began bringing patients to Headache on the Hill in 2012 to advocate for those living with headache diseases. In addition, they have participated in many other legislative and regulatory activities to ensure access to the best treatment options for the patients they serve.

Clusterbusters fights to improve access to high-flow oxygen for cluster patients. For 50 years evidence has existed showing that oxygen is the safest and most effective acute treatment for cluster attacks. However there are still many obstacles to access. Clusterbusters has partnered with the Alliance for Headache Disorders Advocacy (AHDA) to appeal Medicare's decision to exclude oxygen coverage. Clusterbusters is also working to address other issues such as patient and doctor knowledge of this highly effective treatment that is not widely marketed and often misunderstood.
Cluster Headache Support Group

Mission
The Cluster Headache Support Group, Inc. (CHSG) is a 501(c)(3) non-profit organization dedicated to improving the lives of those living with cluster headache. CHSG was founded in 2010. CHSG’s mission is to provide a safe, supportive community for patients and caregivers affected by cluster headache. CHSG offers patient education and access to accurate, relevant information and resources. The organization drives and supports scientific research that results in treatment advances for patients with cluster headache and other trigeminal autonomic cephalalgias.

Vision
Improve the lives of patients with cluster headache by providing patient-directed support and education, collaborating with healthcare systems to drive research, and empower patients to advocate for and raise awareness of cluster headache.

Core Values
Accuracy – All medical information is reviewed by a board-certified headache specialist to ensure accuracy.

Integrity – CHSG adheres to the highest standard of non-profit ethics, including disclosure of any and all competing interests.

Compassion – Humanity for those affected by cluster headache drives CHSG’s operations.

Collaboration – CHSG believes in collaborative decision-making within their team, soliciting member input, and are committed to working with other headache organizations to further shared goals.
The Danielle Byron Henry Migraine Foundation was established in memory of Danielle who courageously battled migraine disease for 10 years until it ultimately led to her death at the age of 17. After Danielle’s death, her father, Dan Henry M.D., began to study and treat headache disease until he became an expert in the field. Frustrated with the small number of providers who treat migraine disease and the lack of public awareness and support for those with migraine, he and his family decided that Danielle was meant to send them on a path to make a difference in this fight, in essence to “Shine Her Light.”

The foundation’s mission is to raise awareness and provide support and access to treatment for those living with migraine disease, especially young adults and children.

Projects include:

Creating better awareness and understanding of migraine in schools by assisting in the creation of Migraine at School (page 27), which provides resources for students, parents, and educators.

Hosting virtual programs, including Resources for Migraine Management workshops, providing participants with coping strategies for migraine, and weekly Restorative Yoga sessions.

Supporting development and promotion of A Migraine Toolbox: A Practical Approach to Diagnosis and Treatment, a comprehensive online course created by the Association of Migraine Disorders and designed to engage a broad range of medical professionals in the management of migraine.

Headache School, in partnership with the University of Utah, provides monthly educational sessions and a Tools for Headache Management series.

Partnering with the Migraine Research Foundation to help fund the 2017 Impact Award, a study on New Daily Persistent Headache (NDPH) in children.

Hosting Shine Her Light, a biennial signature event to raise community awareness and celebrate those living with migraine.
The mission of HMPF is to advance public policies and practices that promote accelerated innovation and improved treatments...

The Headache & Migraine Policy Forum (HMPF) is a coalition of more than two dozen patient advocate groups, scientists, clinicians, issue advocates, and social media influencers with a particular focus on patient access challenges and preserving the clinician-patient relationship for those living or caring for persons with headache disorders and migraine disease.

Specifically, the mission of HMPF is to advance public policies and practices that promote accelerated innovation and improved treatments for persons living with headache and migraine disease. HMPF serves as a unique platform using a campaign approach to amplify the work of its coalition members and their individual campaigns related to policy and access. This supports the education of patients, healthcare providers, and other stakeholders about policy issues that impact access to new and existing therapies such as prior authorization, prescriber restrictions, step therapy, combination therapy, and access to preventive treatments. A 501(c)(4) organization, HMPF directly advocates with plans, policymakers, and other decision makers to expand patient access to approved therapies on a state-by-state level and ensure coverage for all patients.

HMPF also raises awareness with federal policymakers through sponsored Capitol Hill policy forums on topics ranging from the impact of migraine therapy access challenges on veterans and disability communities to those living with co-morbid conditions.
HealthyWomen is the nation’s leading independent, nonprofit health information source for women. Their mission is to educate their audience of women age 35+ so that they can make informed health choices for themselves and for their families. They combine a 24/7 online health media platform with award-winning education and advocacy campaigns, including objective, medically accurate, research-based health information.

HealthyWomen connects with its audience through an inclusive, highly engaged, proactive community where women have a voice through surveys, blogs and social media. For 30+ years, women have turned to HealthyWomen for answers to their most personal healthcare questions, with 8 million unique visitors to their site annually and 63,000 subscribers to their e-newsletters.

HealthyWomen makes women’s health a priority in the national healthcare dialogue. They raise awareness for women and decision makers about the impact health policy has on women and families, educate women about the importance of participating in clinical research trials, advocate for funding of women’s health research, and support studies on sex differences to improve women’s health.

As migraine disease is three times more common in women than in men, HealthyWomen continues to use its digital platforms to raise awareness about this debilitating disease. The organization has also hosted Science, Technology & Innovation round-table meetings where stakeholders gather to advance the conversation around migraine therapies in women.

It is a priority to keep women’s health part of the national dialogue.
MigraineDisease.org's mission is to empower people living with migraine and other headache disorders through training and mentoring. They are developing a patient advocate incubator to train and mentor patients and caregivers with the skills necessary to take an informed and active role in their own healthcare; encourage, educate, and advocate for others; raise awareness through involvement in local, regional, national, and international advocacy efforts; and volunteer or work for migraine and headache organizations. Their team has over 30 years of experience in patient education and healthcare advocacy, and has earned the respect and confidence of leading physicians, researchers, and patients. A team of headache specialists reviews all of the organization’s content for medical accuracy. MigraineDisease.org produces all content in house with complete editorial-control - content is never curated, purchased or outsourced. They have also made a public commitment to their readers that their team will receive continuing medical education through attendance at medical conferences, access to medical journals, and personal study.
History demonstrates that diseases that are stigmatized, like HIV and breast cancer, can only change in the public’s mind when patients and their families come together in community action demanding recognition. Diseases in which the patients do not stand up for themselves remain badly stigmatized, and patients do not receive the research or therapies needed to effectively treat their condition. This is true even if doctors speak up for the disease; patients and their families must take over the effort.

Patients with migraine often do not have the chance to stand up for their disease, and thus themselves. They desperately need an opportunity to do something positive about their condition. It is basic psychology that by collaborating positively with a group, you will feel better about yourself. Patients also need a way to encourage their families and friends to participate for migraine; doing something for someone else’s disease transforms attitudes and provides them an opportunity to learn about the scope of migraine.

Migraine is a major disease that receives about a 20th of the research dollars that should be given to it based upon its impact. Migraine patients desperately need new research to discover new treatments, and headache researchers and clinical specialists need to be trained. Miles for Migraine does all of these things; it does so by bringing patients together in the community while also participating in an activity that is good for your health!

Miles for Migraine creates live, patient-participatory events that reduce the burden of isolation and stigma for people with migraine and headache diseases and their caregivers. It builds community by bringing people together at fun walk/runs and through educational and support programs. Miles for Migraine also has programs specifically focused on engaging and supporting adolescents. Its programs foster empowerment, increase disease awareness, teach skills to advocate for better access to treatments, and raise funds for headache fellowship programs.
Founded in 1970, the National Headache Foundation (NHF) is the oldest and largest foundation for patients with headache disease. Its mission is “To cure headache, and end its pain and suffering.” Its vision is “A World Without Headache.” The Foundation is the premier educational and informational resource for those with headache, healthcare providers, and the public. The work of the Foundation is through education, raising awareness, advocacy, and research.

Almost 40 million Americans experience migraine, and less than 600 physicians have received subspecialty certification in headache medicine – meaning that there is only 1 physician for every 85,000 people living with migraine disease.

In order to help people access quality and safe healthcare for their headache, the Foundation has established the Certificate of Added Qualification in Headache Medicine (AQH) for physicians, nurse practitioners, physician assistants, dentists, and clinical psychologists who treat headache patients. The exam is offered twice a year in all 50 states. Please visit their website for more information on the AQH exam.

NHF supports research efforts by physicians and scientists into the diagnosis and treatment of headache. They provide support to those conducting patient-centric research and determining how patients have been denied access to care.

At the national and state levels, they are informing policymakers and the general public of the need to help patients get access to safe and appropriate care. They are reaching out to employers throughout the US to provide education for their staff and support for efforts to minimize the costs and the personal/social impact of chronic headache. They also educate and encourage patients with migraine and chronic headache to become self-advocates with their healthcare practitioners, insurers, employers, and families.
The Patient Advocate Foundation (PAF) provides help for patients facing critical illness and debilitating disease as they encounter barriers in their healthcare. Utilizing experience from 20+ years working alongside patients, PAF is well-known for its quality educational materials that help patients overcome common challenges. In addition, PAF’s skilled staff deliver tangible assistance through personalized case management services, financial support towards medication co-payments, and connection to vital community resources, all at no cost to the patient or their caregiver.

PAF is excited to share its expertise surrounding the challenges people with migraine and headache disorders experience when it comes to financial stability, medical debt crisis, and insurance denials, all delivered in an online tool. Migraine Matters is built to serve the needs of patients and providers working on behalf of their care with actionable information on a variety of topics.

When challenges exceed self-navigation, the Migraine CareLine provides hands-on support for uninsured, underinsured, and insured patients.

At no cost to the patient, PAF will:

- Work with provider or patient prior to expiring assistance programs to ensure continued access to prescribed medication
- Screen patient for eligibility and assist with enrolling in available prescription drug assistance programs
- Help navigate insurance processes including step therapy protocols and prior authorizations
- Educate on existing medication formulary and insurance benefit design
- Collaborate on filing insurance appeals for denied treatment and medications
- Locate available clinical trial options and screen for eligibility
- Guide patient through eligible workplace protections like Family Medical Leave Act (FMLA) and Americans with Disabilities Act (ADA)
- Give assistance engaging existing workplace benefits including short-term and long-term disability
- Assist with the Social Security Disability application and appeal process
- Search for and enroll in health insurance coverage for uninsured patients or those with inadequate insurance coverage
- Find an in-network second opinion or headache specialist, and help patient to understand benefits if there is not an in-network specialist
The U.S. Pain Foundation was created by people with pain for people with pain. U.S. Pain works to enhance the quality of life for people with pain, improve patient outcomes, address access and affordability issues, and increase public awareness.

U.S. Pain programs and services address support, education, empowerment, and advocacy. U.S. Pain helps people wherever they are on their pain journey.

**Direct Support:** Pain Connection is a national network of in-person and over-the-phone support groups, developed by a clinical social worker who lives with pain. The Pediatric Pain Warrior program offers weekend retreats, scholarships to a special summer camp, webinars, a pen pal program, and more for kids with pain and their families.

**Education:** U.S. Pain offers hour-long educational webinars, called PEP Talks, featuring renowned experts on topics ranging from massage to how to enroll in clinical trials. Take Control Of Your Pain Days are free, daylong seminars that offer patients the chance to learn about the latest advances in treatment, research, and other helpful resources. U.S. Pain offers a variety of tools and resources, like a 16-page booklet with tips and information about pain management or an infographic on chronic pain in America.

**Awareness and Empowerment:** The INvisible Project is a print magazine and traveling display that highlights the bravery of pain warriors through stories and photos -- along with educational articles. Pain Awareness Month is 30 days dedicated to elevating the discussion around pain through a unique awareness campaign created each year. The Ambassador Network is made up of volunteers who work to raise awareness about chronic pain and offer support and information to fellow pain warriors.

**Advocacy:** The Advocacy Program makes sure people with pain are heard by policymakers at the state and federal levels. U.S. Pain works to improve policy and legislation in the following areas: high-quality treatment; patient safety; fair, accessible insurance coverage; innovation and research; and quality of life. The Medical Cannabis Program seeks to increase safe, fair access to medical cannabis for people with chronic pain and provide education and training on medical cannabis as a treatment option.
The Daily Headache by Kerrie Smyres is a blog that candidly addresses the emotional experience of living with migraine and headache disorders and also explores coping strategies, treatments, and research. Although living with these stigmatized disorders can feel lonely and bewildering, millions of other people face similar struggles. The Daily Headache is a place where people with migraine and headache disorders come together and remind each other that none of us are facing this alone.

Kerrie is the patient advocate and writer behind The Daily Headache.

“I started The Daily Headache as a creative outlet and it quickly grew into a way to connect with and learn from others who were also struggling.”

Kerrie Smyres

She has had chronic migraine for more than 30 years. Her passions are to write about the emotional experience of living with chronic illness and to translate medical research to make it understandable to the general public. In addition to her work on The Daily Headache, Kerrie has been writing for Migraine.com since 2011. She is also a patient advocacy consultant and volunteers with several patient advocacy organizations. Kerrie is the co-founder of TheraSpecs, which makes therapeutic eye-wear for migraine, post-concussion syndrome, and other conditions triggered or worsened by light.
Katie M. Golden is a professional patient, advocate, and writer living a fulfilled life with chronic migraine. She worked for 15 years in commercial real estate finance at a community bank when her episodic migraine attacks became a chronic, every day occurrence. Unable to return to her career, she found purpose in her pain through writing and began authoring articles for Migraine.com in 2013. She soon found ways to advocate for others with headache diseases and said, “advocating helped me reclaim power that migraine had stolen from me.”

For the past nine years, Katie has not experienced a break in pain. The pain fuels her personal mission: “Never Let Your Pain Go to Waste.” Through her blog, Golden Graine, Katie connects with others trying to navigate life when medical curveballs become the norm.

She openly shares her experiences navigating the complex insurance and medical systems, applying for and maintaining Social Security Disability benefits, and sharing the trial and errors faced in finding the right balance between medications and alternative methods.

She is passionate about telling the stories of those living with migraine, headache disorders, and chronic pain. She does so as Contributing Editor of the INvisible Project magazine.

Katie has participated in Headache on the Hill for the past five years, advocating for more research and funding for headache diseases. She provided patient testimony for Health & Human Services led Pain Management Best Practices Inter-Agency Task Force and gave testimony and served on the policy roundtable of ICER’s review of CGRP inhibitors and acute treatments for migraine. Katie is the patient expert for the Migraine Clinical Outcome Assessment System (MiCOAS) research project, funded jointly by the NIH and FDA.

Katie is the Director of Patient Relations for CHAMP and Migraine Advocacy Liaison for the U.S. Pain Foundation. She serves on the National Headache Foundation’s Patient Leadership Council and is a member of the Miles for Migraine Warrior Advisory Board, where you can easily spot her at one of their events wearing a purple wig and tutu.
The Hope for Migraine Community: CGRP & Emerging Treatments is a peer-to-peer community for people who live with migraine. They seek to support, guide and educate people who are navigating the new CGRP medications and other emerging treatments. These treatments are a new frontier in the management of an often disabling disease that impacts 1 billion people globally. They include the first ever medications designed specifically to prevent migraine, as well as the first new abortive options seen in decades!

The Hope for Migraine Community provides up-to-date, easily understood, evidence-based information, together with tools to help with access and insurance. They encourage their members to authentically share real-life experiences and questions. Recognizing that there is so much more to migraine than the new treatments, they partner with Migraine Meanderings, which seeks to encourage, empower, and inspire people living with migraine. Through initiatives such as “Out From the Shadows: Let’s Talk Migraine,” “The Real Face of Migraine,” and easily shareable articles and memes, this community offers a supportive place for people at all stages of their journey, whether newly diagnosed or life-long warriors.

The Hope for Migraine Community was founded by Shoshana Lipson, patient advocate, speaker, and writer, who has lived with migraine since early childhood. Shoshana is helped by an amazing team of migraine warriors, who create and edit materials, provide support, and research and post the most recent articles and information available. Shoshana collaborates with other organizations and leaders who advocate for people with migraine, as well as consulting with leading certified headache specialists to ensure that information given is current, accurate, and evidence-based. Their vision is that together, as people who live with migraine, they can connect and support each other, as well as become a voice that partners with the medical community to help bring about effective treatment and, ultimately, a cure!

Recognizing that there is so much more to migraine than the new treatments...

Hope for Migraine Community

CONNECT

facebook.com/groups/CGRPandMigraine
@MigraineMeander
@MigraineMeanderings
MigraineMeanderings.com

"
Jaime’s journey with migraine has been a life-long one. From a toddler with abdominal migraine to a wife and mother with chronic intractable migraine, Jaime has learned to turn her pain into empowerment. She also manages her daily life with depression and anxiety, surviving two suicide attempts, along with fibromyalgia, carpal tunnel syndrome, spinal stenosis, and chronic back pain. Despite these conditions and their limitations, she strives to do her best to find her optimal health. Advocating for headache disorders and mental health are her passions.

Despite living a life of chronic pain, she has always managed to find the strength and will to move forward in life. Having a debilitating illness that carries a stigma is no easy life to live. Wanting to remove that stigma, educate society, and provide support to other people with migraine prompted Jaime to start her award winning blog, The Migraine Diva. Through her own challenges, failed treatments, and successes Jaime can champion for herself and for the millions of others who live and fight silently with this chronic disease.

The mission of The Migraine Diva is to help empower and educate people living with headache, migraine disease, and mental illness through patient advocacy. Seeking valuable relationships with like-minded organizations, its goal is to share ideas, resources, and information on accessible treatments to better the lives of migraine patients and their caregivers. By sharing the realities of living with chronic intractable migraine, major depression disorder, and anxiety, The Migraine Diva hopes to empower, elevate, and validate the patient voice and experience.

Jaime has collaborated with many organizations, including being the Migraine Patient Advocacy Coordinator for Global Healthy Living Foundation. She also partners with the American Migraine Foundation and Shades for Migraine and is a stakeholder with the Headache & Migraine Policy Forum.
Few people really understand what it’s like to live with migraine disease. It’s not just the pain and agony of the migraine attack itself, but the risk of the next migraine attack occurring at the worst possible time, keeping you on edge, making it nearly impossible to confirm plans, and driving a wedge between you and everyone else.

Migraine is a neurobiological disease that can eventually impact every aspect of your life. Research has shown the heavy toll chronic migraine takes on relationships, work, happiness, and quality of life.

Effectively managing chronic migraine can feel like an impossible feat. But it is possible. 3% of chronic migraine patients transition back to episodic migraine every year.

You can be smart, persistent, conduct research, follow the doctor’s instructions, and still fail over and over.

That is why Carl Cincinnato created MigrainePal. It helps those with migraine get the facts with medically referenced answers. Readers can find practical and evidence-based information to empower themselves.

Carl, a former chronic migraine patient himself, also works with several other charities and organizations to help fight the global burden of migraine. These include Headache Australia, the Brain Foundation, CHAMP, and the European Migraine and Headache Alliance.

He is a member of the International Headache Society, and co-host for the Migraine World Summit.

Carl is a passionate advocate who has been featured on national TV, in print, and on radio stations advocating for the need to increase research funding, reduce stigma, and increase patient support.
To help you to survive and even thrive in this world despite chronic pain

Migraine Again

MigraineAgain.com is an authentic wellness community founded by patients, for patients with migraine and frequent headaches. They help you to survive and even thrive in this world despite chronic pain. It’s a supportive and empowering environment where people can find the most effective solutions for more migraine-free days — until there’s a cure.

Founded by Patients, for Patients

Migraine Again was founded by a lifelong migraine warrior and leading patient advocate, Paula K. Dumas. An American Migraine Foundation Board member, CHAMP participant, and co-host of the groundbreaking Migraine World Summit, Paula regularly partners with top doctors, researchers, policymakers, and industry leaders to bring the community the latest ways to improve the quality of life with migraine. She’s joined by an experienced team who know what it’s like to struggle with migraine, cluster headache, and disabling pain. Migraine Again is a proud employer of people with migraine and headache disorders. They are committed to donating a portion of their advertising revenue to support migraine research, education, and awareness efforts.

Supported by Top Experts

Migraine Again regularly features the leading American Headache Society (AHS) and International Headache Society (IHS) migraine and headache experts to provide you with trusted health information that is medically-reviewed and evidence-based. They stay on top of scientific research and what’s working in clinical practice. They look at the evidence behind anything that claims to help prevent or relieve migraine, dispel myths, call out snake oil salesmen, and share promising new or obscure treatments and ideas to make it easier to cope with the pain.

MigraineAgain.com offers free digital access to empowering articles, videos, podcasts, and Migraine Journeys from people just like you. You’ll discover life-changing insights you won’t learn from your local doctor. You’ll find ways to Eat, Breathe, Survive, Thrive, and Engage better with migraine.
Health Union encourages social interactions that evolve into valuable online health conversations, helping people with chronic conditions find the information, connection, and validation they seek. The company creates condition-specific online communities – publishing original, daily content and continuously cultivating social conversation – to support, educate, and connect millions of people with challenging, chronic health concerns.

Migraine.com, which launched in 2010, is Health Union’s first online health community, is the largest and fastest growing online community dedicated specifically to patients and caregivers of those with migraine disease. It is a community for and created by people living with migraine. Patient advocates share their personal experiences, expertise, frustrations, and challenges of living with migraine and encourage others to do the same. The result is a unique dialogue about important topics that are rarely discussed in doctors’ visits and medical literature, such as unusual but frustrating symptoms, impact on quality of life, and tips for managing the strain migraine has on personal relationships. Migraine.com is distinct in that it continuously reflects the needs, desires, and frustrations of real people with migraine.
Our mission is simple. To reduce the global burden of migraine.

The Migraine World Summit is the largest international migraine patient conference of its kind. It is a combination of both an in-person and online live event lasting for nine days each year. It provides viewers with a chance to improve their understanding of migraine and headache from over 30 of the world’s leading experts and specialists.

Experts, doctors, and specialists from around the world are interviewed to help answer the most difficult questions for those with migraine in desperate need of relief.

At the last Migraine World Summit, over 115,000 participants attended from over 154 countries.

Its mission is to reduce the global burden of migraine by providing free world-class education and fundraising toward research and advocacy. Each year their event helps support 12 migraine and headache nonprofits.

The online Migraine World Summit is free for the live event period. The annual event is live in March each year. For those who miss out or cannot attend live, all the interview recordings and more are available to order for home delivery or instant online access. All the video, audio, and transcripts are available anytime on demand.

The Migraine World Summit is a socially driven organization that partners with and supports nonprofits. Up to 50% of funds raised from the Migraine World Summit are donated to migraine nonprofit partners listed on the homepage, who are doing wonderful work to help fund migraine research, support patients, and advocate for those living with migraine.

To date, Migraine World Summit has donated over $20,000 to migraine and headache nonprofits, groups, and foundations. The Migraine World Summit does not solicit donations or compete with other nonprofits for fundraising.

Visit the website to discover the in-depth topics covered by world-leading experts at the Migraine World Summit.
Eleventh Hour Films partners Jacki Ochs and Susanna Styron made the feature documentary Out of My Head to bring the reality of migraine into the broader public discourse. Designed to educate, enlighten, entertain, and inspire, they use the magic of cinema to paint a portrait of life with migraine, allowing those who suffer to feel more understood and less alone, and helping those who do not suffer to have understanding and compassion for those who do.

In the award-winning Out of My Head, the director sets out to investigate the devastating migraine attacks that have her daughter in their grip. As mother and daughter seek understanding and ever-elusive treatment, the audience follows them into a bizarre and fascinating world populated by doctors, neuroscientists, patients with migraine, and such unexpected characters as Lewis Carroll, Sigmund Freud, and Joan Didion. It teaches that, rather than a terrible headache, migraine is a complex, deeply stigmatized neurological disease afflicting a billion people worldwide. This kaleidoscopic journey, told through interviews, cinema verité, art, and animation, explores the history, impact, and raw emotion evoked by this unpredictable and confounding condition. This is the story of people living in chronic pain, with a disease that has no cure – how it affects them and their loved ones, how they cope, how they see the world through its prism. It’s the deeply felt story of a daughter and mother coming to terms with a condition that will always be a part of their lives.

To screen Out of My Head, visit outofmyheadfilm.com/buy-the-film/ and learn where you can stream the film, or purchase a DVD or digital download.
National Migraine & Headache Awareness Month

June is National Migraine & Headache Awareness Month (#MHAM), and the full headache, migraine, and cluster community works together to create recognition. Each year, the National Headache Foundation creates a unique theme for June for the full community to use. The MHAM website serves as a central hub for all information related to this disease recognition month.

Each year, days are recognized as special Observance Days, each one representing a significant topic within our community. CHAMP participants and the public are asked to help spread awareness and recognition on these days by posting information on their social media accounts.

Additionally, the MHAM community hosts a daily blog series that featured the voices of advocates on a wide range of topics.

A few programs from CHAMP participants are highlighted below. Shades For Migraine is a campaign hosted by the Association of Migraine Disorders to promote migraine awareness during MHAM. It creates viral buzz for a disease that affects 1 billion people worldwide.

On Migraine Solidarity Day, June 21, people can show the world they care about migraine by wearing sunglasses and posting a photo to social media with the hashtag #ShadesForMigraine.

Chronic Migraine Awareness (CMA) increases awareness of chronic migraine throughout June with various activities. People can participate in CMA’s Faces of Chronic Migraine social media campaign, Rally Against Chronic Migraine, help recognize June 29th as Chronic Migraine Awareness Day via proclamation by state or local government, and replace their outdoor lights with purple bulbs to Shine a Light on migraine.

To learn more visit MigraineHeadacheAwarenessMonth.org
People with migraine are discriminated against in many different ways, particularly if they are not able to always perform expected tasks – in their work, with family, at home, or even self care. This is due to the stigma of migraine or the negative attitude of society toward people with this disease. It results in sanctions – it is harder to get disability due to migraine, accommodations at work, sympathy from family, or understanding from friends compared with other diseases. Less money is spent on caring for people with migraine and less effort is expended to find treatments for them that actually work. The most toxic type of stigma, is self-stigma, which results from years of exposure to judgmental attitudes from others. This can lead people with migraine to question their own worth and the validity of their condition.

CHAMP has made it a priority to directly address stigma, and has created a new program, Migraine at School, to reach into schools to address this problem for kids, while educating their teachers and parents about migraine – all the while embedding messages that reduce stigma.

Thanks to the support of the Danielle Byron Henry Foundation (page 9) materials were provided for the pilot launch. CHAMP also hosted the “Shut the Door on Stigma” symposium in 2019 to align stakeholders on how to more effectively combat stigma. These learnings are guiding our community’s actions.

To learn more about Migraine at School visit
MigraineAtSchool.org
RetreatMigraine is a conference specially designed for people living with migraine disease.

The goal is to support and strengthen the migraine community from the inside out. The conference is a safe space where people can learn about treatments, connect with their migraine peers, explore how to become an advocate, and experience complementary therapies.

The first RetreatMigraine in 2019 took place in San Antonio, Texas. The event occurred over 3 days with more than 200 attendees. With sessions like What Happens in My Mind & Body During a Migraine Attack, Fighting Migraine Stigma, and New & Emerging Treatments for Migraine, attendees had a comprehensive agenda to learn more about the migraine community, their disease, and how to get involved.

According to data collected post-event, 93% of attendees said they left RetreatMigraine knowing more about how to be an empowered advocate.

Given the challenges of 2020, the RetreatMigraine team wanted the second annual event to be a safe experience for everyone. RetreatMigraine went virtual in April with a second more comprehensive virtual event in November 2020.

The team looks forward to seeing everyone in person next year at RetreatMigraine 2021.

To learn more visit RetreatMigraine.org
Changing the Language & Imagery of Migraine

Language plays a vital role in how the world is understood. Too often, language can be used to disparage and belittle people living with disease, labeling them as helpless or as victims. This ultimately creates shame and stigma, and illegitimately justifies the notion that people with diseases should be ignored or feared. This has prominently played out in the headache disease area. The language used by medical experts, the media, the public, and stakeholders of this community can greatly impact how people living with headache diseases are perceived and treated. This, in turn, affects the resources society makes available to support the community’s pain and disability.

Likewise, the images associated with headache, migraine, and cluster diseases often do not accurately depict the full range of symptoms connected to these diseases and minimizes the severity of impact on daily lives. Images used by media or depicted in popular culture often overlook the diversity of races, ages, and genders that are impacted by headache diseases. This adds to the mislabeling, misunderstanding, minimization, and stigmatization of the individuals living with these diseases.

Building on the published 2011 study, Naming Migraine and Those Who Have It, by Dr. William B. Young, CHAMP and the coalition participants worked together to create the Headache & Migraine Language & Image Guide to help address these issues.

To download the guide please visit HeadacheMigraine.org/LanguageGuide.pdf
The ECHO program provides training and community for the headache patient communicators that moderate online headache communities and create headache-focused content. By connecting and investing in the people that are leading and contributing headache communications, ECHO’s aim is to enhance the already strong headache communities and content online, expand audience size, increase organic reach via content sharing, and expand PR efforts to garner more mainstream media coverage.

Over the course of 2020, ECHO is providing educational support through 18 webinars and a closed Facebook Group. ECHO exists to help patient communicators achieve their communications goals.

Participants in the ECHO program learn:
- Best practices for moderating and managing online headache communities
- Tips and tricks for creating engaging content that cuts through the digital clutter
- How to take advantage of the Facebook (and other social media) algorithms and gain increased exposure
- Packaging and pitching stories and events for broader media

Details on the ECHO program for 2021 and beyond are being finalized and will be shared once ready.

To learn more visit HeadacheMigraine.org/echo/
The migraine patient journey is a tragically broken system. Just 1 in 20 people with chronic migraine have seen a doctor, been accurately diagnosed, and are being treated according to medical guidelines. The vast majority of people living with migraine are not receiving appropriate care thatempowers them to effectively manage their disease.

To address the many gaps, CHAMP launched the Mapping the Migraine Patient Journey process. Through a collaboration of CHAMP coalition participants, industry stakeholders, and leading researchers, they have identified all the common steps in the migraine patient journey. The team focused on 3 key areas where there are major needs for improvements:

1) Reaching, engaging, and activating the 20 million people with migraine disease who remain undiagnosed and are solely relying on over-the-counter medicines or no treatment.

2) Increasing access to quality migraine care: expanding healthcare providers willing to diagnose and treat migraine, and expanding access points for migraine care.

3) Better guidance for when and how patients should evaluate and adjust their migraine treatment plan and the healthcare providers they see for care.

In September 2020 the Mapping process participants heard pitches from migraine patient advocacy leaders for 7 new programs designed to help fix the gaps in the patient journey. The CHAMP coalition has pledged partnership with these new initiatives and are hopeful that industry will provide support for the launch of these programs.

The next Mapping meeting will take place in March 2021, where stakeholders will explore and discuss the roll-out of and access to FDA-approved innovative medicines used to treat migraine disease.
Disparities in Headache Advisory Council (DiHAC)

The Disparities in Headache Advisory Council (DiHAC) was born from the need to address the inequities and systemic racism of the American healthcare system. Unfortunately, African Americans bear the brunt of existing healthcare challenges, especially when related to headache diseases. DiHAC is a cross-functional group of patient advocacy organization leaders, BIPOC headache patients, and healthcare providers. Working with Sheila Thorne, a leading expert in multicultural healthcare marketing, the Council is tasked with identifying and supporting solutions to racial disparities in headache medicine and diversifying the engaged headache patient community.

DiHAC is hosting weekly webinars on cross-cultural competency training and guest presentations from leaders of effective disparity reduction campaigns in other disease areas. The Council will review and support proposals for new initiatives that will diversify the engaged headache patient community and reduce disparities in headache medicine.

The Council is organized by CHAMP in partnership with the Migraine Diva Jaime Sanders (page 20). Together they will create and distribute an Issue Brief on Disparities in Headache. This document will deliver concrete recommendations for the headache community to create tangible action moving forward.

The Issue Brief will also serve as the foundation for Sanders’ new nonprofit focused on the supporting the underserved in headache medicine.
CHAMP firmly believes that every person living with migraine, cluster, and other headache diseases should have affordable access to the right treatment(s) at the right time without insurance restrictions getting in the way. CHAMP has compiled the best information, resources, and support from the coalition to help you be proactive about your care.

**Supporting Patient Access to Necessary Treatments**

**Treatment Access Guide**
headachemigraine.org/help/

Insurance companies put up roadblocks that deny coverage for treatments you and your healthcare professional have decided are essential. These barriers include prior authorization, fail-first, and non-medical switching. CHAMP’s Treatment Access Guide explains these barriers and provides templates to use in fighting them.

**Financial Assistance Guides**
headachemigraine.org/treatment-financial-assistance-guides/

More new medicines and devices for migraine have come to market in the past few years than in the previous 30 years combined. Pharmaceutical and device companies offer financial assistance programs to help patients afford innovative treatments. Each program varies, which is why CHAMP created Financial Assistance Guides that provide easy-to-understand overviews.

**Policy Advocacy for Access**
headachemigraine.org

CHAMP works with the Headache & Migraine Policy Forum and the Alliance for Headache Disorders Advocacy to improve state and national policies that affect treatment access. Individual patient voices are essential to make the grassroots tactics effective. Make sure you sign up to receive CHAMP emails so you are alerted when your story is needed.

**Help for Individuals from the Patient Advocate Foundation**
patientadvocate.org/migrainematters

Managing an invisible illness is a full-time job. The Patient Advocate Foundation provides information and one-on-one case management to battle insurance denials, ensure workplace accommodations, and support applications for Social Security Disability.
Thank you to the generous sponsors who make all the work of CHAMP possible.

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