Hope in Pain, Inc.

dba Migraine Meanderings

Education. Awareness. Support. Research.

Hope
in
Pain

Migraine
Meanderings

HOPE IN PAIN, INC. — MIGRAINE MEANDERINGS

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“For an indomitable spirit, the insurmountable is faced every day! We do not give up, we refuse to quit, we purposely hold on to hope. We are migraine warriors!”

—Shoshana Lipson
Founder/Executive Director

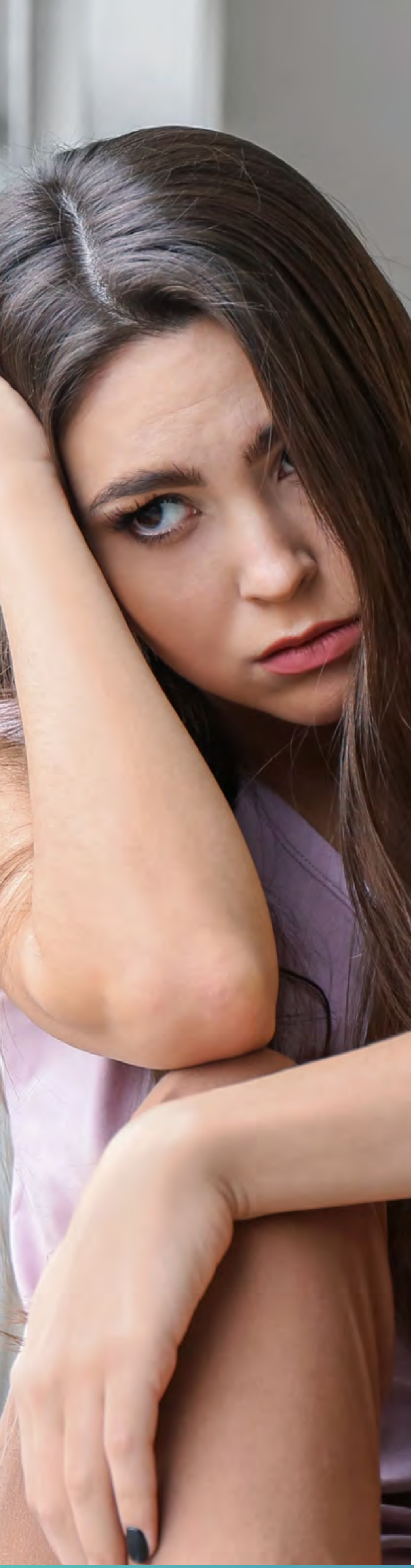
Migraine Meanderings—a dba of Hope in Pain, Inc., a 501(c)(3) non-profit—is an organization for people living with migraine. Our patient-run organization is small, but mighty. All members of our team—both paid and volunteer—live with migraine. Many are also caregivers for family members with the disease. This gives our organization a deeply personal understanding of the many challenges this often debilitating condition presents in all aspects of life. It also makes us uniquely qualified to set goals for improving the quality of life for people living with migraine.

Our organization has a trusted presence across multiple social media channels including Facebook, Instagram, X, Pinterest, TikTok and YouTube, raising awareness, and offering education and support to people who live with migraine and their loved ones. Our social media groups promote patient advocacy by providing an open space for learning, and by focusing on unique initiatives from a predominantly peer-to-peer perspective. We form industry partnerships to help us reach a large and engaged patient community, create educational resources, and raise awareness about this devastating disease.

We are committed to helping bring migraine “out from the shadows” by putting a real face to this disease. We work to inspire people with migraine to find ways to thrive, not just survive, and to hold on to hope.

OUR VISION & MISSION

1. **Provide migraine patient- and caregiver-oriented advocacy, support and education services.**
2. **Help people who are affected by migraine disease through social media outreach, websites, meetings, and educational materials.**
3. **Empower patient voices and raise public awareness of disease symptoms, risk factors, and treatment options, and promote research to help treat, manage, and ultimately cure migraine.**
4. **Help close the loop of communication between patients, clinicians, pharmaceutical and medical device companies in order to optimize patient care, improve disease management, and support research into new treatment options and understanding of migraine.**



ABOUT MIGRAINE

Migraine is so much more than just a headache. It is a complex neurological disease with many often-incapacitating symptoms.

Migraine affects **approximately 42 million people** in the USA and **1 billion globally**. Symptoms, attack triggers, severity, and response to treatments vary widely. Migraine is in the top ten most disabling diseases worldwide. However, despite this prevalence, the disease is still largely misunderstood and stigmatized in society. It is also under-diagnosed and often either mistreated or under-treated by health care professionals.

Research into migraine and treatment options is ongoing, but funding is very limited compared to other diseases. The actual cause of migraine is still unknown, though scientists have isolated several genes that are involved in it, as well as various pathways and peptides that are impacted. What we do know is that migraine disease is highly hereditary. When one parent has migraine there is a **50% chance any child will also have it; that risk increases to 75% when both parents have migraine**.

Migraine disease impacts all areas of daily life. It negatively affects patients' relationships with family and friends, limits what they can do in their education and careers, and takes a heavy toll on their mental and physical wellbeing.

The unpredictability of migraine attacks severely disrupts patients' ability to plan and maintain a normal routine. Not to mention, the challenges of navigating the healthcare system, finding a certified headache specialist, and the constant fear of the next attack, often results in heightened anxiety, and can have profound negative effects on mental health. The combination of unpredictability, challenges and fear significantly diminishes the overall quality of life for individuals, creating a cycle of disability that further exacerbates effective disease management.

In addition to the above, migraine is a progressive disease—without proper diagnosis and appropriate care, patients risk disease chronification and increased comorbidities. This makes awareness and early intervention critical.

91%

of people miss work or can't function normally during a migraine attack

50%

of people with migraine have their first attack before the age of 12

Less than

1,000

certified headache specialists are practicing in the USA

OUR WORK

An informed patient is an empowered patient.

We believe that as patients learn more about the disease they live with, they are better able to partner with their doctors on treatment decisions, advocate for themselves, and receive better care. **With support from industry partners and donors like you**, we are able to create relevant and impactful, custom projects and educational resources which do just that.

When we educate, support and inspire people with migraine, we empower them to successfully manage migraine and improve their quality of life. **You can help too!** Your support provides critical funding for the creation and delivery of all of our programming.

This important work includes:

- Awareness-raising initiatives
- Community and support
- Peer-to-peer patient education
- Improved communication across the healthcare spectrum

> "By taking the time to educate ourselves, we can improve our mental and emotional well-being and minimize our triggers."
>
> **—Allison, Chronic Migraine Patient**

RAISING AWARENESS

Let's bring migraine "out from the shadows" together.

Your support allows us to provide patients with the latest migraine and treatment information. By raising awareness we are arming them with the tools they need to be empowered, as well as changing the way this disease is understood. This awareness impacts the way people with migraine are treated in education, the workplace, healthcare, and society in general. A snapshot of our most recent awareness initiatives includes:

- Our **Migraine Treatment Toolbox** is a patient guide to managing migraine. While there currently is no cure for migraine, there are many treatment options—none of which work for everyone, and many of which need to be tried for a few months to see if they are effective. Often, people who live with migraine experience the most success managing their disease with an approach that combines different treatment options.

- The launch of our **Stages of Life with Migraine** project. Our goal is to provide migraine educational resources to patients in all stages of their lives, from childhood to adulthood and into their senior years. The first stages covered were adolescence and young adulthood, two underrepresented groups in the migraine space. In 2025 we hope to cover Children with Migraine, and looking ahead we will be covering the child-rearing years, perimenopause and menopause, and seniors.

RAISING AWARENESS

Advocating for Migraine Treatment:

A Focus on Insurance Barriers

A "how-to" toolkit on advocating for access to migraine treatment by removing insurance barriers

Migraine Doesn't Wait—It Chronifies

While patients wait for effective treatment of this debilitating disease, migraine doesn't wait. The disease can get worse, quality of life diminishes, and the cost rises with ER visits and loss of work.

LEARN MORE!
www.MigraineMeanderings.com
www.HeadacheMigraineForum.org

- Partnering with the Headache and Migraine Policy Forum, we developed an **Advocating for Migraine Toolkit** to help patients understand insurance utilization policies. The toolkit provides action steps for working with insurance companies to reduce treatment delays and denials.

Different migraine attacks require different treatment approaches.

For some attacks, non-oral medications like nasal sprays and injectables can provide better absorption and faster relief.

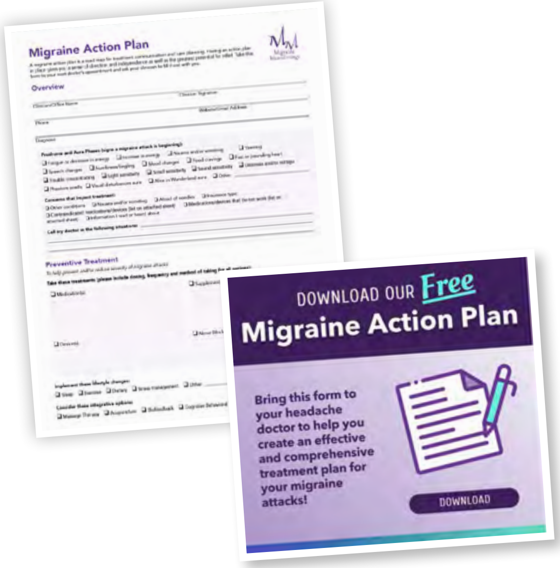
Talk to your doctor about these treatments for acute migraine symptoms.

LEARN MORE

www.MigraineMeanderings.com

What do migraine patients say about non-oral acute medications and why are they an essential part of the migraine toolbox?

- How patients take their acute medication can be just as important as the medication they take. Our **Non-Oral Medication Awareness campaign** educates patients on how nasal sprays and injectables bypass the gut and may provide quicker and more effective relief during attacks which often cause nausea, vomiting, and gastroparesis.



Migraine Action Plan

DOWNLOAD OUR Free Migraine Action Plan

Bring this form to your headache doctor to help you create an effective and comprehensive treatment plan for your migraine attacks!

DOWNLOAD

- Our **Migraine Action Plan** is a written plan developed by the Migraine Meanderings team, medical advisory board, and patients. The goal of the document is to streamline communication between patients and doctors, and equip patients with an easy-to-follow plan that explains which treatments to take, when, and how much. Patients are encouraged to download the document and bring it to their doctors' appointments.

SHARING COMMUNITY FEEDBACK

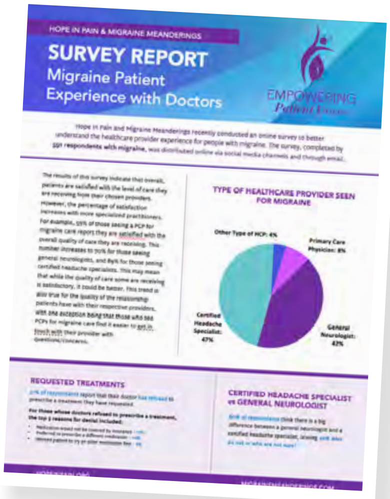
Empowering patient voices, strengthening the healthcare landscape.

Patients' unique experiences lend much-needed perspective and understanding to life with migraine. Our aim is to get a **direct perspective from the migraine community** on the use of treatments and medical devices, relationship with doctors, insurance coverage challenges, and how this disease affects their overall quality of life.

The feedback we collect through surveys, polls and online support groups guides our education and advocacy work, and is shared with our migraine patient community and supporters. The information sheds light on this debilitating condition, and is used to help effect payor and policy change for improved access to treatment options.

Understanding the patient experience is critical in providing tailored care and support, ensuring quicker diagnosis, and reducing the emotional, physical and economic toll of this chronic illness.

With your support, we can continue to **share genuine lived-experiences** and **break down the communication gap between patients, pharma and healthcare professionals**.



HOPE IN PAIN & MIGRAINE MEANDERINGS

SURVEY REPORT

Migraine Patient Experience with Doctors

EMPOWERING Patient Voices

TYPE OF HEALTHCARE PROVIDER SEEN FOR MIGRAINE

REQUESTED TREATMENTS

CERTIFIED HEADACHE SPECIALIST vs GENERAL NEUROLOGIST

EMPOWERING
Patient Voices

> "I will not let migraine drive my life, but I have learned that I can empower others and provide support, because we are all warriors of this disease."

—Lizzy, Episodic Migraine Patient

PROVIDING SUPPORT

Drawing strength by standing together.

Having migraine disease can make people feel isolated and lonely. For those who live with this often invisible chronic disease, connecting with others who "get it" can be life-changing. Our organization provides a compassionate online community where patients are able to turn for evidence-based information, emotional support, helpful advice, motivation, and a sense of belonging. Our trained moderators, all of whom also have migraine, ensure our social media channels and support groups are safe, respectful places.

> "I want to tell you how grateful I am to have this group. The information is invaluable, and I often have 'a-ha' moments when I think, 'Oh, that explains everything!' Thank you!"
>
> **—Migraine Meanderings Facebook Group Member**

Your support helps us run patient communities across multiple social media channels and continue to provide free patient resources. Each of our channels is unique, offers something different, and reaches a unique demographic of people. As a whole, our organization **reminds those who live with migraine that they are NOT ALONE, and that there is HOPE.**

> "When we connect with others who also live with migraine we are in this together."
>
> **—Ernie, Migraine Patient**

EDUCATING PATIENTS

Sharing knowledge, building compassion.

One of the greatest challenges in dealing with migraine disease is its complexity. In addition, it is a disease that is unpredictable and highly stigmatized, often making it **challenging for patients to find accurate and current information**. In response, Migraine Meanderings hosts live Q&A sessions with top headache specialists and healthcare professionals. These educational events cover a wide range of topics, including new migraine treatments, non-oral acute medications, dispelling migraine myths, navigating side effects, and "ask us anything" open mic events.

In addition to regular events, our blog also focuses on an array of topics from treatment options and common migraine symptoms, to shared personal stories from our community. Written by our staff and volunteers who all live with migraine, our blogs offer a varied and unique perspective on managing this chronic illness.

We believe the better educated patients become, **the more involved they can be in their own care** and the closer we get to effectively managing migraine and ending stigma.

LET'S TALK MIGRAINE *Live*

New Migraine Treatments: What's on the Horizon?

Dr Stewart Tepper
Vice President, New England Institute for Neurology & Headache, Stamford, CT
Professor of Neurology, Geisel School of Medicine, Dartmouth, NH

ZOOM LIVE EVENT - REGISTER NOW!

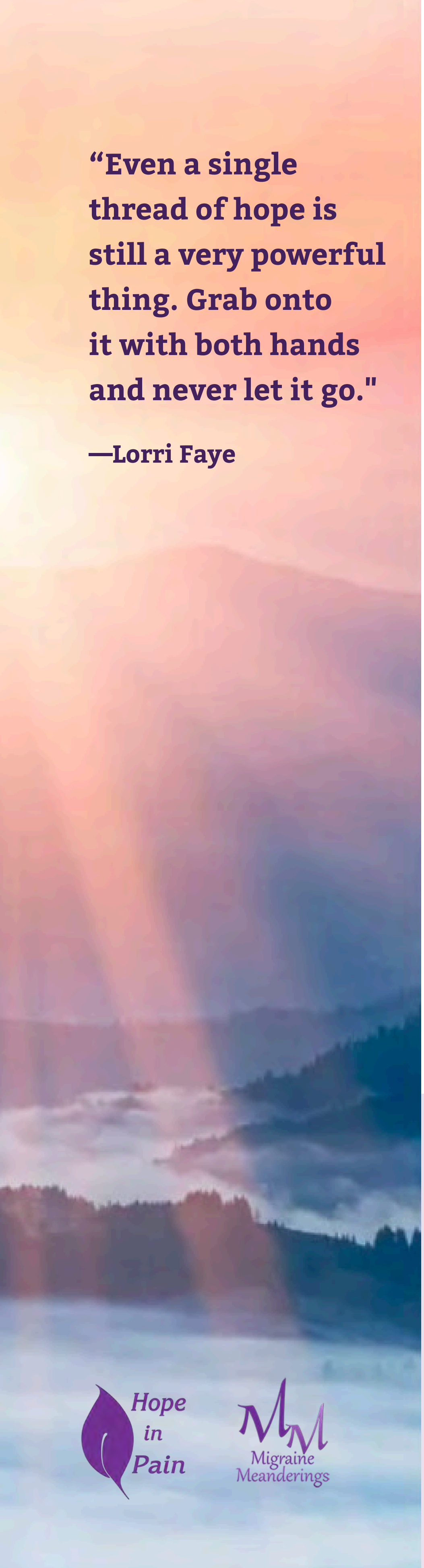
MONDAY, OCTOBER 21, 2024 - 8PM ET
(7PM CT, 6PM MT, 5PM PT)

NEW BLOG POST

Managing Migraine at Work:
Strategies for Success

www.MigraineMeanderings.com

> "Knowledge is power! Having been diagnosed over 25 years ago with migraine, I realize how important it is to not only educate yourself, it is equally important to pass knowledge along."
>
> **—Andrine, Chronic Migraine Patient**



> “Even a single thread of hope is still a very powerful thing. Grab onto it with both hands and never let it go."
>
> —Lorri Faye

LOOKING AHEAD

Holding on to hope.

When we combine the strength and resilience of people living with migraine with the support of donors like you, we can truly bring migraine “out from the shadows” and help patients improve their quality of life.

Currently, there is a crucial need for:

- Educated, informed and compassionate healthcare providers
- Effective and affordable treatment options
- Increased societal awareness and understanding
- Better accommodations and support in workplaces, schools, etc.
- Assistance in navigating through the healthcare system
- Easily understood information about treatment options
- Dispelling myths and outdated information about treatment options and the real-world impact of this disease
- Communication and support that offers real hope

People with migraine disease need our help, but we cannot do this work alone. **Will you support our non-profit organization** as we work to develop more awareness-raising initiatives, create new education events and resources, and continue to empower patients to share their voices?

Please consider giving a donation to support this important work and help make a difference in people’s lives. Your generosity helps us continue to share the message,

“Migraine is NOT just a headache.”

WAYS TO MAKE A DONATION:

- **Send a check to:**
  Hope in Pain
  2618 San Miguel Drive, #272,
  Newport Beach, CA 92660
- **Make a bank transfer (email us at info@hopeinpain.org for more information)**
- **Donate online at: www.MigraineMeanderings.com/Donate**

We greatly appreciate your support!

Hope in Pain

Migraine Meanderings