



U.S. PAIN
FOUNDATION



2019 Annual Report

The nation's leading nonprofit organization for chronic pain.

PROGRAMS AND SERVICES

Our Programs at a Glance

Awareness & Advocacy Programs

INvisible Project - The *INvisible Project* is a magazine and traveling display that highlights the bravery and perseverance of pain warriors through stories and photos.
invisibleproject.org

Advocacy Program - Whether meeting with policymakers, submitting letters, or rallying volunteers to act, U.S. Pain's Advocacy Program seeks to create change for pain patients across the country.
uspainfoundation.org/advocacy

Pain Ambassador Network - Pain ambassadors are volunteers who work to raise awareness about chronic pain and educate others on available resources and information.
uspainfoundation.org/ambassadors

Pain Awareness Month - During September, U.S. Pain hosts a number of activities, events, and initiatives to empower pain warriors and draw attention to the challenges they face.
uspainawarenessmonth.com

Medical Cannabis - This program seeks to increase safe, fair access to medical cannabis for people with chronic pain; it also provides credible information and resources on medical cannabis as a treatment option.
uspainmedicalcannabis.org

Education, Support & Empowerment Programs

Pain Connection - Pain Connection is a national network of peer-led support groups offered in person and over the phone; all leaders receive evidence-based training from a licensed social worker.
painconnection.org

Pediatric Pain Warrior Program - The Pediatric Pain Warrior Program offers hope and resources, and brings together children and their families for educational events.
pediatricpainwarrior.org

Living with Pain - This dedicated section of our website and corresponding print booklet provide detailed tips for living day-to-day with chronic pain.
uspainfoundation.org/living-with-pain

Pain Education Portal (PEP) Talks - This program offers hour-long educational webinars featuring renowned experts on topics from meditation to clinical trials.
uspainfoundation.org/webinars

KNOWvember - Each November, the organization takes a closer look at a particular topic through online events, social media content, and fun activities for pain warriors.
uspainfoundation.org/knowvember

Share Your Story Storybank - U.S. Pain invites people with pain to share their stories online; in return, they receive a kit in the mail chock full of resources and information.
uspainfoundation.org/share-your-story

For Clinicians

National Coalition of Chronic Pain Providers and Professionals (NCCPPP) - This network of health providers, professionals, and organizations offers education, networking opportunities, and more.
nccppp.org



To our valued supporters,

Right now, 50 million Americans live with unrelenting pain. Tragically, nearly 20 million of them live with high-impact chronic pain, or pain that frequently limits daily activities. Pain continues to be the leading cause of disability, and the number one reason patients go to the doctor. We know pain costs at least \$635 billion annually, and that's not to mention the toll it takes on quality of life—for both the individual and the entire family. Pain has far-reaching, biopsychosocial effects; one report found that at least 10 percent of all suicide cases in the United States involve someone with chronic pain.

Meanwhile, our treatment options are imperfect at best. Multidisciplinary care is often too expensive or otherwise inaccessible to the average patient, and conventional quick fixes offer limited results, not to mention risks and side effects. Experts extoll the virtues of multimodal, comprehensive pain management, but most insurers have done little to make it financially feasible, and clinicians typically are not empowered with the tools, time, and training it takes to provide integrative care.

The Pain Management Best Practices Report, released in 2019 under the auspices of the Department of Health and Human Services, provided a glimmer of hope for those suffering. But we are still waiting for its recommendations to be implemented.

Until our nation truly prioritizes solving the problem of chronic pain, and especially in light of the added challenges of COVID-19, organizations like the U.S. Pain Foundation remain essential in filling gaps in our health care system and social safety nets.

It is our honor and privilege to serve this community, but I look forward to the day when our programs and services are no longer needed. A day when patients do not have to fight for basic rights, needs, and help.

For now, thank you for recognizing the immense challenges people with pain face. **Through your continued support, I believe we can change the paradigm.**

Sincerely,

A handwritten signature in black ink that reads "Nicole Hemmenway". The signature is fluid and cursive, with a long, sweeping tail on the "y".

Nicole Hemmenway
CEO, U.S. Pain Foundation

In this Report:

Programs and
Services

Community
Testimonials

2019 Milestones and
Accomplishments

Our Sponsors

COMMUNITY TESTIMONIALS

How We Help

I am a U.S. Pain ambassador and a facilitator of a chronic pain support group. U.S. Pain is my support system and gives me the feeling that what I do matters in this world of chronic pain. The members of this organization are part of my extended family.



Ernie Merritt,
2019 Ambassador of the Year,
INvisible Project participant, and
support group leader

As a pain specialist who treats patients with very complicated chronic pain problems, I gladly recommend the U.S. Pain Foundation as a trusted resource to my patients. The U.S. Pain Foundation is comprised of a passionate, caring, and knowledgeable group of volunteers that touch the lives of so many in need of guidance and support.



Peter Abaci, MD,
author and medical director of
the Bay Area Pain and Wellness
Center

I've suffered from chronic pain for over a decade. I'm a very sociable person and enjoy engaging in community organizing activities. My pain is very sporadic and had taken away my ability to engage in my community. The U.S. Pain Foundation has given me another opportunity to support others with chronic pain in a meaningful way.



LaSheila Yates,
INvisible Project participant, support group leader, and ambassador

U.S. Pain Foundation continues to support the need for a patient-centered approach to advocacy and policy-making. Approaching things from a person-centered perspective has never been more important as it is now.



Vanila Singh, MD, MACM,
chair of Pain
Management Best
Practices Task Force
and Stanford University
pain specialist

U.S. Pain has made a tremendous impact in my and my family's life. Specifically, the Pediatric Pain Warrior Program has provided hope, friendship, and inspiration to my children and joy to us as parents. The amazing retreats have given us the unique gift and opportunity to meet others who truly understand our struggles and triumphs. We know we aren't alone anymore.



Johanna Young,
Pediatric Pain
Warrior parent and
ambassador

Through their various programs, my children and I have been encouraged, equipped, and empowered to become the best possible version of ourselves. The greatest gifts we have been given by the foundation, however, are the connections made with other families. Simply put, the U.S. Pain Foundation and the Pediatric Pain Warrior Program have changed our lives.



Jennifer Potter,
Pediatric Pain Warrior parent
and ambassador

I am a disabled veteran. U.S. Pain Foundation has let me know I am not alone and there are others out there that hurt as I do and are there for me. They have helped me to live and want to live a better quality of life and to not focus so much on myself, but others also.



Kraig Morris,
veteran and ambassador

U.S. Pain Foundation has provided me with tools and resources to support myself as a chronic migraine patient and also lead a group to support others. I am always reminded that the load I carry won't break me down if I change the way I carry it.



Anikah H. Salim,
support group leader

Working with U.S. Pain Foundation and its community members through my virtual reality/biofeedback app, my team has been able to see firsthand the impact they have made on chronic pain warriors and their families.



Celine Tien,
founder of Flowly

The U.S. Pain Foundation is the only patient advocate group that is working on behalf of all pain patients, old and young alike. Whether it's influencing federal and state policy, empowering and training people to advocate, or educating people on issues that are important to them, the organization is ALWAYS focused on the patient.



Ed Coghlan,
former editor-in-
chief of *National
Pain Report*

The U.S. Pain Foundation helps me along my pain journey in so many ways. They welcome me into a community of people with whom I find acceptance and understanding. They alert me to committees, reports, and activities that impact my access to care and teach me how to advocate for myself and others to make sure our needs are met.



Heidi Brehm,
ambassador and
Headache on the
Hill participant

2019 MILESTONES AND ACCOMPLISHMENTS

State and Federal Advocacy



Cindy Steinberg made national headlines as **ONE OF FOUR INVITED EXPERTS** at a Congressional hearing on pain and the opioid crisis before the Senate Health, Education, Labor and Pensions (HELP) Committee.

Launched the **INvisible Project** state advocacy tour, with events in Rhode Island and California.

At the national level, held 32 VISITS with federal policymakers, wrote three letters on federal issues, and signed on to six group letters.

At the state level, wrote 45 LETTERS on state issues, signed on to six group letters, and testified in person six times.

Sponsored 23 INDIVIDUALS with migraine and headache diseases to attend Headache on the Hill, an annual advocacy day.



Engaged a record 2,224 ADVOCATES to send emails to their policymakers through 23 total state and federal campaigns.



ORGANIZED A PATIENT LISTENING SESSION at the Food & Drug Administration with **three individuals** with osteoarthritis and one caregiver.

Cindy Steinberg *served as* **THE ONLY PATIENT AND PATIENT ADVOCATE on the Pain Management Best Practices Task Force.**

Steinberg also led the Consumer Pain Advocacy Task Force in submitting joint comments on the final report.

Participated in 32 STATE AND NATIONAL COALITIONS, and led two coalitions at state and national levels.



Gwenn Herman, LCSW, DCSW, Clinical Director of Pain Connection, served on the **INTRA-AGENCY PAIN RESEARCH COORDINATING COMMITTEE**, the highest ranking permanent pain policy committee in the United States.



24 U.S PAIN VOLUNTEERS *received in-depth training* at a weekend-long Advocacy Summit in Dallas, TX, featuring presentations, panels, and interactive workshops.

Education, Empowerment, and Support



HELD TWO Pediatric Pain Warrior weekend retreats in Gurnee, IL, and San Antonio, TX, which were **attended by 327 KIDS AND FAMILY MEMBERS** total.

Mailed 1,254 resource kits, helped deliver **250 migraine “triage kits,”** and distributed **15,288 pain warrior bracelets.**

Published 32 ARTICLES in our educational blog, “Remedy.”

Catalogued 555 STORIES from pain warriors via our Storybank.



Expanded to 19 IN-PERSON SUPPORT GROUPS and five monthly support calls, helping an **estimated 1,434 PATIENTS** total.



Trained 32 PEER LEADERS and mental health professionals at two Pain Connection support group trainings in San Francisco, CA, and Newark, NJ.



Held **22 ONLINE EDUCATIONAL EVENTS** on topics ranging from acupuncture to pharmacogenetics, which **were watched live or as recordings 10,493 TIMES.**

Organized a creativity-themed **KNOWEMBER CAMPAIGN**, featuring three interactive events, and artwork and writing submissions from **81 PAIN WARRIORS.**



Exhibited the ***INvisible Project*** and handed out free materials at **35 events and conferences.**



Collaborated with **HealthUnion** on a large-scale survey, "Chronic Pain in America," which **received 4,725 RESPONSES.**



Developed a **16-PAGE TREATMENT GUIDE**, "Living Well with Chronic Pain," **distributing 1,613 COPIES** over four months.

Partnered with **FIVE PATIENT GROUPS** on a special research report, "Chronic Pain Assessment: Patient Perspectives."

Awareness and Outreach



Coordinated a Pain Awareness Month campaign, #LetsTalkAboutPain, featuring 31 PATIENT VIDEO STORIES, which were *viewed nearly 12,000 TIMES* in four months.

Grew mailing list to 23,000 SUBSCRIBERS, and volunteer network to 2,313 INDIVIDUALS.

Volunteers and staff **obtained 51 STATE AND LOCAL PROCLAMATIONS** and **lit up 40 LANDMARKS** in blue during Pain Awareness Month.



Volunteers and staff **hosted EIGHT IN-PERSON fundraising events** and **28 ONLINE FUNDRAISERS.**



Presented to 290 TOTAL MEDICAL STUDENTS and **health care providers** at Brown University, John Hopkins University, and Massachusetts General Hospital.



Staff invited to share patient perspective with numerous organizations, including

HealthyWomen, the Marfan Foundation, Americans for Safe Access, the Alliance for Balanced Pain Management, RetreatMigraine, and others.

NICOLE HEMMENWAY, CEO, served as a **keynote speaker** at the **American Massage Therapy Association Annual Conference.**

Team members were highlighted or quoted 49 TIMES in **media outlets**, including the *Hartford Courant*, *New Hampshire Union Leader*, *National Pain Report*, *Practical Pain Management*, *MedPage Today*, and *NBC News*.

Collaborated with BOWTIE CAUSE and **Fox Sports** announcer **Ken Rosenthal** to launch a Pediatric Pain Warrior-themed fundraising initiative.



Published TWO ISSUES of the **INvisible Project** and **ONE SPECIAL EDITION** for RetreatMigraine, with **20,250 COPIES** total distributed.



Co-sponsored ONE FEATURE-LENGTH DOCUMENTARY on invisible illness: **Becoming Incurable.**

Reached 243,000 FOLLOWERS across Facebook, Twitter, Instagram, and YouTube.

OUR SPONSORS

Thank you!

The programs and services of the U.S. Pain Foundation would not be possible without the support of our donors. Their contributions help advance our mission of improving the lives of people with pain. Detailed information about all of our donors, including private donations, can be found on our website, uspainfoundation.org.

We'd like to give special thanks to our 2019 Corporate Council members:

..... Senior Leaders



..... Members







U.S. PAIN
FOUNDATION

uspainfoundation.org