Dear friends and supporters,

For many people, the COVID-19 pandemic was the first time they were forced to confront a truly life-altering challenge. An obstacle that, at best, impacted nearly every aspect of life: work, school, family, social activities, and hobbies, and, at worst, resulted in the tragic loss of life and human potential.

While the introduction of vaccines has added some level of protection for millions across the country, the uncertainty, isolation and suffering that became so familiar during the COVID-19 crisis will only continue for the 50 million Americans who live with chronic pain. Pain remains the number one reason people visit the doctor, the leading cause of long-term disability, the cause of $635 billion in expenditures, and an immeasurable source of suffering (nearly 10% of suicides involve someone with pain).

While the pandemic has taught us all so much about what matters in life and the fragility—and resilience—of humankind, I also hope it offers valuable lessons about our interconnected health as a society and the need for empathy for the chronically ill.

With that in mind, let me express my deepest gratitude for your continued support of the U.S. Pain Foundation. There has never been a more important time to continue to provide help and hope to people with pain.

Sincerely,

Nicole Hemmenway
CEO
U.S. Pain Foundation

Note: U.S. Pain moved its headquarters in 2021. Its prior mailing address was 670 Newfield St #2, Middletown, CT 06457
OUR TEAM

Staff

Nicole Hemmenway
CEO and Director of the INvisible Project

Pamela Lynch
CFO

Emily Lemiska
Director of Communications & Educational Programming

Cindy Steinberg
Director of Policy & Advocacy

Gwenn Herman
LCSW, DCSE, Clinical Director of Pain Connection

Malcolm Herman
Director of the National Coalition of Chronic Pain Providers and Professionals

Casey Cashman
Director of Fundraising and the Pediatric Pain Warrior Program

Ellen Lenox Smith and Stu Smith
Co-Directors for Medical Cannabis Advocacy

Jose Garcia
Web Design and Graphics

Michaela O’Connor
Community Outreach and Communications Specialist

Janet Jay
Communications Specialist

Katie Golden
Migraine Advocacy Liaison

Lori Monarca
Office Manager

NEW HIRES IN 2021

Scott Rogers
Director of Communications

Johanna Young
Assistant Director of the Pediatric Pain Warrior Program

Board of Directors
U.S. Pain is proud to have a passionate group of directors, three of whom joined in 2020.

Edward Bilsky, PhD
Treasurer

Jessica Begley, MFT
Secretary

Shawn Dickens, MBA
Chairperson

Ellen Lenox Smith
Marv Turner

Disparities Solutions Advisory Council
In 2020, U.S. Pain formed this group to improve health equity and inclusion within the chronic pain community.

Calvin Eaton, MEd, MS
Elisa Friedlander, LMFT
Janet Jay
Isiah Lineberry
Sheila Jones Lineberry, MA
LaQuinda McCoy, RN
Diana Nunez, RN
Jose Nunez
Linda Shaw
LaSheila Yates, MA, SHRM-CP, CPM
PROGRAMS AND SERVICES

Our programs at a glance.

Awareness & Advocacy Programs

INvisible Project - The INvisible Project is a print and online magazine that highlights the bravery and perseverance of pain warriors through stories and photos.

State and Federal Advocacy - We fight for change at the state and federal level on a range of priority issues related to pain care.

Pain Awareness Month - During Pain Awareness Month in September, U.S. Pain hosts a number of activities, events, and initiatives to empower and educate pain warriors and increase awareness about pain.

Medical Cannabis - U.S. Pain’s Medical Cannabis program seeks to increase safe, fair access to medical cannabis for people with chronic pain. It also aims to provide education and resources on medical cannabis as a treatment option.

Educational Programs

About Pain - This dedicated section of the U.S. Pain website, along with a corresponding 16-page print booklet, provides detailed information about how to live day-to-day with chronic pain.

MyPainPlan.org - This interactive site allows individuals to explore 85+ types of treatment across seven categories of pain management. Users can then create a personalized list of treatments to discuss with their health care provider.

Webinars and Pain Education Portal - U.S. Pain offers educational webinars featuring renowned experts on topics ranging from meditation to clinical trials.

*NEW* Building Your Toolbox - This monthly educational series invites practitioners to teach individuals a pain management strategy or skill. Unlike traditional webinars, events are held in a meeting format so that participants can interact with the speaker directly.

KNOWvember - Each November, this educational campaign takes a closer look at a particular topic through events, informative materials, and social media content. Past topics include creativity through pain and neuromodulation.

Educational Materials - U.S. Pain regularly creates informational handouts and worksheets, all of which are available free of charge.

Support & Empowerment Programs

Volunteer Network - This volunteer network raises awareness about chronic pain, educates those living with pain on available resources, and advocates for change at all levels of government.

Pain Connection - A national network of support groups, Pain Connection provides compassionate support and evidence-based education to help people with pain reclaim their quality of life. The support groups, which are offered nationally and by state, are led by individuals who receive comprehensive training from a licensed social worker.

Pediatric Pain Warrior Program - The Pediatric Pain Warrior Program assists children and their families in finding a network of support and resources. This program offers in-depth retreats and programming featuring expert speakers, workshops, and more.

Share Your Story Storybank - U.S. Pain invites people with pain to share their stories online. Each person who submits details about their pain journey receives a packet of information and resources, along with a pain warrior bracelet, in the mail.

Clinician Programs

*NEW* Patient Professors Program - The Patient Professors Program creates a forum for patients to educate medical students about their lived experiences and how to provide more patient-centered care.

National Coalition of Chronic Pain Providers and Professionals - This network of health providers, professionals, and organizations has come together in a coalition to more effectively serve the chronic pain community. It offers networking, education, and more.
2020 IN A SNAPSHOT

THREE NEW BOARD MEMBERS

TWO NEW PROGRAMS

135,386 total unique visitors to our websites

26,800 email subscribers

2,087 volunteers

219,517 Facebook followers

15,629 Twitter fans

4,412 Instagram followers

649 YouTube subscribers

THREE NEW BOARD MEMBERS

TWO NEW PROGRAMS

219,517 Facebook followers

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649 YouTube subscribers
ADVOCACY RESULTS

Moving the needle on pain care nationally

- U.S. Pain spearheaded two group letters to Congressional committees, signed by 49 and 30 groups respectively, urging them to implement recommendations of the Pain Management Best Practices report.

- U.S. Pain’s Gwenn Herman, LCSW, DSCW, took part in two virtual meetings as a member of the Interagency Pain Research Coordinating Committee, the highest-ranking permanent pain policy committee in the United States.

- In partnership with the Alliance to Advance Comprehensive Integrative Pain Management, U.S. Pain co-hosted a symposium, “Equity in Access to Comprehensive Integrative Pain Management in Chronic Pain.”

- In response to a January congressional hearing on cannabis, U.S. Pain ran an action campaign to urge a second hearing and team member Ellen Lenox Smith published an op-ed in Morning Consult.

- U.S. Pain submitted a five-page letter to the Centers for Disease Control and Prevention, urging it to incorporate recommendations of the Pain Management Best Practices report as it revises the 2016 guidelines.
State-level impacts

- In honor of Migraine and Headache Awareness Month, the INvisible Project State House tour went virtual, with a video and action campaign. **200 individuals took part in the campaign.**

- U.S. Pain led a coalition in New Hampshire to **urge insurer coverage of a wider range of therapies** for chronic pain.

- **Kentucky State Rep. Cherlynn Stevenson** spoke at a U.S. Pain webinar about state advocacy and her bill to increase coverage for pain therapies.

- A bill Cindy Steinberg helped pass in 2018 took effect as of January 1, 2020 in Massachusetts; now, payers must cover two alternate medications and three alternate non-medication pain options.

- In Rhode Island, Ellen Lenox Smith’s advocacy helped introduce a **new bill aimed at increasing the affordability of medical cannabis.**

Empowering grassroots advocates

- A five-part online training series **enrolled 32 patient advocates,** featuring story-telling workshops, role-play scenarios, and expert speakers.

- The training series and a webinar featuring Vanila Singh, MD, led up to our #APlanforPain virtual advocacy day in June. **More than 750 people in 49 states took part** to send emails, tweet, and call their legislators about chronic pain-related budget asks.

- We sponsored **15 migraine advocates to attend Headache on the Hill**—an annual advocacy day that brings patients and providers together in Washington, D.C.—and held an event to connect 24 INvisible Project participants and writers.

In 2020, **a total of 1,300 individuals took action through 25 state and national advocacy campaigns.**
More than 1,700 patients created custom pain care plans using the site, MyPainPlan.org, which U.S. Pain launched as part of Pain Awareness Month. The site features in-depth information about 80+ multidisciplinary treatment options.

**GETTING PATIENTS THE INFORMATION THEY NEED MOST**

**Bringing information to patients’ fingertips**
- In 2020, U.S. Pain held 19 educational webinars on topics ranging from yoga to over-the-counter medications with a total of 1,272 live attendees, 2,483 recording views, and 18,723 views on Facebook Live.
- We also distributed 644 resource kits and 1,579 Living Well with Chronic Pain booklets.

**Tackling timely and complex topics**
- U.S. Pain held five COVID-19 related webinars. Our COVID-19 resource webpage collated over 30 resources to help individuals navigate the crisis.
- U.S. Pain’s 2020 KNOWvember campaign, #NeuromodulationKnowledge, covered the world of neuromodulation, with two webinars and one Twitter chat featuring leading experts in the field; three infographic resources; and a myths and facts series on social media.
- During Migraine and Headache Awareness Month, U.S. Pain hosted two webinars on cluster headache and disparities in migraine care.

**Educating providers**
- Thanks to Board Member Ed Bilksy, PhD, and in partnership with the Pacific Northwest University of Health Sciences, U.S. Pain co-hosted its first CME on COVID-19 and pain.
- U.S. Pain staff spoke about pain to 435 total medical students at leading institutions like Johns Hopkins University, Tufts University, and Brown University.
A different kind of support group
• Before the pandemic hit, U.S. Pain brought 25 individuals to San Diego for a weekend of in-depth training on how to run a successful support group that is rooted in education and empowerment.

• In honor of a late volunteer and support group leader, U.S. Pain established the Sue Ann Stelfox Scholarship to cover travel expenses for future in-person leader trainings.

Pivoting to meet patient needs
• With people increasingly turning to social media as a resource, Gwenn Herman, LCSW, DCSW, began hosting weekly Facebook Lives to highlight support resources.

• In light of the pandemic, U.S. Pain transitioned its in-person groups to be virtual or by phone, reaching more people than ever before.*

*Due to COVID-19 and the cancellation of many groups/transition to virtual groups, this year we do not have exact numbers of attendees.
A total of **338 kids with pain and their family members** participated in the first-ever virtual retreat.

**During the retreat, which spanned eight months,** we held seven educational webinars, 10 fun live events plus a biweekly videogame night, provided two advocacy opportunities, and offered four monthly or bimonthly support groups targeted to dads, moms, teens, and preteens.

**Grassroots fundraising**

Several special fundraising campaigns benefitted the Pediatric Pain Warrior Program.

- Tyler Cashman, Director of Pediatric Fundraising, raised $2,500 at a Points for Pain game, bringing his total raised to **$110,000 over five years**.
- A new campaign, "My Marathon," encouraged kids to set a month-long goal of any kind, e.g. taking a three-mile or three-minute walk each day and getting pledges for achieving that goal. **The campaign raised a total of $8,500.**
AMPLIFYING THE PATIENT EXPERIENCE

10 decades of courageous stories
• The INvisible Project published its fourth edition highlighting migraine and headache.
• Producers from Good Morning America found the INvisible Project online and highlighted two past participants during a segment on headache and migraine.

Uncovering new data
U.S. Pain conducted two large-scale surveys and published in-depth reports on its findings.
• The first survey collected information from 664 individuals with pain about the impact of COVID-19. The 18-page report was covered in Practical Pain Management, Psychology Today, and MarketWatch.
• In honor of Pain Awareness Month, the second survey drew details from 1,581 people with pain on barriers to individualized, multidisciplinary care. The report was covered in the American Journal of Managed Care, Pulmonary Hypertension News, and highlighted at the Alliance to Advance Comprehensive Integrative Pain Management pain equity symposium.

Reaching out
• Despite cancellation of many in-person events, U.S. Pain still participated in or spoke at a number of meetings and conferences for organizations including: the Society for Pediatric Pain Medicine, the Orthopedic Research Society, the American Academy of Pain Medicine, RetreatMigraine, the Duke-Margolis Health Policy Center, and the Protecting Access to Pain Relief Coalition.
• U.S. Pain’s efforts or team members were mentioned or featured in 24 articles, from Health Union to Arizona Public Media.

In 2020, the INvisible Project celebrated its 10th anniversary, with a total of 19 editions published, more than 100,000 copies distributed, and 200 patients featured to date.
The programs and services of the U.S. Pain Foundation would not be possible without the support of our donors. Their contributions help us improve the lives of people with pain.

We’d like to give special thanks to our 2020 Corporate Council members:

**Senior Leader**

![Lilly logo]

**Members**

![AMGEN, Boston Scientific, Centrexion, Salix Pharmaceuticals, Primus Pharmaceuticals, Johnson & Johnson logos]

Detailed information about all of our donors, including private donations, as well as our 2020 990 Return and Audited Financial Statements, can be found on our website.
Thank You

It is only through the support of our donors, volunteers, and community that we are able to make a difference in the lives of people with pain. Thank you.

HELP US MAKE AN IMPACT:

DONATE > VOLUNTEER > SUBSCRIBE >