



U.S. Pain Foundation 2020 Annual Report
“New challenges, new opportunities”



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



GET IN TOUCH



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West Hartford, CT 06107

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, DCSW,
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
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Specialist



Katie Golden
Migraine Advocacy
Liaison



Lori Monarca
Office Manager



Scott Rogers
Director of
Communications



Johanna Young
Assistant Director of the
Pediatric Pain Warrior Program

NEW HIRES IN 2021

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.

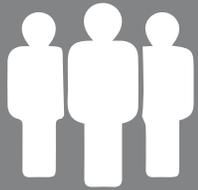
Share Your Story Storybank - U.S. Pain invites people with pain to share their stories online. Each person who submits details about their pain journey receives a packet of information and resources, along with a pain warrior bracelet, in the mail.

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



U.S. Pain’s advocacy efforts, led by Cindy Steinberg, **were successful in getting chronic pain-related appropriations language included** in both House and Senate FY2021 Reports.

[READ THE LANGUAGE >](#)

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.

ADVOCACY RESULTS

(CONTINUED)

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.

[GET INVOLVED >](#)

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.

[VISIT MYPAINPLAN.ORG >](https://www.mypainplan.org)



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.



In May, Pain Connection launched a new program, “Building Your Toolbox,” in which an expert speaker discusses a therapy for 10 minutes and then fields live questions and encourages dialogue amongst patients for an hour or more. **More than 250 total attendees joined the meetings.**

[EXPLORE OUR SUPPORT OFFERINGS >](#)

EVIDENCE-BASED SUPPORT

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.**

HELP FOR OUR MOST PRECIOUS PATIENTS KIDS

- 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.**



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.

[VIEW THE LATEST ISSUE >](#)

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.

OUR SPONSORS

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

The Lilly logo is written in a red, cursive script font.

Members

The AMGEN logo consists of the word "AMGEN" in a bold, blue, sans-serif font.The Boston Scientific logo features the words "Boston Scientific" in a blue serif font, with the tagline "Advancing science for life™" in a smaller blue font below it.The CENTREXION logo features the word "CENTREXION" in a blue, sans-serif font, with a blue starburst graphic to the right of the letter "O".The Salix Pharmaceuticals, Inc. logo features the word "Salix" in a blue, serif font, with a green circular icon containing a stylized plant to the right, and "PHARMACEUTICALS, INC." in a smaller blue font below.The PRIMUS PHARMACEUTICALS logo features a stylized "P" icon composed of red and yellow shapes to the left of the word "PRIMUS" in a blue, sans-serif font, with "PHARMACEUTICALS" in a smaller blue font below.The Johnson & Johnson logo features the words "Johnson & Johnson" in a red, cursive script font.

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.

[VIEW FUNDING & FINANCIALS >](#)

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:

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