



A YEAR OF SUCCESS

2022 ANNUAL REPORT



A LETTER FROM OUR CEO



We know that 50 million Americans live with chronic pain, or pain that lasts most days or every day for three months or more. Of this group, nearly 20 million experience high-impact chronic pain, or pain that interferes with basic functioning and activities of daily living. Pain is the number-one reason that Americans access the health care system, and it costs the nation up to \$635 billion each year in medical treatments, disability payments, and lost productivity.

Despite these staggering numbers, chronic pain is vastly under-recognized, underfunded, and under-treated when considering its significant impact on American lives. Research, treatment options, and support for those affected individuals still lag behind other major diseases.

In essence, not enough is being done for the management of chronic pain in America.

This is why we, as an organization, remain steadfast in pulling back the veil to increase awareness of chronic pain as a disease itself while highlighting what life with daily pain looks like for 20% of the population.

This annual report offers an overview of how we addressed the challenges patients faced in 2022 and our efforts to elevate the patient voice, increase disease-state education, discuss top policy challenges, expand outreach to underserved and marginalized communities, and provide comprehensive resources to ensure people with chronic illnesses or serious injuries that lead to chronic pain are supported and empowered along their journeys.

It is our honor and privilege to serve this community. Thank you for recognizing the need for our programs and services. There is much more work to be done, and so many more pain warriors that need our help. But with your continued support, I believe we can move the needle toward a better future for people with pain.

Sincerely,

Nicole Hemmenway
CEO, U.S. Pain Foundation

TABLE OF CONTENTS

04

By The Numbers

05

A Chronic Pain Crisis

06

INvisible Project

07

Mental Health and Support

08

Advocacy

10

Pediatric Pain

11

Awareness Efforts

12

Educational Endeavors

13

Campaigns

14

Our Corporate Council

BY THE NUMBERS



228,116

SOCIAL MEDIA
FOLLOWERS



30,479

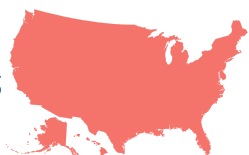
INDIVIDUALS ON
MAILING LIST



4,703

ACTION
ALERT
ADVOCATES

VOLUNTEERS IN **50** STATES



MEMBER OF **17**
COALITIONS
OR ALLIANCES

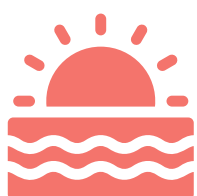


SUBMITTED **3** COMMENT
LETTERS TO FDA, CMS, AND CDC



62

EVENTS AND
WEBINARS



50 FAMILIES

ATTENDED FIRST-ANNUAL
PEDIATRIC PAIN WARRIOR
FAMILY SUMMER CAMP



HOSTED **2** ONLINE CHRONIC
PAIN SUPPORT GROUP
LEADER TRAININGS



TRAINED
25 ADVOCATES
THROUGH ONLINE
ADVOCACY
TRAINING SERIES



FACILITATED **396**
CHRONIC PAIN
SUPPORT GROUPS



DISTRIBUTED
24,394

EDUCATIONAL
MATERIALS TO
PATIENTS,
CAREGIVERS,
AND HEALTH
CARE
PROFESSIONALS



PUBLISHED
THREE
INVISIBLE
PROJECT
MAGAZINES



U.S. PAIN STAFF
MEMBERS
QUOTED IN **10**
NATIONAL NEWS
MEDIA ARTICLES

A CHRONIC PAIN CRISIS

Pulling back the veil on chronic pain.

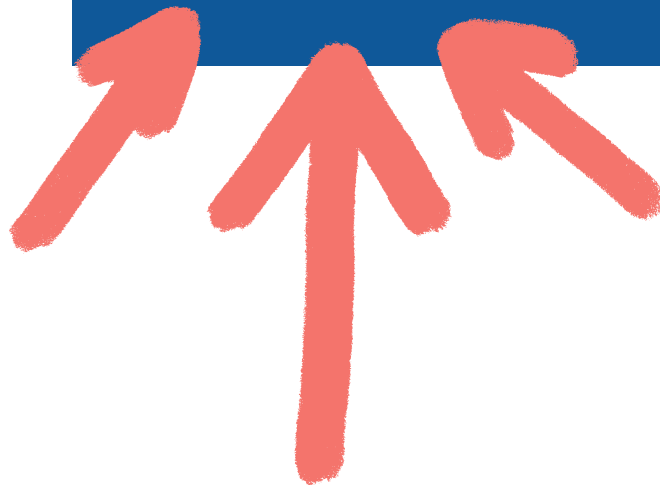
Between March 29 to April 12, 2022, the U.S. Pain Foundation conducted a nation-wide comprehensive survey to better understand the public health crisis of chronic pain. Topics explored included types of pain, ability to work, patient-provider relationships, treatment options, mental health, and more.

2,378 individuals responded. Respondents included 31 health care professionals, 72 caregivers, and 2,275 people with chronic pain, with chronic pain being defined as pain lasting three months or more.

By and large, the results clearly underscore the enormous gap in patient care. Key findings include:

1. Chronic pain has **devastating consequences** on function, quality of life, and mental health.
2. At best, people with pain feel their health care providers are not equipped to manage their pain effectively; at worst, people with pain feel **unsupported and stigmatized**.
3. Medications remain the **most effective treatment option**, but people with pain face significant barriers in accessing certain drugs.
4. Due to high out-of-pocket costs—coupled with pain's drastic impact on the ability to work—**cost remains the primary barrier** to pain care.
5. Multidisciplinary approaches, particularly self-management techniques, are **under-recognized components** of effective pain management.

- 71% said they considered themselves to be disabled
- 99% reported pain has restricted their ability to engage in routine activities
- 79% feel stigmatized because of pain
- 30% reported living with 6-10 conditions
- 52% reported an average pain level of 7 or more
- 53% said their current provider doesn't or only sometimes helps them understand different options for managing chronic pain
- 24% said NO side effect would prevent them from trying a medication to manage pain
- 35% reported one or more of their conditions is the result of trauma or injury



INvisible Project

U.S. Pain believes every person has a unique story to tell. Getting to know an individual and what they have experienced has a multiplying effect, changing the way society and the field of medicine view pain—one story at a time.

As the flagship program of the U.S. Pain Foundation, the *INvisible Project* shares the personal stories and photographs of people living with chronic pain in a print and online magazine. The goal is to show the reality of life with pain—both the major challenges and the small triumphs. It also serves as a way to highlight the unique journey of each person with pain, and the necessity of finding an individualized treatment plan. In addition to opening the eyes of health care providers, policymakers, and members of the public to the reality of chronic pain, the *INvisible Project* helps those living with pain know that they're not alone. Beyond compelling patient stories, each edition includes articles featuring leading experts on timely topics, ranging from the value of clinical trials to self-management strategies for pain.

In 2022, the organization published three different magazines, added a “subscribe” option so individuals could automatically receive the latest magazine upon printing, and implemented QR codes on each article and patient profile for easier sharing and saving.

- Magazines published:
 - Health Care Disparities: 2nd edition
 - Neuropathic Pain
 - Acute-to-Chronic Pain
- 2,900+ magazines immediately shipped to individuals, doctor's offices, and providers upon the latest magazine printing
- Individuals have scanned the QR codes in the magazines to find stories online version in 21 states, plus Washington, D.C.



Mental Health and Support

Finding community support is essential to living with chronic pain.

Chronic pain has devastating consequences on mental health, and the intersection between chronic pain and mental health is not being adequately addressed. From our survey, we discovered that nearly 60% of respondents felt anxiety-like or depression-like symptoms daily or a few times a week. However, 38% respondents reported that their current health care professional DOES NOT ask about their mental health or if they are experiencing feelings of anxiety or depression.

As an organization, we are committed to removing the stigma of mental health and chronic pain through education and our monthly support group meetings. Our utmost goal is for individuals to connect in a safe environment to share feelings, gain emotional support, discover strategies for coping with the daily realities of pain, feel more empowered to take an active role in their care, and learn about pain relief options.

- Facilitated 33 Pain Connection chronic pain support groups monthly
 - 5 national meetings
 - 18 state-based location groups
 - 10 specialized population groups
- Initiated a mentoring program for new leaders
- Hosted two online chronic pain support group leader trainings
- Continued to host a weekly Facebook Live: “Mindful Mondays”
- 2,100+ individuals signed up for upcoming support group reminder emails



Advocacy

People living with chronic pain are underserved relative to its enormous impact and face significant obstacles each day ranging from stigma to lack of access to multidisciplinary pain care. Speaking up for these individuals is the only way to move the needle on greater understanding and effective, equitable care.

We are dedicated to making sure people with pain are heard by policymakers at both the state and federal level. Our objectives are ensuring that pain advocates have a solid understanding of the most pressing issues facing people with pain today, feel informed about the legislative and regulatory process, know when their participation matters most, and have the resources and tools they need to share their stories. Secondly, we seek to improve health outcomes by advocating for access to multidisciplinary care; increases in payer coverage; reductions in harmful utilization management practices; improvements in provider knowledge about best practices; permanent expansion of telehealth coverage; and more.



Pain Advocates in Action

- 2,000+ messages sent to Congress members during our Virtual Advocacy Day urging CMS to cover more options for pain
- Trained 25 volunteer advocates through a six-part Virtual Advocacy Training Series

Medical Cannabis Advocacy

- Started a monthly Facebook Live to provide a better understanding of medical cannabis
- Submitted a letter to the Speaker of the House and Minority Leader urging the advancement of clinical research on CBD and marijuana
- Advocated for the Medical Marijuana and Cannabidiol Research Expansion Act, which passed the Senate and was signed into law by President Biden

Advocacy Efforts

- Signed on to more than a dozen sign-on letters
- Successful in getting Appropriations Report Language directing CDC to conduct and report on population health data on chronic pain in House Budget Report for FY 2023
- Successful in getting Appropriations Report Language about the dissemination of the HHS Task Force Report in the Senate Budget Report for FY 2023
- Submitted comment to CMS regarding its Physician Fee Schedule. CMS quoted our comment 12 times in the Physician Fee Schedule final rule that includes the first-ever separate codes for Chronic Pain Management
- Submitted comment about FDA's Acute Pain Guidance urging FDA to play a more proactive role engaging with developers
- Submitted comment to the CDC regarding Updated Guideline for Prescribing Opioids for Chronic Pain pointing out continued problems for people living with pain
- NPR's "All Things Considered" interviewed Cindy Steinberg, U.S. Pain National Director of Policy & Advocacy, twice to discuss the patient perspective on the updated CDC guideline



Pediatric Pain

Kids and their families face a unique set of challenges everywhere from the doctor's office to the classroom.

Millions of children live with chronic pain. With limited options available for children, this subset population within the chronic pain community is vastly underserved and underrecognized. The Pediatric Pain Warrior program seeks to address and fill those gaps so that families feel equipped with resources and support while kids feel understood.

In 2022, the program offered its first family summer camp at Morgan's Wonderland Camp, in San Antonio, Texas. For five days, pediatric pain warriors and their families participated in fun camp activities, educational sessions, and optional daily support groups. Kids and families met others living with similar conditions that ranged from migraine and headache diseases, lupus, Crohn's disease, ulcerative colitis, irritable bowel syndrome, irritable bowel disease, brittle bone disease, Ehlers-Danlos syndrome, Sjögren's syndrome, dysautonomia, psoriatic arthritis, osteoarthritis, rheumatoid arthritis, juvenile arthritis, amplified musculoskeletal pain syndrome, myasthenia gravis, musculoskeletal pain, rare diseases, and more.

For these kids, the camp was a life-changing experience. They met friends, they felt included, they gained confidence: they had the opportunity to just "be a kid."

- Hosted 50 families for a five-day camp experience at Morgan's Wonderland Camp
- Three pediatric pain warriors featured in 2023 editions of the INvisible Project
- Received a proclamation from the city of San Antonio, Texas, recognizing June 19-22 as Pediatric Pain Warrior Week
- Pediatric Pain Warrior family invited to present at Society for Pediatric Pain Medicine Annual Meeting on complex regional pain syndrome
- 15 nonprofits participated in providing support and educational material for families attending camp



Awareness Efforts

To shift the paradigm, we must focus on creating public awareness about the issues affecting people living with chronic pain.

In order to see improved access to pain care, the public, media, health care professionals, and policymakers must understand what it is like to live with chronic pain. From sharing disease-state information, to discussing challenges in receiving a diagnosis and care, to highlighting the lack of research and understanding of pain, we aim to shine a light on the barriers to living with pain.



- Started bi-monthly meet-and-greets with new volunteers to introduce them to staff, our programs, and ways to become involved
- Participated in awareness days to highlight chronic conditions and their intersection with pain, including Rare Disease Day, World Lupus Day, World Autoimmune & Autoinflammatory Arthritis Day, Migraine and Headache Awareness Month, Constipation Awareness Month, and more
- Updated Share Your Story form to collect more demographic data and disease-state information from individuals in our community who hope their experiences can make a difference in public perception of pain

Educational Endeavors

Education is fundamental in helping improve patient-provider relationships, increasing positive treatment management outcomes, and ensuring patients are more connected to the health care system.

Our 2022 survey results highlighted the need for more information. When asked, “When connecting with a patient organization, what information is the most helpful?”, the top response was informative articles quoting key experts, followed by educational webinars, educational handouts, and infographics.

We believe that disease-state and patient-focused education is vital. It is our overall goal to ensure individuals have the knowledge, access to information, resources, and confidence to advocate for better health outcomes.

- Hosted monthly educational series, Building Your Toolbox, where practitioners teach individuals a pain management strategy or skill
- Updated our Living Well With Chronic Pain educational booklet
- Translated two of our most important educational resources into Spanish: Vivir Bien Con Dolor Crónico y Disparidades 2da Edición



Campaigns

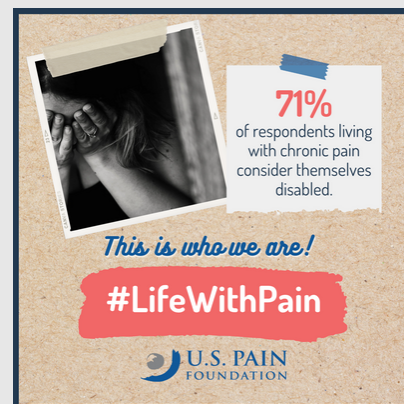
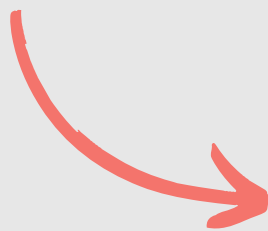
Public campaigns engage those living with pain while also creating public awareness and providing pain education. They are a way to connect with the larger public about the devastating consequences of pain on individuals, their families, their employers, and their communities, while sharing information to help the 50 million Americans living with pain.

Each year, we take the lead on two campaigns: Pain Awareness Month in September, and a month-long educational campaign in November, called KNOWvember. Our goal when developing campaigns is to share the patient perspective about living with pain as well as empower people with information and tools to assist them along their personal pain journey.

Pain Awareness Month: #LifeWithPain

The goal: to better highlight the real-life impact and devastating burden of chronic pain on the patient journey

- Social Media metrics: 10.3M reach and 43K interactions
- Published weekly articles
- Hosted a two-part webinar series with CMS participation looking at the fraught patient/provider relationship
- Shared daily social media stat
- Led a community challenge



KNOWvember: #KNOWpain

The goal: to highlight differences between acute and chronic pain, and the transition of acute-to-chronic pain

- Developed an educational handout
- 4th-most-viewed article of the year: "Acute Pain - Managing pain immediately"
- Created and shared social media facts
- Hosted a webinar looking at acute pain, chronic pain, and treatment options available



OUR CORPORATE COUNCIL

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.

We'd like to give special thanks to our 2022 Corporate Council members

