



# THE TRIALS OF PAIN: OUR IMPACT IN 2023

2023 ANNUAL REPORT



# A LETTER FROM OUR CEO



## To our valued friends and supporters:

Within the vast landscape of American health care, it's crucial to acknowledge the staggering reality: more than 51.6 million individuals grapple with chronic pain, enduring its relentless grip on their lives. Among them, a significant subset of 17.1 million face high-impact chronic pain, where even basic daily activities become arduous battles. Pain drives millions to seek help from the health care system, exacting a toll of up to \$635 billion annually in medical expenditures, disability compensations, and lost productivity.

Yet, despite its pervasive reach and profound societal implications, chronic pain remains a largely silent epidemic—under-recognized, under-funded, and tragically, under-treated. While pain exacts an immeasurable toll on countless lives, resources allocated for its research, treatment, and support still fall woefully short, trailing behind other prevalent diseases.

Indeed, the landscape of pain management in America is marked by a stark inadequacy.

In response to this pressing need, the U.S. Pain Foundation remains committed to creating awareness about chronic pain and how it is a disease in its own right. We seek to illuminate the stark realities faced by 21% of our population living with daily pain, striving to foster greater understanding and empathy.

This annual report reflects on the strides made in 2023—our tireless efforts to shine a light on the myriad challenges confronting individuals living with pain. From amplifying the voices of patients to advancing disease-state education, addressing policy hurdles, and extending outreach to underserved communities, our mission remains steadfast: to provide unwavering support and empowerment to those navigating chronic pain.

With profound gratitude, we extend our heartfelt appreciation to you, our invaluable supporters, for recognizing the need and impact of our programs and services. As we look ahead, with your unwavering support, we can continue to effect tangible change together—creating a future where the plight of pain warriors is met with compassion, understanding, and effective solutions.

Together, let us continue to champion the cause of alleviating the burden of chronic pain and uplifting the lives of those who face its challenges. There is indeed much work yet to be done.

With deepest gratitude,

*Nicole Hemmenway*  
Nicole Hemmenway  
CEO, U.S. Pain Foundation

# TABLE OF CONTENTS

**04**

By The Numbers

**05**

Advancing Research for  
Chronic Pain Act

**06**

Advocacy

**08**

INvisible Project

**09**

Mental Health and Support

**10**

Pediatric Pain

**12**

Pain Awareness Month

**13**

KNOWvember

**14**

Education and Awareness

**15**

Our Corporate Council

# BY THE NUMBERS



**228,899**

SOCIAL MEDIA FOLLOWERS



**32,330**

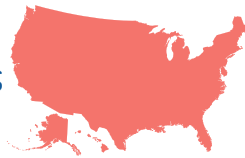
INDIVIDUALS ON MAILING LIST



**5,013**

ACTION ALERT ADVOCATES

VOLUNTEERS IN **50** STATES



MEMBER OF **20** COALITIONS OR ALLIANCES

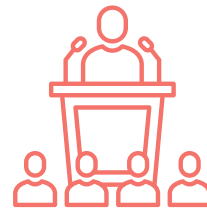


**34**

EVENTS AND WEBINARS



PRODUCED **4** HEALTH HACK VIDEOS FOR PAIN AWARENESS MONTH IN COLLABORATION WITH THE HUMANA NEIGHBORHOOD CENTER



U.S. PAIN STAFF MEMBERS SPOKE AT **16** KEY NATIONAL CONFERENCES, SYMPOSIUMS, AND WEBINARS



**52 FAMILIES**

ATTENDED 2ND-ANNUAL PEDIATRIC PAIN WARRIOR FAMILY SUMMER CAMP



TRAINED **25 ADVOCATES** THROUGH ONLINE ADVOCACY TRAINING SERIES



FACILITATED **719** ONLINE PEER SUPPORT GROUP MEETINGS AND INITIATED THE DAILY GROUP, WHICH MEETS ON WEEKDAYS AND MOST WEEKENDS



DISTRIBUTED **26,709** EDUCATIONAL MATERIALS TO PATIENTS, CAREGIVERS, AND HEALTH CARE PROFESSIONALS



PUBLISHED **3RD** HEALTH CARE DISPARITIES EDITION OF THE INVISIBLE PROJECT MAGAZINE



# ADVANCING RESEARCH FOR CHRONIC PAIN ACT

A defining moment for those living with chronic pain.

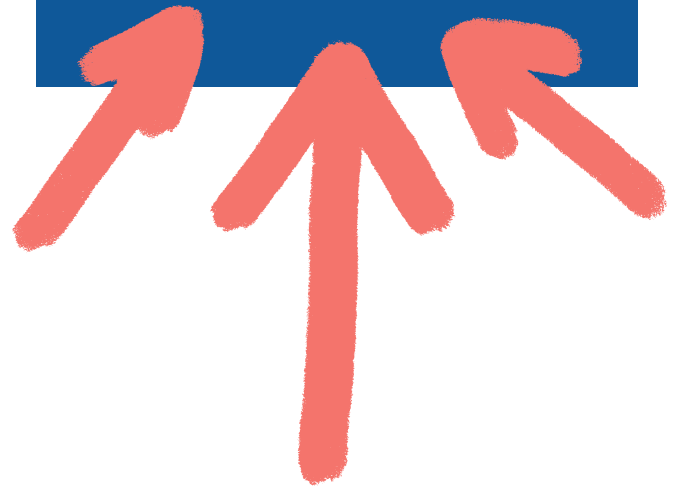
One of the most significant moments of last year was the introduction of S.2922, the Advancing Research for Chronic Pain Act. This legislative milestone, introduced by Senators Casey, Blackburn, Kaine, and Cramer to bring greater awareness to the enormous problem of chronic pain, resulted from years of dedication and advocacy from the U.S. Pain Foundation. U.S. Pain initiated the bill in collaboration with the Pain Care Coalition, which we lead, and the Protecting Access to Pain Relief (PAPR) Coalition, which we are a part of.

The bill, if enacted, would shine a light on pain's burden to the nation—in terms of human suffering and in health care costs—as the leading cause of disability. Its passage would stimulate greater action and investment in improving pain care.



The Advancing Research For Chronic Pain Act would direct the Centers for Disease Control and Prevention (CDC) to:

- Utilize available research data to clarify the incidence, prevalence, demographics, risk factors, and co-morbidities of chronic pain
- Identify the incidence and prevalence of specific known pain conditions
- Determine the direct and indirect costs of chronic pain to the nation
- Create a centralized Chronic Pain Information Hub to aggregate and summarize available data; maintain a summary of complete, ongoing, and planned research; and translate findings to recommendations for clinicians and scientists





# Advocacy

Those with chronic pain face substantial barriers, from stigma to limited access to comprehensive care, despite pain's significant impact. Advocating for these individuals is crucial for advancing understanding and providing equitable, effective treatment.

The U.S. Pain Foundation is dedicated to amplifying the voices of individuals with pain in the state and federal policymaking arenas. Our mission has two primary objectives. First, we provide pain advocates with comprehensive knowledge of the critical issues faced by those living with pain. We strive to empower them with insights into legislative and regulatory procedures, enabling them to identify crucial moments for engagement. We also provide them with the necessary resources and tools to effectively communicate their experiences.

Secondly, we aim to improve health outcomes by advocating for broader access to multidisciplinary care, expanded coverage from health care payers, mitigation of harmful utilization management strategies, increased awareness among health care providers of best practices, sustained expansion of telehealth coverage, and much more.

Through these initiatives, we strive to foster a health care environment where individuals grappling with pain find comprehensive support and improved avenues for managing their conditions.

U.S. Pain collaborated with federal agencies on several advocacy initiatives:

## **Department of Health and Human Services Office of the Assistant Secretary for Health (OASH):**

U.S. Pain Director of Policy and Advocacy Cindy Steinberg was invited to present at the HHS Healthy People 2030 Spotlight on Health Webinar on Best Practices in Pain Care in May. U.S. Pain joined Paul Reed, U.S. Deputy Assistant Secretary for Health, and officials from the Centers for Medicare & Medicaid Services, the National Institutes of Health, and the Centers for Disease Control and Prevention in presenting findings from the HHS Pain Management Best Practices Inter-Agency Task Force, of which Steinberg was a member. More than 1,400 health care providers attended the webinar.

**NIH Helping to End Addiction Long-term® (HEAL) Initiative:** NIH HEAL Director Rebecca Baker and HEAL researchers from the University of Michigan and Mayo Clinic participated in U.S. Pain Foundation's Pain Awareness Month efforts in September. They discussed pain research during two national webinars hosted by U.S. Pain, as well as three state-based support group meetings in Massachusetts, Northern California, and New York/New Jersey that involved HEAL researchers from the Boston Medical Center, Kaiser Permanente, and Memorial Sloan Kettering.

**Centers for Medicare and Medicaid Services Annual Quality Conference 2023:** Steinberg also presented at the CMS Quality Conference with NIH's Linda Porter and CDC's Jan Losby in a session entitled *New Opportunities for Advancing Chronic Pain Care*, moderated by CMS's Scott Lawrence.

## Pain Advocates in Action

- Trained 25 volunteer advocates through a six-part Virtual Advocacy Training Series
- More than 5,000 individuals signed up to receive action alerts
- Worked with our trained advocates in 4 states to promote and introduce multidisciplinary pain care coverage legislation

## Advocacy Efforts

- Added our organizational support to more than 15 sign-on letters
- Succeeded in getting Appropriations report language in the Senate and House FY2023 budget reports on 2 pain policy issues.
- Continued leadership of a federal pain care coalition and participation in 10 like-minded coalitions

## Medical Cannabis Advocacy

- Started a Facebook Live to provide a better understanding of medical cannabis
- Focused our KNOWvember awareness and education effort on understanding medical cannabis and CBD





# INvisible Project

Recognizing the significance of individual narratives.

Understanding everyday individuals' experiences holds transformative potential—reshaping societal and medical perceptions of pain, one narrative at a time.

The **INvisible Project**, the flagship initiative of U.S. Pain, is a magazine that disseminates personal stories and images of individuals living with chronic pain through both print and online channels. With more than 20 editions published, its objective is to authentically depict the complexities of life with pain, showcasing both the formidable challenges and the victories, large and small. Moreover, it emphasizes the distinct journey of each person with pain and underscores the importance of personalized treatment approaches.

Beyond raising awareness among health care providers, policymakers, and the general public regarding the realities of chronic pain, the project offers comfort to those grappling with pain, reassuring them that they are not alone. Furthermore, each publication features articles quoting leading experts, covering pertinent topics such as the significance of clinical trials and pain management strategies.

In 2023, the organization published its third edition highlighting health care disparities—covering topics such as health care deserts, medical gaslighting, and tips for navigating emergency room visits. By shedding light on these issues, we continue to advocate for change and inclusivity in health care.

- Third magazine focused on health care disparities published
- Magazine translated and printed in Spanish
- 1,473 individuals, doctor's offices, and providers have subscribed to receive the latest magazine upon printing
- Individuals have scanned the magazines' QR codes to find online versions of articles in 28 states, plus Washington, D.C.





# Mental Health and Support

**Pain Connection: A place to grow and connect with people who get it.**

Chronic pain can have a profound effect on mental health, yet the link between the two is often misunderstood. U.S. Pain Foundation is dedicated to raising awareness and reducing stigma surrounding this connection. We offer free online peer-led support group meetings, providing a platform for individuals to share experiences and learn from one another.

U.S. Pain's support groups cater to diverse needs. National groups focus on monthly themes and accommodate various schedules. A daily group ensures continuous support on weekdays and most weekends, aiming to eliminate feelings of isolation. State-based groups offer localized support, while specialized groups cater to specific populations, such as LGBTQ+ and BIPOC individuals, teens, caregivers, and care partners. These specialized groups also focus on activities like reading, writing, creative arts, and mindful meditation. All groups are led by trained peer facilitators.

The foundation's main goal is to create a safe environment for individuals to express emotions, receive support, explore coping strategies, and actively engage in their well-being. We aim to empower individuals to manage pain effectively and connect with different pain management approaches.

- Hired Melissa Geraghty, PsyD, as new director of mental health and support
- Started the Daily Group, a peer support group that meets on weekdays and most weekends
- Offer 33 peer support groups, including national, daily, state-based, and specialized groups
- Facilitated more than 700 online peer support group meetings
- Created a new peer leader training manual to support our volunteer facilitators and trained current leaders on the new manual
- 3,540+ individuals signed up for upcoming support group reminder emails



# Pediatric Pain

Millions of children with chronic pain are under-served and under-recognized.

Children living with pain and their families encounter a myriad of challenges across various facets of life, ranging from medical consultations to educational settings and day-to-day interactions. Recognizing this, the Pediatric Pain Warrior program endeavors to bridge these gaps by furnishing resources and fostering support networks for affected children and their families, thereby empowering them with much-needed tools and understanding.

Central to this initiative is U.S. Pain's family summer camp. In 2023, children living with pain and their families came together for our second annual Pediatric Pain Warrior Family Summer Camp at Morgan's Wonderland Camp in San Antonio, Texas. This week-long event provided peer support for children and families, and camp activities made accessible for kids living with pain. Representatives from Texas Children's Hospital, Morgan's Wonderland's STRAPS program, and Paige Figi (executive director of Coalition for Access Now) all contributed valuable education, developing connections and understanding.



Furthermore, the Pediatric Pain Warrior program has expanded its educational endeavors, broadening its scope to encompass kid-friendly and family-oriented learning initiatives. These efforts aim to equip children with the knowledge and skills necessary for a brighter, healthier future. Key areas of focus covered in our educational initiatives and resources include pediatric clinical trials, effective advocacy strategies to ensure children's and families' voices are heard, and comprehensive disease-state education.

# Pediatric Pain

- Hosted 52 families for second annual five-day camp experience at Morgan's Wonderland Camp
- Organized seven webinars for kids with pain and their families, ranging from clinical trial education to tools to advocate for better care
- Collaborated with Children's Specialized Hospital of Rady Children's
- Texas Children's Hospital providers volunteered and presented educational sessions to families attending summer camp
- Active participant in key committees and coalitions at Cincinnati Children's, University of Texas at Arlington, and Stanford University to improve pediatric pain care
- Five nonprofits, including Lupus and Allied Diseases Association, Infusion Access Foundation, Clusterbusters, Association of Migraine Disorders, and CHAMP, helped support families attending camp
- Collaborated with Migraine at School on developing an infographic discussing 504s and IEPs



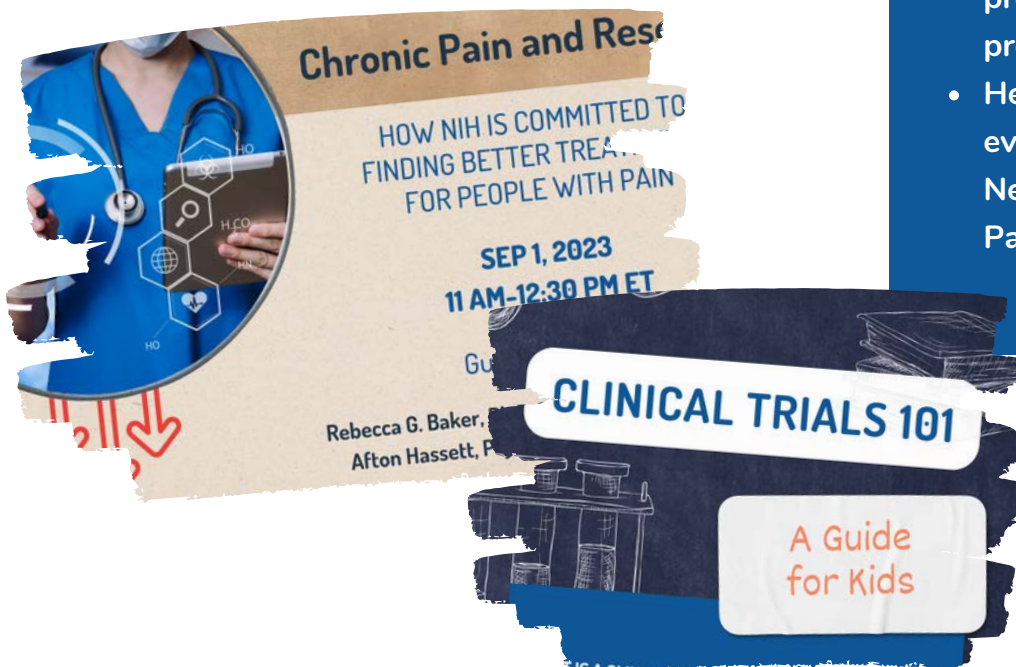


# Pain Awareness Month

30 days nationally dedicated to increasing public awareness about pain and its devastating impact on individuals, families, communities, and the nation.

During Pain Awareness Month in September 2023, the U.S. Pain Foundation raised awareness about pain research and its effects on the more than 51.6 million Americans who live with chronic pain. #PainTrials explained the significance of pain research and clinical trials and how they impact individuals dealing with chronic pain in their daily lives, spotlighting how research drives improved care and the importance of participating in trials. One of the notable achievements of this campaign was U.S. Pain's collaboration with the National Institutes of Health (NIH) in various aspects of the initiative.

- Hosted three webinars about: NIH's HEAL Initiative's pain research, pediatric clinical trials, and resilience and chronic pain
- Published weekly articles delving into different aspects of research and chronic pain
- Posted daily statistics and facts about pain research on social media
- Developed an educational guide, Clinical Trials 101 (plus a second family-friendly resource, Clinical Trials 101: A Guide for Kids), to download or order
- Enlisted the participation of local NIH researchers in three of our online state-based peer support groups to share an overview of HEAL's efforts and present on local research projects
- Held in-person education events at two Humana Neighborhood Centers during Pain Awareness Month



# KNOWvember

November is the month of KNOWledge.

The U.S. Pain Foundation dedicates each November to exploring a different topic related to pain management through informational articles, webinars, social media posts, free resources, and more.

Last year, the organization explored the topic of understanding cannabinoids. #KNOWmyCannabinoid broke down the differences between CBD, medical cannabis, and other cannabinoids used to help manage pain. The month-long initiative also highlighted key factors to consider when looking to use cannabinoids as medicine, including researching legality and discussing treatment options with medical providers.



- Hosted two webinars discussing the importance of CBD and medical cannabis education, testing, and regulation
- Published three articles related to the month's theme
- Posted statistics and facts about cannabinoids on social media throughout the month
- Developed three educational resources available to download or order: Hemp/CBD 101, Medical Cannabis 101, and Other Cannabinoids 101





# Education and Awareness

Generating public awareness and providing education on pain management is crucial.

The U.S. Pain Foundation prioritizes creating awareness and educating people about chronic pain. A deeper understanding of pain and its effects is essential in empowering individuals on their journey. It can improve patient-provider relationships, lead to more positive treatment outcomes, and ensure patients are better connected to the health care system.

- Hosted monthly educational series, Building Your Toolbox, where individuals learn a pain management strategy or skill
- Collaborated with the Humana Neighborhood Center on four Health Hack videos related to chronic pain, and held in-person education events at three Humana Neighborhood Centers
- U.S. Pain staff were invited to speak at 16 key conferences, events, and symposiums this year
- U.S. Pain staff and key volunteers were invited to speak to four medical schools to inform medical students about life with pain
- 26,709 materials were mailed free of charge to patients, health care professionals, and caregivers
- 2023 engagement rates of 14.8% on Facebook and 12.8% on Instagram show we are moving the needle in terms of public education and awareness





# OUR CORPORATE COUNCIL

The U.S. Pain Foundation's programs and services are made possible by the generous support of our donors. Their contributions help us further our mission to improve the lives of people living with pain—making it possible for us to provide a wide variety of services and resources, all free, to those who need them. You can find detailed information about our donors and benefactors on our website.

We'd like to give special thanks to our 2023 Corporate Council members

## LEADER



## MEMBERS

