

VIRTUAL ADVOCACY TRAINING SERIES

November 4-21, 2022

Make yourself comfortable. We will get started
in a few minutes.

U.S. PAIN FOUNDATION

SESSION 3 :
Federal Pain Policy
Players, Priorities, Accomplishments &
Opportunities to Engage
Tuesday, November 12, 2024

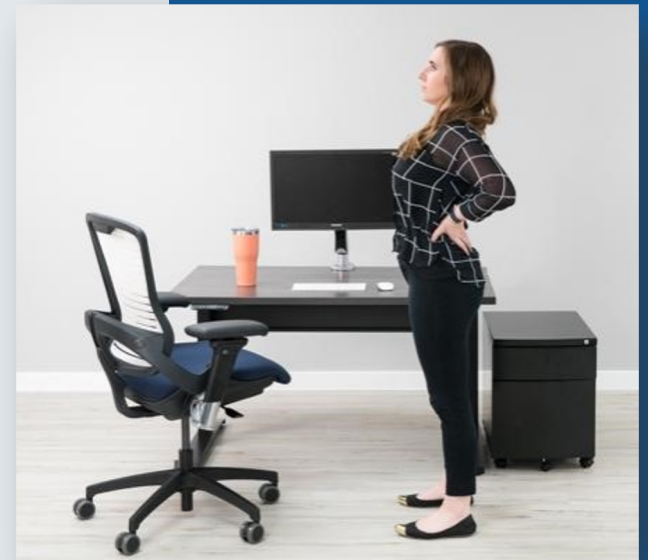
Cindy Steinberg, Director of Policy & Advocacy

Agenda

- Review Webinar Guidelines
- Federal Policy – Players, Priorities & Opportunities to Engage
- Important Pain Policy Developments
- The Task Force Report
- The Advancing Research for Chronic Pain Act (ARCPA)
- **Break (25 minutes)**
- **Workshop**
- Sharing
- Q & A
- Closing

Rules and Guidelines

- **Take care of your health and pain first!**
 - Be comfortable, move around if you need to, stand, lie down
 - If you need to move around, keep the camera on your device stationary and move yourself
 - **Mute your line when you are not speaking**
 - **Be respectful of others.**
 - **If you have questions or concerns, contact us!**
michele@uspainfoundation.org
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Overview & Resources

- Third of 5 two-hour webinars Nov 4 - 21 at 2pm ET
- If you attend all 5 webinars and complete 10 hours on your policy project, you will receive a U.S. Pain Foundation Certificate of Completion and fun U.S. Pain swag
- Check out our portal for more resources and pdf's of completed webinar slides

uspainfoundation.org/virtualadvocacyseries





Small Group Leaders



Rebecca



Michele



Sam



Victoria



Janet

Our Sponsors



The 2024 Virtual Advocacy Training Series was developed independently with funding support from Vertex Pharmaceuticals.



Thank you also to our Corporate Council for their continued support of this program, and other U.S. Pain initiatives.



Who Makes Federal Pain Policy?



2024 US Pain Advocacy Priorities

- Individualized, Integrated, Multidisciplinary Pain Management– **promoting movement toward this as best practice**
 - Improve Access to a Broad Range of Therapies– **including complementary modalities, behavioral health, novel therapeutics, innovative medical devices, etc.**
 - Pain Management Best Practices Report Dissemination– **to educate front-line clinicians & raise awareness about CP**
-



2024 US Pain Advocacy Priorities

- Population health data collection, analysis & reporting on CP **to better understand who is affected, co-morbidities, cost, etc.**
- Improve telehealth coverage **for pain care.**





2024 US Pain Advocacy Interest Areas

Issues we follow & take action on when there are opportunities:

- Access to opioids for those who benefit from them
 - Access to medical cannabis for those who benefit from use
 - Removing insurer roadblocks to treatments: Step Therapy, Prior Authorization, Non-medical Switching, etc.
 - Improving pain education for providers
 - Reducing the cost of prescription medication
 - And others...listed under Advocacy in uspainfoundation.org
-

Opportunities to Engage in Federal Pain Policy

- US Pain Action Alerts – separate sign-up for this. Please sign up.
 - <https://votervoice.net/USPF/Register>
 - Comments on federal regulations & policies with open dockets
 - Federal meetings with open public comment periods
 - Lobby days and Advocacy days focused on Capitol Hill
 - Calls to lawmakers' staff
 - Meetings with lawmakers' staff – local offices, virtual, Capitol Hill
-



Opportunities to Engage in Federal Pain Policy

- Testimony at FDA Advisory Committees
- FDA Patient Focused Drug Development days
- Meetings with your House Representatives' or Senators' aides
- Appointments to Federal Commissions, Task Forces, Committees *
- Testifying at Congressional Hearing*

(* these are rare, by invitation & extremely difficult to obtain)



Congress and Federal Pain Policy



- Most pain policy initiatives come from Congress & Congress responds to constituent concerns; therein lies our power!
- Critical to be engaged with Congress. I meet frequently with key offices; they will look to experts they trust for input when creating legislative initiatives and writing legislation.
- Two significant positive policy developments for the pain community since 2019 are:
 1. The Pain Management Best Practices Interagency Task Force Report (2019)
 2. The Advancing Research for Chronic Pain Act of 2023 (ARCPA)



Pain Management Best Practices Task Force

- The Pain Management Best Practices Inter-Agency Task Force (PMTF) was written into the Comprehensive Addiction and Recovery Act (CARA), the first major federal opioid legislation passed in 2016.
 - It was the first & only section in CARA pertaining to pain management.
 - Its Congressional mandate, HHS stamp & expert panel give the report authority
-



Why was this report created?

- Congress wanted to know what pain experts consider best practice in pain management, understand gaps & recommendations for closing them
 - Congress also asked the Task Force to review the CDC Guidelines for an expert opinion
 - Law specified PMTF to be overseen by the Office of the Secretary of the Department of Health and Human Services (HHS) which is above all the federal health agencies.
-



Who Created the Report?

- CARA was very specific about the types of experts that should be chosen for the task force. A panel of 29 members were appointed by the U.S. Secretary of Health & Human Services, Alex Azar.
 - Chair was Vanila Singh, MD, chief medical officer for the Office of the Assistant Secretary for Health and a pain physician
 - I was the only patient and pain advocate appointed to the panel
-



What Resources Were Considered in Drafting the Report?

- Diverse expertise of Task Force members; we met every 2 weeks for nearly a year
 - Extensive body of research reviewed (nearly 500 references).
 - Over 9,000 comments received from organizations and individuals (80% from patients)
 - Testimony from meetings with public comment periods
 - Invited patient testimonials
 - Invited speakers: Surgeon General, HHS Secretary, Assistant Sec'y Health, FDA Commissioner, Physician members of Congress, VA, Deputy CMS CMO, IHS CMO
-



What is the best way to manage pain now?



Comprehensive: assessment; diagnosis; development and revision of treatment plan; facilitation, communication, and coordination with other healthcare providers



Individualized: in selection, duration, and consideration of risks/benefits of treatments and optimal dosing of any medication



Multidisciplinary & Integrative: combining a full range of pharmacological and non-pharmacological treatments

Combining Multiple Treatments from **5** Treatment Approaches



Medication



Restorative
Therapies



Interventional
Procedures

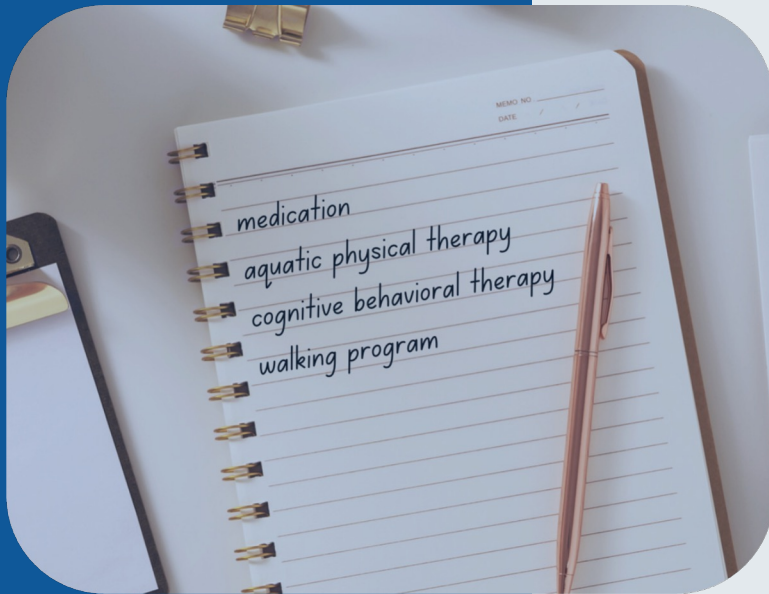


Behavioral
Health
Approaches



Complementary
& Integrative
Health

Individualized Treatment Plan



- If each therapy reduces pain by 10-15%, combination of 3 or 4 treatments could lead to a 30 - 45% reduction in pain
- Result is a HUGE difference in function and quality of life
- Could make the difference in being able to play with your child or not, socialize with friends or not, and work part time or not
- Goal of medical management is to reduce the pain enough to allow active patient engagement

Overwhelmingly Positive Response to Report

- Over 160 organizations endorsed the final report including physician groups & societies, patient groups, other health provider groups & companies, even Human Rights Watch
- AMA issued a press release calling the report a “roadmap for future policy”
- AMA President, Dr. Patrice Harris spoke at last PMTF mtg:
“These recommendations are a lifeline to pain patients who have been caught in the middle of policy efforts that have produced harmful unintended consequences”
- Findings of the PMTF have become widely accepted as best practice in pain management field
- Unfortunately, findings were never disseminated to practicing PCP’s
- Medical schools generally do not spend much if any time on pain management education



What is the Advancing Research for Chronic Pain Act? (ARCPA)



→ It is a federal bill

- ◆ Introduced in U.S. Senate Sept. 2023 by a bi-partisan group of four senators: Casey (D-PA), Blackburn (R-TN), Kaine (D-VA), and Cramer (R-ND).
 - The bill was led by Senator Bob Casey as S.2922
 - Included in Senate SUPPORT Reauthorization Act in Dec. 2023
- ◆ Introduced in the U.S. House Jan. 2024 by Rep. Yadira Caraveo, MD (D-CO-08) and Rep. Zach Nunn (R-IA) as H.R.7164



How Did it Come About?

- Long personal interest in population health data on chronic pain.
 - Essential to raising awareness about the scope and burden of pain, and the need for the government to do more to address it
 - Longtime advocate worked with me to create a first draft of the bill in 2018 for the SUPPORT Act
 - I went back to the bill & brought to many Hill offices in 2022
- In Feb. 2022, an aide to Sen. Casey, expressed an interest in the bill & took it to the Senator.
 - Aides got CDC and other stakeholder input
 - Shared drafts with me and others for input



What is in the Advancing Research for Chronic Pain Act?

→ The bill would require CDC to:

- ◆ Analyze, report on, and aggregate population health data on chronic pain in general and all known pain conditions
- ◆ Identify and fill gaps in the research data
- ◆ Develop standard definitions in collaboration with stakeholders (including patients and patient advocates)
- ◆ Translate research into clinical tools and resources
- ◆ Make all information available on a public information hub and keep it updated



What Information Would be Required?

For chronic pain in general and all known pain conditions:



- Incidence and prevalence — these are different
- Demographics such as age, race, gender, and geographic location
- Risk factors such as genetic and environmental risks
- Diagnosis and progression markers
- Direct and indirect costs
- Detection, management, and treatment data on pain
- Detection, management, and treatment of co-occurring conditions such as anxiety and depression
- Utilization of medical and social services
- Effectiveness of evidence-based treatment approaches

Why Does This Matter for People with Chronic Pain?



- It would give us accurate, reliable, and updated numbers to cite when making the case for greater resources for research and improvements in care.
 - ◆ For example, exactly how many people have diabetic neuropathy in the United States? What are their ages at onset? What is the relationship between disease progression and pain?

Why Does This Matter for People with Chronic Pain?

- These are BIG numbers that get media attention and raise awareness of the scope of suffering and loss of productivity.
- ◆ In April 2023, when CDC MMWR published again on chronic pain (because we had Congress pressure CDC to release this data) showing that **51.6 million** American adults live with chronic pain and **17.1 million** American adults live with high-impact chronic pain, it was widely reported the next day in:

The New York Times

FORTUNE

The
Weather
Channel

The Washington Post

STAT

Why Does This Matter for People with Chronic Pain?

→ It will identify and quantify consequences of chronic pain.

◆ Consequences of chronic pain are enormous. Some examples:

- Inability to carry out basic activities of daily living like cooking, bathing, etc.
- Inability to concentrate
- Inability to care for one's children and family
- Inability to work
- Inability to sleep

→ Documenting these with data can help make the case for Social Security disability determinations, and long- and short-term disability benefits.



Why Does This Matter for People with Chronic Pain?



- It will pinpoint disparities so more can be done to focus resources.
 - ◆ Accurate annual numbers of prevalence of chronic pain among different racial groups, indigenous groups, and those traditionally disadvantaged like LGBTQ+ individuals will make the case for directing more resources to, and improving access for, these groups.
- It will better identify who is at risk for chronification and co-occurring conditions.



Why Does This Matter for People with Chronic Pain?



- Cost and health care utilization data is invaluable in making the case for earlier and better access to innovative treatments.
 - ◆ Chronic pain has been documented to account for a high proportion of Emergency Department visits and multiple physician visits prior to diagnosis, which is costly.
- Data on the effectiveness of treatment will enable more individualized and tailored treatment plans.



BIG MOMENT: Bill introduced on Sept. 26, 2023

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SEPTEMBER 26, 2023

Introduce Legislation to Support People Living With Chronic Pain | Senator Bob Casey...

living with chronic pain Washington D C Today U S Senators Bob Casey D PA Marsha Blackburn R TN Tim Kaine D VA and Kevin Cramer R ND introduced legislation to close gaps in chronic pain research and help...propel chronic pain research forward The Advancing Research for Chronic Pain Act would centralize current information and data to help clinicians and scientists more effectively research chronic pain conditions...crippling pain that may prevent them from working taking care of their children...

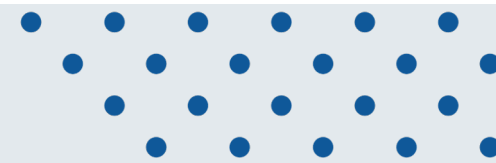
Advancing Research for Chronic Pain Act...

Advancing Research for Chronic Pain Act U S Senators Bob Casey Marsha Blackburn Tim Kaine and Kevin Cramer Chronic pain research lags behind need Approximately 1 in 5 adults are living with chronic pain...pain and 7 4 of those individuals have pain that significantly impacts their ability to live and work The prevalence of chronic pain and high impact chronic pain increases with age which is a growing concern...the prevalence of chronic pain its socioeconomic burden and the recognized need for...

- Casey's aide, Kate contacted me in late summer of 2023 to say they were working to introduce bill
- The final bill: not everything we wanted
 - Registry for longitudinal data cut

Successful advocacy = patience + persistence + compromise

A Great Opportunity Arises in the U.S. Senate!

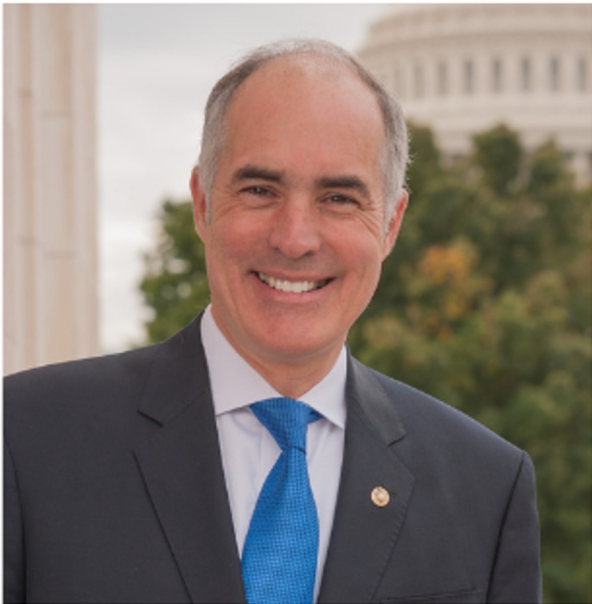


An opportunity arose when the Senate HELP Committee announced a mark-up on the SUPPORT Act Reauthorization for Dec. 12, 2023.

- Knowing partisanship in DC, started meeting with “Rs” on HELP to educate on why bill is important
 - Met with Senators Collins, Murkowski, Mullin, Romney, Cassidy, Braun, and Budd
- Sen. Casey introduced as an amendment
 - Took a vote—all the “Ds” and three “Rs” (Collins, Murkowski, and Romney) voted YES
- Casey Amend 1 passed, and was added into the SUPPORT Act with favorable recommendation received by HELP
 - Next step: SUPPORT Reauthorization needs a full Senate vote

U.S. SENATE COMMITTEE ON
Health, Education
Labor & Pensions

Senator Casey (D-PA) on Advancing Research for Chronic Pain Act



Senate HELP Committee Markup
December 12, 2023



What About the House of Representatives?

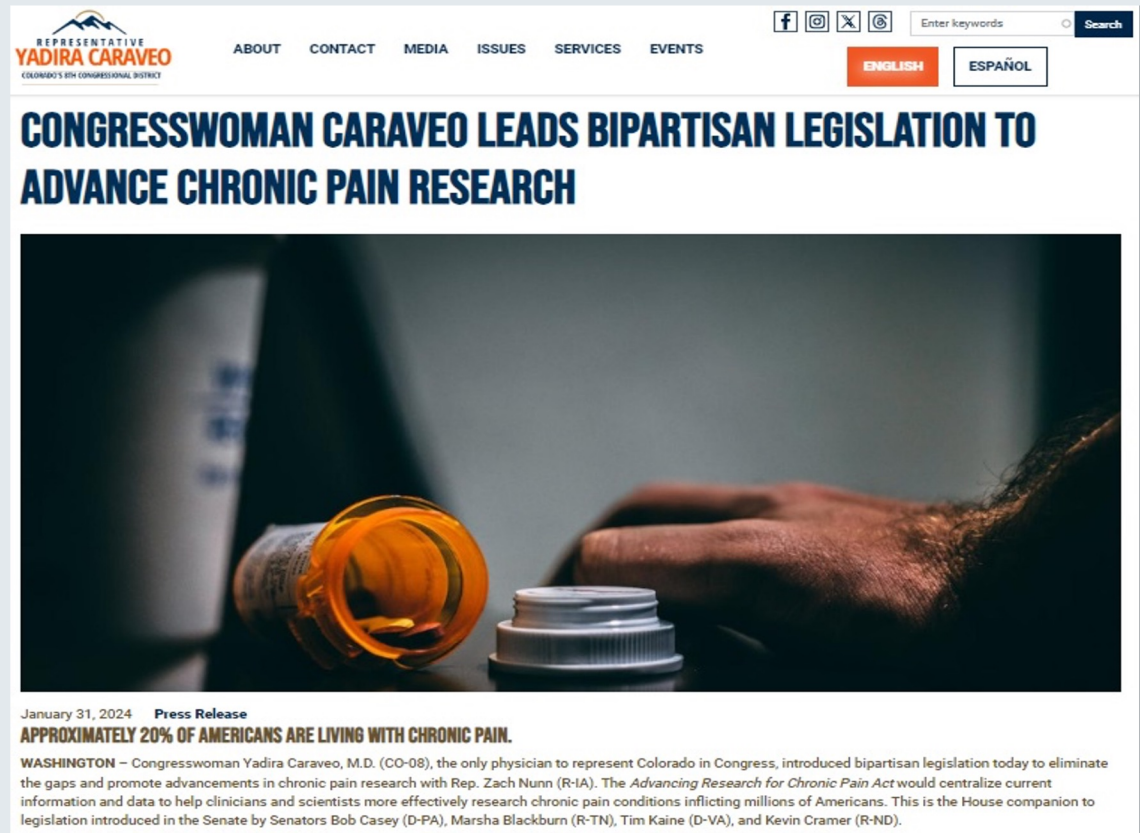

House had already taken up the SUPPORT Reauthorization Act prior to the Senate introduction of bill. It passed favorably out of committee on July 19, 2023, and subsequently passed in the full House.

- Best to get our bill introduced in the House in the event SUPPORT goes to conference
 - Started meeting with Reps offices to see if we could get a member to introduce
- Soon thereafter, Kate (from Sen. Casey's office) reached out sharing that Congresswoman Yadira Caraveo, MD (D-CO-08) was interested in introducing the bill in the House



What About the House of Representatives?

- Introduced Jan 31, 2024 by Reps Caraveo and Rep Zachary Nunn (R-IA-03)
- Has 6 co-sponsors so far



The screenshot shows the website for Representative Yadira Caraveo, Colorado's 8th Congressional District. The header includes navigation links: ABOUT, CONTACT, MEDIA, ISSUES, SERVICES, and EVENTS. There are also social media icons (Facebook, Instagram, Twitter, YouTube) and a search bar. Language options for ENGLISH and ESPAÑOL are available. The main headline reads: "CONGRESSWOMAN CARAVEO LEADS BIPARTISAN LEGISLATION TO ADVANCE CHRONIC PAIN RESEARCH". Below the headline is a photograph of a hand holding a pill bottle. The text below the image states: "January 31, 2024 Press Release APPROXIMATELY 20% OF AMERICANS ARE LIVING WITH CHRONIC PAIN. WASHINGTON – Congresswoman Yadira Caraveo, M.D. (CO-08), the only physician to represent Colorado in Congress, introduced bipartisan legislation today to eliminate the gaps and promote advancements in chronic pain research with Rep. Zach Nunn (R-IA). The *Advancing Research for Chronic Pain Act* would centralize current information and data to help clinicians and scientists more effectively research chronic pain conditions inflicting millions of Americans. This is the House companion to legislation introduced in the Senate by Senators Bob Casey (D-PA), Marsha Blackburn (R-TN), Tim Kaine (D-VA), and Kevin Cramer (R-ND)."

What is Next For ARCPA?



- Nearing the end of the 118th Congress; only in session Nov 12 – 21 & Dec 3 – 19
- A lot has to get done; CR expires Dec 20 & has to be extended or budget bills need to get passed to avoid a gov't shut down
- Many big bills held up awaiting action
- SUPPORT is an important bill and there is a chance it could be taken up in an end of year omnibus bill

What Can We Do to Take Action Now On ARCPA?

In the House the “ask” to your Congressperson:

- Asking you to urge leadership to include SUPPORT Reauthorization bill in an end of year package
- If you do, please prioritize inclusion of the bipartisan Advancing Research for Chronic Pain Act (ARCPA) (S.2922/H.R.7164)
- ARCPA was included in the Senate’s marked up reauthorization bill



What Can We Do to Take Action Now On ARCPA?

In the Senate the “ask” to your Senators:

- Asking you to urge leadership to take a full Senate vote on S.3393, the SUPPORT Reauthorization Act
- And, if House & Senate agree to include SUPPORT in an end of year package, please prioritize the bipartisan Advancing Research for Chronic Pain Act (ARCPA)
- ARCPA was included in the Senate’s marked up reauthorization bill, S.3393



Break

We'll take a 25 minute break now.

Please return in 25 minutes!

What Are Our “Asks” of Congress Regarding ARCPA?



Senate

- Urge leadership to take a full vote on SUPPORT. Or,
- If preconference SUPPORT for inclusion end of year package, include bipartisan ARCPA
- ARCPA was included in the Senate’s marked up SUPPORT Reauthorization bill S.3933

House

- If preconference SUPPORT for end of year package, include ARCPA
 - ARCPA was included in the Senate’s marked up SUPPORT Reauthorization bill S.3933
-

Breakout Session

Draft an e-mail/letter to your 3 Congressmembers making the case for these asks and relate them to your personal story.

Why do you care about this bill? Why does it matter to people with pain?



Debrief and Share Your Messages

- How did it go?
 - Were you able to make your message compelling and concise?
 - Who would like to share with the group?
-

Questions?



Thanks for joining us today!

- Homework is to finish your message/letter to your 3 Congressional representatives.
- Look up how to send them an e-mail on their websites or call the DC office and ask for the e-mail of the health policy aide to whom to send a message. Say you are a constituent and want to convey a request for action on a specific h/c bill that is important to you
- Don't send the messages to your senators yet. Please send them to Michele so she can review and give you feedback before you send them. Time is critical now so do asap.
- Sign up for Action Alerts: <https://votervoice.net/USPF/Register>
- Next webinar is Tuesday November 19 from 2-4pm ET ; same Zoom link
- Check out our portal for more resources:
uspainfoundation.org/virtualadvocacyseries
- Any questions or issues? Reach out to Michele Rice:
michele@uspainfoundation.org

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