

U.S. PAIN FOUNDATION

VIRTUAL ADVOCACY TRAINING SERIES

November 4-21, 2024

Cindy Steinberg, Director of Policy and Advocacy

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



Agenda



- Welcome to our 2024 Virtual Advocacy Training Series!
- Overview & Zoom instructions (Cindy, 10 minutes)
- **Breakout session #1** (Nicole, Michele, Rebecca, Cindy, Sam 10 minutes)
- What is Advocacy? (Cindy, 25 minutes)
- Rest Break (25 minutes)
- **Breakout session #2** (Nicole, Michele, Rebecca, Cindy, Sam 10 minutes)
- What is Pain Policy and Why Should We Care? (Cindy, 25 minutes)
- Q&A (10 minutes)

Overview and Resources

- Trainings sessions:
 - November 4, 7, 12, 19 and 21
 - 2-4 p.m. ET
 - 1-3 p.m. CT | 12-2 p.m. MT | 11 a.m.-1 p.m. PT)
 - If you attend all five training sessions and complete a 10-hour policy project of your choice, U.S. Pain Foundation will send you a special swag and Certificate of Completion
 - *We do understand if you miss one session due to an emergency or medical need.*
 - All resources can be found here:
 - uspainfoundation.org/virtualadvocacyseries
-

What's Ahead



- Thursday, November 7, 2-4pm ET
 - *The Power of Your Story*
 - Featuring Dionne Dougall, Communications Professional
- Tuesday, November 12, 2-4pm ET
 - *Federal Pain Policy*
- Tuesday, November 19, 2-4pm ET
 - *State Pain Policy*
- Thursday, November 21, 2-4pm ET
 - *Your Pain Policy Projects*



Advocacy Series Objectives



Learn how and when to use your voice to advocate for better pain care.



Be more comfortable speaking or writing to lawmakers or in public forums.



Understand the basics of how federal and state pain policy works.



Articulate the main findings of the *Pain Management Best Practices Report*.



Articulate three reasons why the *Advancing Research for Chronic Pain Act* is important for people with chronic pain.



Learn how to actively engage in advocacy!

Your Hosts



Cindy



Nicole



Janet



Michele



Sam



Rebecca



Rules and Guidelines

- **Take care of your health and pain first!**
 - Be comfortable. Move around if you need to, stand, or lie down; if moving, please keep device stationary.
 - Please be on camera today except for the break, and for all small group activities in remaining classes.
 - Please mute your sound when not speaking.
 - Please check email everyday between Nov 4 – 21.
- **Be respectful of others.**
- **If you have questions or concerns, contact:**
michele@uspainfoundation.org



Speaking as a Patient versus Speaking as a Representative of U.S. Pain



- You are always encouraged to speak from a personal perspective as a patient or caregiver.
- If you wish to represent the U.S. Pain Foundation in a formal capacity, such as during testimony or public speaking, please request a review of your messaging to ensure alignment with the organization.
- As an organization, we maintain specific positions on various issues, and consistency in our messaging is critical.

Thank you for following this guideline!

Phone controls:

*6 to
mute/unmute
*9 to raise hand

Turn on/off
your sound
and your video

Adjust between
different views

To type questions
or comments

This is where you find
“raise your hand”

“Share screen” and “record”
are disabled

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.



Breakout Session #1

Take turns sharing:

- Your name
- Where you live
- Your primary pain condition, if you live with pain (only give 1). If a caregiver, share the pain condition of your loved one.
- One thing that brings you joy? Favorite hobby, activity, pet, food, place, person?

Please limit your response to one to two minutes per person.

SESSION 1 – PART 1:
What is Advocacy?
*Turning Your Passion into
Action*

Why Are We Here?

- We all care deeply about improving pain care in the United States.
 - We have all experienced challenges when seeking help.
 - Chronic pain is undertreated, underfunded, misunderstood.
 - People with pain are often forced to see multiple providers in order to find help.
 - People with pain are stigmatized, marginalized, and not believed.
 - Finding effective treatments is often trial-and-error.
 - People with pain continually confront roadblocks to getting the care needed.
 - This situation is appalling and does not have to be this way.
-



Why Should We Advocate?

- Advocacy is the act or process of supporting a cause.
 - “Turning your passion into action.”
 - Speaking out about injustices you see or experience in order to make positive change.
-



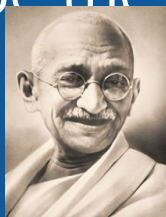
What is Advocacy?

- It is the belief that we can make a difference.
- We can change how people with pain are treated.
- We have a voice. We can speak up and be heard.
- “You’ve got to get in the arena to create change...democracy is not a spectator sport...”
-Obama
- There is strength in numbers.
- We can be more effective if we work together.



Inspiration from Advocacy Leaders

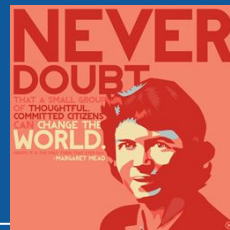
“You must be the change you wish to see in the world.”



—Mahatma Gandhi

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

—Margaret Mead



Inspiration from Social Movements

Civil Rights Movement



Gay Rights Movement



AIDS Activist who changed stigma to compassion

Disability Rights Movement



Feminist Movement



How Did They Do It?

Advocacy Can Take Many Forms

- **Using Traditional Media:** Op-eds, LTEs, quotes in articles, TV, or radio.
- **Using Social Media:** Opinion Blogs, X, Facebook, Instagram, TikTok, podcasts, etc..
- **Public Speaking:** Conferences, public forums, meetings, or rallies.
- **Using the Political Process:** Meetings to educate lawmakers, testifying, public comment periods on laws and regulations, etc.
- **Shaping Public Policy:** Weighing in on specific laws, regulations, or policies.

Over the next few weeks, we will be discussing how to effectively use these forms of advocacy.



Advocacy in Action: Examples



Advocacy in Action Successes



CARE Act in MA passed in 2018 (state)

- Establishes free pain management phone consultation for PCPs
- Requires insurers to cover a “broad spectrum of pain management services”

Pain Management Best Practices Task Force Report (federal) (2019)

- Congress directed HHS Sec to appoint 29 pain experts to recommend best practices for the nation

NIH HEAL Initiative (federal) (2019 – present)

- Since 2019 more than a \$1B increase in pain research funding at NIH

Advancing Research for Chronic Pain Act (ARCPA)

- Requires population data & cost info on chronic pain (bill)



BREAK

Let's take a 25-minute break. When we return, we will have another breakout session.

Please return in 25 minutes! Thanks.

Breakout Session #2

Take turns sharing:

1. Have you ever used the different forms of advocacy we discussed? Which one(s)?
2. Describe your experience. What did you do and what were you advocating for?

Please limit your answer to one to two minutes per person.



SESSION 1 – PART 2: What is Pain Policy & *Why Should We Care?*

Policies That Affect Pain Care

- **Laws** – a broad term that refers to rules of conduct with ***binding legal force***
- **Statutes** – a type of law enacted by a legislature; proposed statutes are called “bills”
- **Regulations** – a type of law issued by an agency of the executive branch of gov’t
Both statutes and regulations have ***binding legal force***



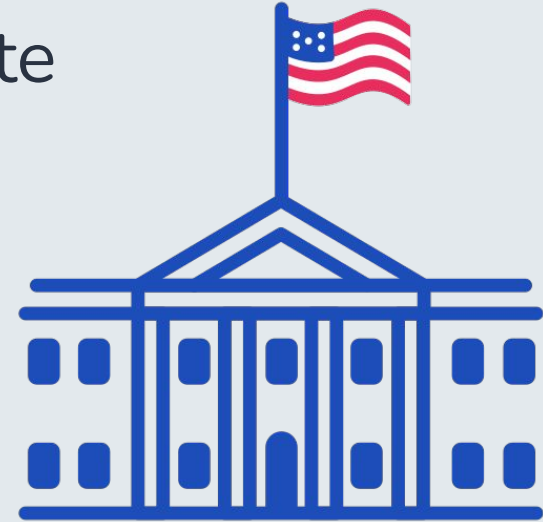


Policies That Affect Pain Care

- ***Guidelines or Policy Rulings*** – other policies that do not have binding legal force but they help those regulated by an agency to better understand the agency's standards of practice
 - ***Other – Plans, Strategies, Guidance, Requests for Information, Requests for Proposals*** – other policies that do not have binding legal force but provide information about future national or state direction
-

Who Makes Federal Policy?

- ***US Congress*** – House and Senate
 - create bills
- ***President***
 - signs bills into law or vetoes
 - can initiate legislation or regulations



Who Makes Federal Policy?

- ***Federal Agencies*** – such as HHS, FDA, DEA, CMS, CDC, etc.
 - They create regulations (rules), guidelines, policy rulings, plans, etc.



Who Makes State Policy?

- **Legislatures:** House/Assembly and Senate (all state govt's are bicameral except Nebraska)
 - create bills
- **Governor:** signs bills into law or vetoes
 - can initiate legislation or regulations



Who Makes State Policy?

- ***State Agencies*** – such as Health Departments, Insurance Divisions, Licensing Boards
 - create regulations, guidelines, policy rulings, plans, etc.



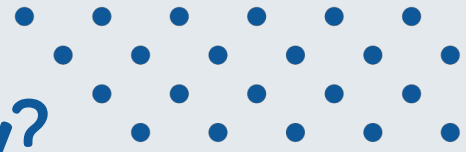
Why Should We Care About Pain Policy?

Policy Directly Affects:

- ***Access to pain care*** – Federal & state statutes guide prescribing & dispensing of medication (ie. Controlled Substances Act)
- ***Knowledge, attitudes & training of healthcare professionals*** – Regulations from licensing boards dictate training of h/c professionals
- ***Healthcare practice*** – Policy rulings from licensing boards guide h/c professional practice



Why Should We Care About Pain Policy?

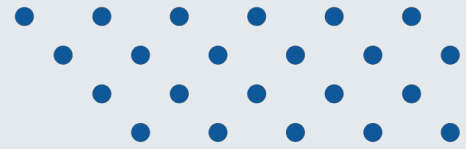


Policy Directly Affects:

- ***Pain Research*** – Congress allocates funds to NIH some of which go to funding pain research
- ***Knowledge, attitudes, and actions of people with pain, family members, caregivers, and the public*** – When FDA issues warnings, recalls, or restrictions on medication, this clearly affects people's' attitudes and actions related to these medicines



Control of Pain Policy is split between State and Federal Governments



Examples of Federal Policies:

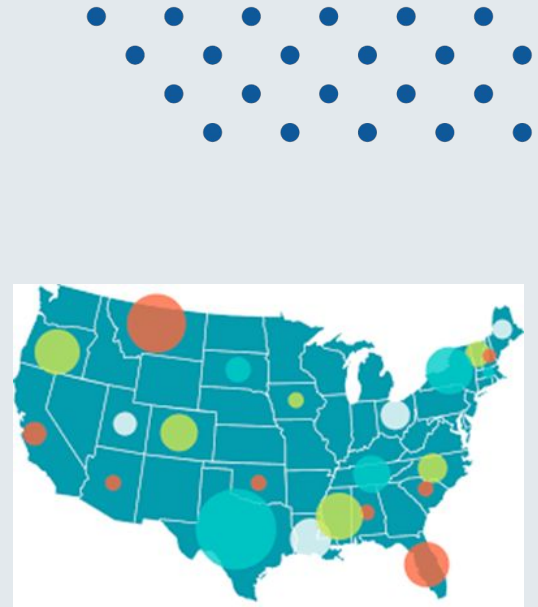
- *Controlled Substances Act (Congress)*
- *Comprehensive Addiction and Recovery Act (CARA) (Congress)*
- *Approval of new medications (FDA)*
- *Pain Management Best Practices Task Force Report (HHS)*
- *Rules regarding coverage of certain pain treatments (CMS)*



Control of Pain Policy is split between State and Federal Governments

Examples of State Policies:

- *PDMP Rules (how frequently must be checked)*
- *Healthcare Professional Licensing Rules*
- *Controlled Substances Act**
- *Private insurer coverage for pain therapies*



Important to know locus of control of policies you want to change!

**State law can be more restrictive but not less restrictive than federal law*

THANKS!

Any Questions?

Homework

- Write your personal story using the worksheet. Make sure to select who your audience is (reporter or lawmaker).
- Review “letter-to-editor/Op-ed” infographic in the portal (uspainfoundation.org/virtualadvocacyseries)

Next webinar

Friday, November 7, from 2-4 p.m. ET | Same Zoom link!

Any questions or issues?

Reach out to Michele Rice: michele@uspainfoundation.org



U.S. PAIN
FOUNDATION