U.S. PAIN FOUNDATION

VIRTUAL ADVOCACY TRAINING SERIES Oct 15-Nov 4, 2024

Cindy Steinberg, Director of Policy and Advocacy

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

Agenda

- Welcome to our 2025 Virtual Advocacy Training Series!
- Overview & Zoom instructions (Cindy, 10 minutes)
- **Breakout session #1** (Cindy, Michele, Victoria, Janet) 10 minutes)
- What is Advocacy? (Cindy, 25 minutes)
- Rest Break (25 minutes)
- **Breakout session #2** (Cindy, Michele, Victoria, Janet) 10 minutes)
- What is Pain Policy and Why Should We Care? (Cindy, 25 minutes)
- Q&A (10 minutes)

Overview and Resources

- Five two-hour webinars each October 15, 22, 23 & 29 & November 4 at 1:30 pm ET/ 12:30 pm CT/ 11:30 am MT/ 10:30 am PT

- If you attend all 5 webinars and complete 10 hours on your advocacy project, you will receive U.S. Pain Foundation swag bag & Certificate of Completion (if you have to miss 1 for emergency or special situation we understand)

What's Ahead

- Wednesday, October 22nd, 1:30-3:30pm ET, The Power of Your Story
  - *Featuring Dionne Dougall, Guest Speaker, Communications Professional*
- Thursday, October 23rd, 1:30-3:30pm ET, Federal Pain Policy
- Wednesday, October 29th, 1:30-3:30pm ET, State Pain Policy
- Tuesday, November 4th, 1:30-3:3pm 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 & state pain policy works

Articulate 3 main findings of the Pain Management Best Practices Report

Articulate 3 reasons why ARCPA is important for people with chronic pain

Actively engage in advocacy!

Your Hosts & Small Group Leaders

Cindy

Nicole

Michele

Victoria

Janet

Rules and Guidelines

- **Take care of your health and pain first!**
  - Be comfortable, move around if you need to, stand, lie down; if move, keep device stationary
  - Please be on camera today except for the break & for all small group activities in remaining classes
  - Please mute your sound when not speaking
  - Please check e-mail every day Oct 15 – Nov 4 & weekly when doing your project & communicating with Michele

- **Be respectful of others.**

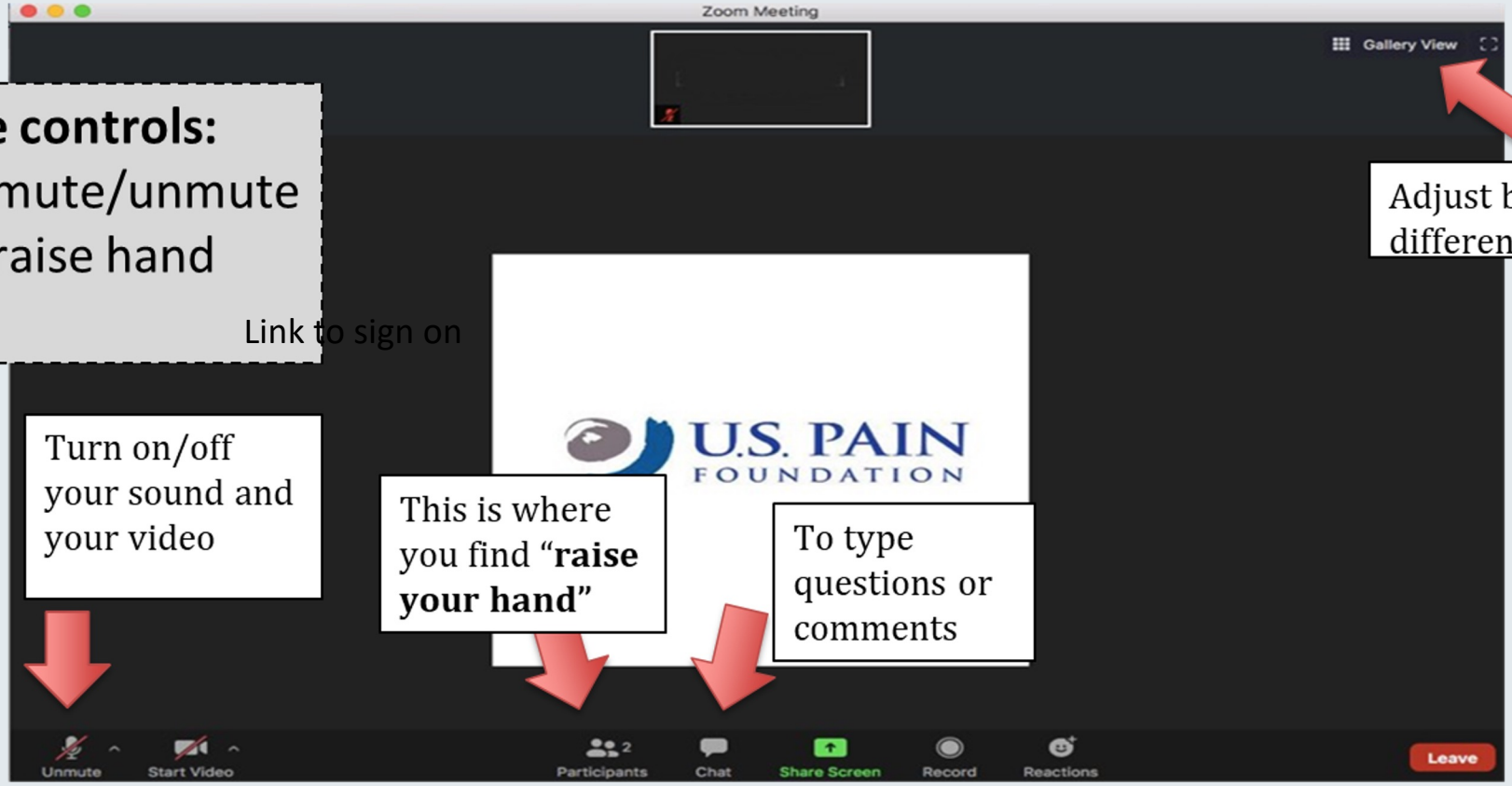
- **If you have questions or concerns, contact:**
  michele@uspainfoundation.org

Speaking as a patient VS. representative of U.S. Pain

- You can always speak as a patient or caregiver, from a personal perspective
- If you want to speak as a representative of U.S. Pain Foundation, please request review of messaging (e.g. if testifying, we would review your speech or talking points)
- As an organization, have specific stances on issues & need to ensure we are consistent

Thank you for following this guideline!

Zoom Controls



Phone controls:
*6 to mute/unmute
*9 to raise hand

Link to sign on

Adjust between different views

Turn on/off your sound and your video

This is where you find "**raise your hand**"

To type questions or comments

"Share screen" and "record" are disabled

Our Sponsors

The 2025 Virtual Advocacy Training Series was developed independently with funding support from Kenvue and 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

- We are going to split you up into 4 groups.
- We ask that you take turns sharing:
    1. Your name
    2. Where you live (city or town & state)
    3. Your primary pain condition, if you live w/pain (only give 1). If caregiver, your care person's pain condition.
    4. One thing that brings you joy? Favorite hobby, activity, pet, food, place, person?
- **Please limit your response to <u>one to two minutes per person.</u>**

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 US
- We have all experienced challenges when seeking help
- Chronic pain is undertreated, underfunded, misunderstood
- Pain sufferers forced to see multiple providers in order to find help
- People w/ pain stigmatized, marginalized, not believed
- Finding effective treatments often trial & error
- Confront roadblocks to getting the care we need
- This situation is appalling and does not have to be this way

What is Advocacy?
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
- It is the belief that we can make a difference

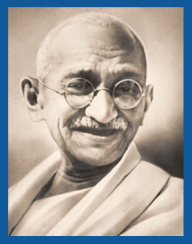
- John Lewis “*When you see something that is not right, not fair, not just, you have to speak up. You have to say something; you have to do something.*”

Types of Advocacy

- Self-Advocacy – individual speaks up for themselves
- Individual Advocacy – an advocate speaks for an individual or small group
- Systems Advocacy – working for broad structural & policy changes that affect a large number of people (eg. communities, corporations, labor unions, citizens in a country)
    - **Public Policy Advocacy – educating & influencing gov't decision-makers to create, abolish or change laws, regulations or other official practices**

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."

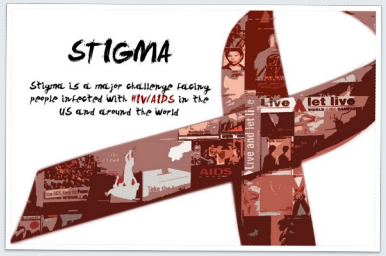
—Margaret Mead

Inspiration from Social Movements

Civil Rights Movement

Gay Rights Movement

AIDS Activist who changed stigma to compassion



Disability Rights Movement

Feminist Movement

Public Policy Advocacy Can Take Many Forms

- Meetings w/ lawmakers/staff to educate on an issue
- Testifying at public hearings
- Forming coalitions of like-minded groups to work together
- Commenting during public comment periods
- Speaking at meetings with gov't agencies
- Grassroots campaigns (ie. e-mails, letters, calls)
- Social media tagging elected officials
- Using traditional media to make the case for the policy change you are seeking

Advocacy in Action: Examples

Federal Coalition

Educating Lawmakers

Speaking at CMS

Testifying at U.S. Senate

Funding New Pain Therapeutics

Advocacy in Action Successes

- CARE Act in MA implemented in 2020 - passed in 2018 (state)
  - Established free pain management phone consultation for PCPs with pain specialists
  - Requires insurers to cover 2 new pain medications & 3 non-pharma treatments
- Pain Management Best Practices Task Force Report completed in 2019 – CARA passed in 2016 (federal)
  - Congress directed HHS Sec to appoint 29 pain experts to recommend best practices for the nation
- NIH HEAL Initiative (implemented 2018 – present) (federal) (Consolidated Appropriations Act of 2018)
  - Since 2018 more than a $1B increase in pain research funding at NIH
- Advancing Research for Chronic Pain Act (ARCPA) introduced in 118th Congress & plan to get it introduced in 119th Congress
  - Requires population health data & cost info on CP

BREAK

We'll take a 25 minute break now and when we return we'll have another break out session.

Please return in 25 minutes! Thanks.

Breakout Session #2

- We are going to split you up into 4 different groups.
- We ask that you take turns sharing:
  1. Have you ever engaged in public policy advocacy? Other forms of advocacy? (self, individual or systems advocacy)
  2. Describe your experience. What did you do and what were you advocating for?
- **Please limit your answer to <u>one to two minutes per person.</u>**

Public Policy Advocacy – educating & influencing gov't decision-makers to create, abolish or change laws, regulations or other official practices

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

Public 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***

Public 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
  - draft & pass bills
- ***President***
  - signs bills into law or vetoes
  - can initiate legislation or regulations
  - issue executive orders

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 & pass 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 & actions of people with pain, family members, caregivers & the public*** – When FDA issues warnings, recalls or restrictions on medication, this clearly affects peoples' attitudes & actions related to these medicines

Control of Pain Policy is Split between State and Federal Governments

Examples of Federal Policies:

- ***Controlled Substances Act (Congress) (state law can only be more strict, not less strict than federal law)***
- ***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 for listening!

Questions?

Homework

1. Write your Personal Story About Pain worksheet; select lawmaker type or reporter as audience
2. Read Advocacy Guidebook & Chronic Pain Fact Sheet

uspainfoundation.org/virtualadvocacyseries/

Next webinar is Wednesday, October 22 from 1:30-3:30 pm ET
Same Zoom link - you should have received it.

Any questions or issues? Reach out to Michele Rice:
michele@uspainfoundation.org

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