

Kate M. Nicholson, J.D.

Position

Executive Director, National Pain Advocacy Center.

Other

Member, NIH Interagency Pain Research Coordinating Committee (IPRCC)
Subject Matter Expert, National Advisory Neurological Disorders and Stroke Council
Board Member, NIH PURPOSE
IASP Global Advocacy Working Group
USASP Advocacy Committee Co-Chair

kate@nationalpain.org



Goals for Session



1. Advocacy Basics

Where, How, Recent Collaborations.



2. Press as Advocacy Adjunct



3. Communication basics:

Framing your message.

Adapting your message: policy, media, individuals.



4. Workshop

Ledes. (mid-way through)

"To be sure" and pivots. (end)

For Workshop

- What might you want to communicate to a policymaker, the press, or even in a blog post?
- Do you want to talk about pain as a public health issue? An economic issue?
- Do you want to talk about reimbursement or the pressures or squeezes in pain management?
- Maybe you have some other burning agenda...

Why Advocate?



UNPRECEDENTED
MISINFORMATION



ATTACKS ON SCIENCE.
ATTACKS ON EXPERTISE.



CUTS TO COVERAGE.
CUTS TO RESEARCH.



HEALTHCARE LIVES IN A
COMPLEX REGULATORY
STATE.



WHO GETS PAID, FOR
WHAT, AND EVEN WHICH
TREATMENT TOOLS CAN
BE USED ALL EMERGE
FROM THE POLICY
ENVIRONMENT.



A COMMON PHRASE IS
“BENCH TO BEDSIDE,”
BUT TRANSLATION
NEEDS TO REACH
POLICYMAKERS.

Where to Advocate? Advocacy is Broad.



Legislatures (Federal and State)

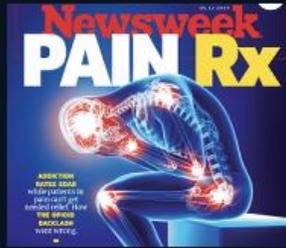


CMS.gov Centers for Medicare & Medicaid Services

Administrative Agencies (Federal, State, Local)



Professional Associations (Guidelines)



\$10.99

NEWSWEEK COVER STORY – HEALTH

How the opioid backlash went wrong

Patients with legitimate medical needs are losing access to opioids while addiction and overdose rates continue to climb

Buy Now – Newsweek Issues

The New York Times

We're Thinking About Pain All Wrong



By **Maia Szalavitz**

Ms. Szalavitz is a contributing Opinion writer who covers addiction and public policy.

They Live in Constant Pain, but Their Doctors Won't Help Them

By Vishakha Darbha, Lucy King and Adam Westbrook • August 17, 2023

TIME

SIGN UP FOR OUR ENTERTAINMENT NEWSLETTER

IDEAS • HEALTH

The Relentless Cost of Chronic Diseases

BY **ALISSA QUART** APRIL 9, 2024 7:00 AM EDT

Critical Role of the Press

- The press plays a key role in policy influence.
- “Whoever tells the best story wins.”
- We use press engagement as a policy adjunct often.

Collaborative Effort



- **Issue:** Administration's proposal to cut research by 40%, eliminate and/or defund institutes, and cap indirect costs.
- **Response:** Meetings with Appropriations Committees and Labor HHS Subcommittees in House and Senate.
 - Sign on letter endorsed by 60 leading pain organizations.
 - Trainings about appropriations and how to meet with policymaker; meetings pairing a policy lead with a researcher/clinician and person living with pain in each jurisdiction.
 - Follow-up meetings through Report stage. Congress is now rushing to fund through "mini-bus" bills by Jan. 30.

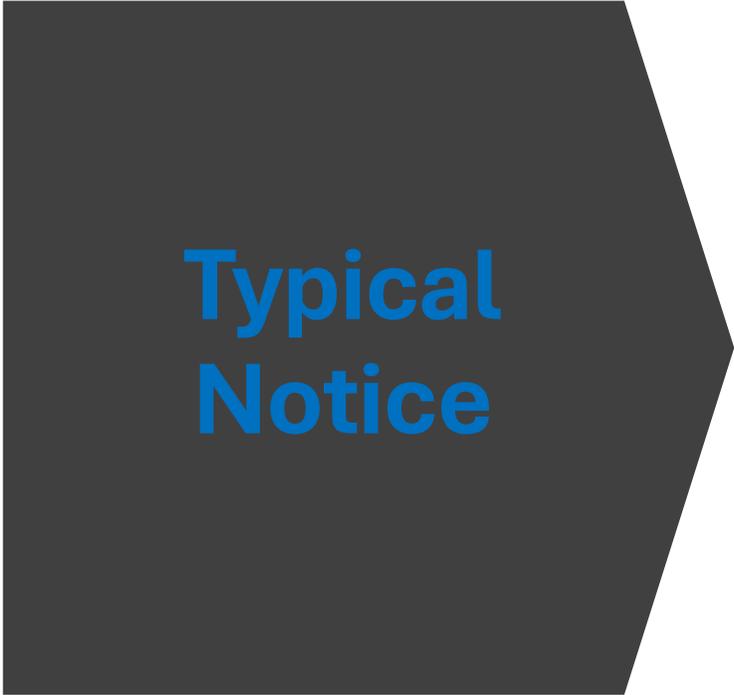
Administrative Agencies (FDA, CDC, CMS)

- **Comments in the Federal Register**

- Big impact with less investment. Designed for expert input.
- Agencies publish Notices in the Federal Register. They read all unique comments.
- Tracking:
 - Sign up at **federalregister.gov** to get notifications for specific keywords, agencies, or document types delivered to your inbox; or use keyword searches for current rules.
 - Follow **@FedRegister on X** for updates.
 - Stay in touch with allied groups to know when something in your area is heating up.

- **Comment deadlines are published in the Notices**

- Label comment with Docket Number (RIN) from the Federal Register
- Submit comments using Regulations.gov.



Development of Non-Opioid Analgesics for Chronic Pain, Draft Guidance for Industry; Availability

A Notice by the Food and Drug Administration on 09/11/2025



PUBLISHED DOCUMENT: 2025-17442 (90 FR 44074)

- PDF
- Document Details
- Document Dates
- Table of Contents
- Public Comments

DOCUMENT HEADINGS

Department of Health and Human Services
Food and Drug Administration
[Docket No. FDA-2025-D-0610]

AGENCY:
Food and Drug Administration, HHS.

ACTION:
Notice of availability.

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Your Voice in Federal Decision Making

SUPPORT

Make a difference. Submit your comments and let your voice be heard.

Search for dockets and documents on agency actions

Or view all recently added

Regulations.gov
Your Voice in Federal Decision Making

SUPPORT

< View Docket

 PROPOSED RULE

Medicare Program: Contract Year 2027 Policy and Technical Changes to the Medicare Advantage Program, Medicare Prescription Drug Benefit Program, and Medicare Cost Plan Program

Posted by the **Centers for Medicare&Medicaid Services** on Nov 28, 2025

Regulations.gov
Your Voice in Federal Decision Making

You are commenting on a Proposed Rule by the **Centers for Medicare&Medicaid Services**

Medicare Program: Contract Year 2027 Policy and Technical Changes to the Medicare Advantage Program, Medicare Prescription Drug Benefit Program, and Medicare Cost Plan Program

Write a Comment

[Commenter's Checklist](#)
[Public Comments on Federal Regulations](#)

Comment*

Start typing comment here...

What is your comment about?

Select a Comment Category

Attach Files

Tell us about yourself! I am...*

(Select an identity below)



An Individual

Yourself or another person whom you represent with their consent



An Organization

A company, organization, or government agency



Anonymous

A person who does not want their name associated with the comment

Collaborative Effort



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Advocacy Efforts

AAPM advances political activism in advocating Pain Medicine needs to Congress.

[JOIN NOW](#)

ADVOCACY EFFORTS

Proposed LCD on Peripheral Nerve Blocks and Procedures for Chronic Pain

Medicare released a Proposed LCD eliminating in many regions nearly all peripheral nerve blocks from coverage policy for chronic pain.

Comments: AAPM, USASP (Anna Woodbury), NPAC , Multi-Society Letter. AAPM submitted publication in *Pain Medicine*.

NPAC
NATIONAL PAIN ADVOCACY CENTER

October 27, 2025

The Honorable Marty Makary, M.D., M.P.H.
Commissioner of Food and Drug
Administration
1092 New Hampshire Avenue
Silver Spring, MD 20993

Re: FDA's Draft Guidance for Industry: Development of Non-Opioid Analgesics for Chronic Pain

Dear Commissioner Makary:

We thank you for the opportunity to comment on the FDA's Draft Guidance for Industry: Development of Non-Opioid Analgesics for Chronic Pain. We appreciate that the FDA has a balanced approach to achieving safe and effective alternatives to opioids, while recognizing the critical importance of maintaining adequate pain control.

Kate M. Nicholson, JD
Executive Director and Founder
kate@nationalpain.org
800-735-0818

NPAC
NATIONAL PAIN ADVOCACY CENTER

March 17, 2025

Derek S. Maltz
Acting Administrator
Drug Enforcement Administration
8701 Montross Drive
Springfield, VA 22152

Dear Acting Administrator Maltz:

Re: Docket No. DEA-407; RIN 1117-AB40; Special Registrations for Telemedicine and Limited State Telemedicine Registrations

Kate M. Nicholson, JD
Executive Director and Founder
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NPAC
NATIONAL PAIN ADVOCACY CENTER

July 30, 2024

Monica M. Bertagnoli, M.D.
Director, National Institutes of Health
8000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Bertagnoli:

Re: HEAL REI, deferred by email to HEALquestions@od.nih.gov.

The National Pain Advocacy Center (NPAC), a 501(c)3 nonprofit organization that supports no industry funding and advocates for the health and human rights of people in pain, thanks you for the opportunity to provide input on the Request for Information (RFI) on the Helping to End Addiction Long-term® (HEAL) Initiative, NOT-NS-24-106 [hereinafter "HEAL RFI"]. NPAC is an alliance of clinicians, scientists, and public health experts led by and for people with lived experience of pain. NPAC envisions a world in which pain is treated equitably and effectively to all people living with pain here an opportunity to meet full and productive lives.

As the HEAL Initiative undergoes strategic planning, we encourage it to prioritize addressing the unmet needs of individuals living with pain, integrating the priorities of people experiencing pain and their loved ones, promoting health equity, and fostering better coordination within the government and with the public. We outline specific suggestions, in turn, below.

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NPAC
NATIONAL PAIN ADVOCACY CENTER

January 20, 2025

Submitted by Federal Register

Jeffrey M. Ziger, Lead
Information Collection Review Office,
Office of Public Health Ethics and Regulations,
Office of Science,
Centers for Disease Control and Prevention
1600 Clifton Road, NE, MS H21-8
Atlanta, Georgia 30329

CDC Desk Officer,
Office of Management and Budget,
725 17th St, NW
Washington, D.C. 20503

Re: Docket No. 2024-30497, ICR No. 202412-0920-006

Dear Dr. Ziger and CDC Desk Officer:

Thank you for the opportunity to provide feedback on the Department of Health and Human Services Centers for Disease Control and Prevention information collection request titled "Comprehensive Evaluation of the Implementation and Uptake of the CDC Clinical Practice Guideline for Prescribing Opioids for Pain."

Examples (DEA, FDA, CDC, NIH, etc.)

Crafting Your Message

- **Use simple, general language.** No jargon. No acronyms. Something your spouse or older children would understand.
- **Make No More than 3 points:**
 - The problem.
 - Why it matters.
 - What you are asking for.

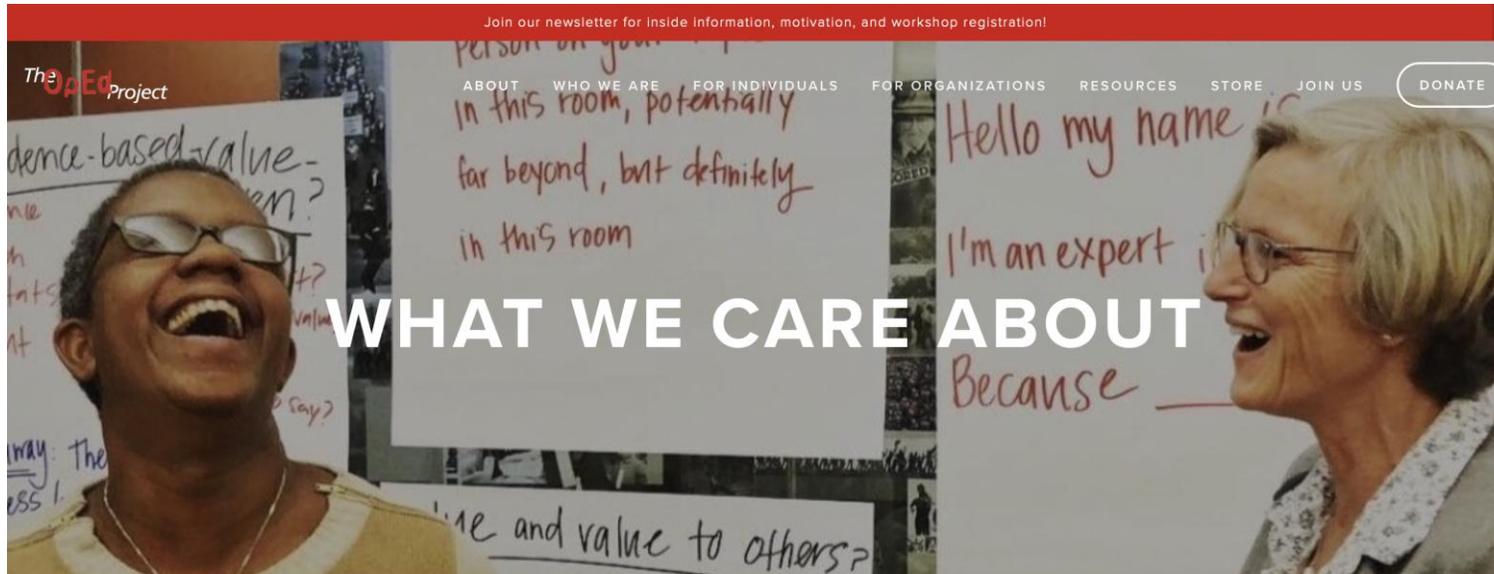


Why should they care?



- Why does it matter now? **Why does it matter to them** (ROI)? This is true whether you are communicating at work or with a policymaker: **human connection**.
- **Use Statistics**. Be specific and show how it fits in the larger context. (Key stats, \$\$\$).
- **Use Storytelling**. Stories are the language of policymaking. (State of the Union).
- **Use Visuals**: charts, etc. (Ex: which institutes have pain research; where \$ are allocated at NIH).

A Great Primer



About

MISSION

IMPACT

OUR PARTNERS

The OpEd Project's mission is to change who writes history.

The Op-Ed Project: <https://www.theopedproject.org>

STRUCTURE

+ LEDE (AROUND A NEWS HOOK)

What sets the scene and grabs your reader's attention – your introduction.

+ THESIS

Your primary point.

+ ARGUMENT

Your points are supported by evidence (such as stats, news, reports from credible organizations, expert quotes, scholarship, history, first-hand experience).

They often move between specifics and the bigger picture -- historical context, global picture, what is driving the problem.

+ 1ST POINT

+ 2ND POINT

+ 3RD POINT

+ “TO BE SURE” PARAGRAPH

You pre-empt your potential critics by acknowledging counter-arguments, flaws.

+ CONCLUSION (OFTEN CIRCLING BACK TO YOUR LEDE)

Usually in an opinion piece you have a call to action. You want something done.

Example

Title states thesis.

One of my early Op-Eds.

Was syndicated: so, ran in internationally.

OPINION

Op-Ed: The clampdown on opioid prescriptions is hurting pain patients

Note: You rarely get to choose your title: but it plainly states the thesis.



(Lawrence H. Ko / Los Angeles Times)

BY KATE M. NICHOLSON

JAN 18, 2010 2:05 AM PT

Ledes

LEDES AND NEWS HOOKS: CATCHING ATTENTION

+ USE THE NEWS

This Wednesday evening Frances Newton, 40, will be put to death for the murders of her husband and two children 18 years ago...

+ TELL A DRAMATIC ANECDOTE

Ten years ago, I asked Bosnian civilians under siege in Sarajevo where they would go if they could escape...

+ REFERENCE POPULAR CULTURE

The marketing campaign shows real women, rather than anorectic teenagers, in white bras and panties posing next to the slogan “New Dove Firming. As tested on real curves”...

+ TURN CONVENTIONAL WISDOM ON END

Sex and the City’s main characters are witty, glamorous, independent and sexually liberated – in short, who wouldn’t want to be them? Me, for one.

+ USE WIT AND IRONY TO POINT OUT A CONTRADICTION

So now we know what “noble cause” Cindy Sheehan’s son died for in Iraq: Sharia. It’s a good thing W stands for women, or I’d be worried.

+ USE AN ANNIVERSARY

Fifty years after the Supreme Court banned school segregation, the battle over the racial composition of America’s schools continues in courtrooms across the country.

+ CITE A MAJOR NEW STUDY

According to a new nation-wide poll, 60% of women have cheated on their husbands at least once.

+ GET PERSONAL

College admissions officers around the country will be reading my applications this month, essays in which I describe personal aspirations, academic goals -- even, in one case, a budding passion for the sitar. What they won't know is that I actually graduated from college more than a year ago, and that the names attached to these essays are those of my duplicitous clients.

Lede

In the summer of 1994, I was working at my desk at the Department of Justice when my back started to burn. Moments later, my body seized up, and I fell to the floor. Suddenly, at the age of 30, I was no longer able to sit or stand. I could barely walk short distances. These limitations, related to a surgical mishap, would continue for almost 20 years.

After dozens of failed treatments, I reluctantly tried prescription opioids. The pain medication enabled me to work despite my condition. I argued cases in federal court from a foldable reclining chair, negotiated settlements by video teleconference and, working remotely, managed litigation in U.S. attorney's offices across the country.

When medical advancements led to an improvement of my health, I went off opioids without incident. [[Lede: personal story](#)]

I was, as it turns out, incredibly lucky. [Unexpected provocation— lucky because I escaped opioids? Luck and disability are rarely correlated.]

Lede (2) and Call to Action in Italics

A [report](#) released last month by Human Rights Watch paints a cautionary and at times harrowing picture of what pain patients are experiencing today. [Thesis and news hook: issuance of a major report that confirms my thesis]

The CDC needs to revise its guidelines to recommend that physicians not abandon pain patients or engage in “forced tapering.”

Argument (Point 1)

Because of well-intended efforts to address the overdose crisis, many doctors are severely limiting opioid prescriptions. Patients who rely on opioid analgesics are being forcibly weaned off the medication or seeing their prescriptions significantly reduced. Other patients are unable to find doctors willing to treat them at all. [Argument – point 1: Explanation of what is happening]

One such patient, Maria Higginbotham, has had more than a dozen surgeries to correct the collapse of her spine. She suffers from a painful condition in which the spinal cord fuses with adjacent membranes. Last year, her physician cut her pain medication by 75%, explaining that the reduction was to comply with federal guidelines.

In the past, Higginbotham could function. Now she needs assistance just to get out of bed and go to the toilet. [Evidence here is a different anecdote]

Argument (Point 2)

The [federal guidelines](#) Higginbotham's doctor cited were issued in 2016 by the Centers for Disease Control and Prevention. They were intended as non-mandatory recommendations for primary care physicians. Increasingly, the guidelines are treated not as recommendations, but as one-size-fits-all mandates. They are being misapplied by physicians, state legislatures, insurers and Medicaid programs. [\[Why it is happening.\]](#)

Some physicians told Human Rights Watch researchers that they had taken patients off opioids, or reduced patients' prescriptions, against their better clinical judgment. "You set yourself up for a liability, even when you know they're not addicted and they're benefiting from opioids," one physician said. Other doctors said that they had stopped treating pain patients altogether — even patients who *don't* use prescription opioids. [\[Impact: providers.\]](#)

To be sure...

It's true that opioids were prescribed liberally in recent decades. Doctors began doing this in the 1990s. There were some bad actors, such as "pill mills" and wayward pharmacies. Opioid medication too often fell into the wrong hands. [\[Here is the To be Sure paragraph\]](#)

Moreover, prescription opioids are not the magic bullet we once believed them to be. The evidence about their efficacy across a broad population is limited. Even when their use is appropriate, opioids carry risks, and the risks increase at higher doses. The CDC was right to encourage judicious, responsible prescribing. [\[Because what I was saying went so against the counter-veiling narrative, I added another To be Sure paragraph\]](#)

Argument (Point 3)

But chronic pain is a large umbrella category, encompassing a wide range of injuries and diseases, some of which are incurable. A one-size-fits-all approach to treatment does not work. [Big picture: Rationale for the misfire.]

The recent clampdown has had harmful consequences. Some patients told researchers that they were forced to quit working or go on disability when their medication was denied. Others are now homebound. Many mentioned the possibility of suicide. [Impact: undermines health, people go to the doctor to improve function.]

Patients also said that they were turning to alcohol or illegal substances to treat their pain. [Impact that is the opposite of the intent of the guideline.]

Conclusion: Call to Action

For all these reasons, the CDC should address the misapplication of its guidelines, as the [American Medical Assn.](#) recently did. The agency needs to revise its guidelines to recommend that physicians *not* abandon pain patients or engage in “[forced tapering.](#)”
[Conclusion: Call to Action]

The CDC should also study and address any unintended consequences of its 2016 guidelines, as it promised to do.

Tackling the overdose crisis is a vital public policy goal. But chronic pain patients should not become casualties in that fight. [A bit of a to be sure, but not this way]

Strategic Communication, In Sum:

- (Lede): Grab attention.
- (Thesis): Main Point.
- (Argument): Explain and Support your point.
- (To Be Sure): Anticipate criticism.
- (Call to Action): Ask for what you want.

Communication Applied to Policy

- I published this and another related opinion piece around the same time in *Washington Post*.
- Went to CDC with HRW asking for a public-facing acknowledgement of misapplication and harms.
- They issued such an announcement.
- When they eventually revised the Guideline in 2022, I was appointed to their opioid workgroup.
- Something as simple as writing a high-impact Op-ed can lead to policy change.

Ledes

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Workshop 1: Ledes

1. Pick a topic:

- Maybe you have a view on something in the news cycle or policy environment;
- Maybe there's something you've been wanting to say that's implicating your work;
- Maybe you want to use the examples I provided:
 - How might you argue for reimbursements if Medicare proposes cutting coverage for chronic pain treatments
 - How might you make the point about the importance of biomedical research?

2. Pick a strategy for a *lede*:

- A story? A study? Something in the news?

3. Share.

Tailoring Communication

Once you know what you want to say, the next step is to tailor that information to your specific audience.

Tailor to context: policymaker/ press.

Tailor to individual: Aderholt, Gillibrand.



Capitol Hill 101

Request a meeting, typically with health policy staffer. Explain who you are, who you represent, what you want to address. Virtual is fine. Member vs. Committee.

Identify Your “ASK.” What do you want them to do and why?

Prepare a one-pager with your ask, main points, story, stats, and your contact information.

Do your research. Different policymakers have different priorities. Google their bills and committee assignments.

Frame your issue as a solution to what they care about.

Chronic Pain is a Public Health Crisis

- The problem:** Chronic pain is the most common, costly and disabling chronic disease in the US today
- The obstacles:** Effective treatments remain elusive because: pain is complex, the problem has been neglected and underfunded, and drug development is slow and costly with a high failure rate
- The solution:** Preserve the NIH pain research budget and critical NIH infrastructure for coordinating pain research, sustain the \$640 million appropriation for the HEAL Initiative in FY26, and oppose changes to the current IDC rate

Chronic pain in the US

- Pain is the #1 reason Americans seek medical care
- Chronic pain affects 50 million adults and almost 15 million children and adolescents
- Rates of new cases of chronic pain surpass that of other chronic diseases, including diabetes and hypertension
- Chronic pain costs more than \$560 billion annually and is the leading cause of long-term disability and workforce reduction
- Chronic pain impacts every aspect of our population from rural communities to military readiness

Barriers to effective treatment

- Chronic pain is a complex neurological disease that often co-exists with other chronic diseases such as cancer, Parkinson's, and Multiple Sclerosis
- Pain research has long been neglected and under-funded by the federal government
- Less than 2% of the NIH budget is spent on pain research, despite its enormous national burden
- Private industry funding of pain research declined due to its complexity and high drug-failure rates
- No new drugs have been approved for chronic pain in 15 years (with the exception of migraine)

How do we SOLVE this public health crisis? → NIH support for pain research

- Pain research has advanced in the past 5 years, despite limited support; **now is not the time for cuts!**
- Protect the overall NIH pain research budget and critical NIH infrastructure for coordinating and administering pain research
- Ensure that a specific FY2026 appropriation for the Helping to End Addiction Long-term (HEAL) Initiative is comparable to FY2025 (\$640 million)
- Sustained support is the only way to solve the complex problem of chronic pain
- Oppose changes to the current indirect cost rate
 - Academic centers perform the vast majority of pain research. The costs include essential fees for physical and technological resources, as well as personnel to ensure compliance with federal regulations
- Federal-academic partnerships are the most cost-effective solution to continuing the growth and innovation of STEM in the US and to training pain researchers and clinicians to ensure the future pipeline grows

65 Million Americans desperately need safe, effective, non-addictive pain treatments

Op-Ed Structure Applied to One Pager

- First line (pink) is a *lede*
- Second lines (orange) are the *arguments*
- **Call to Action** (light blue): tying the *lede* to the solution
- Specific steps requested
- **Conclusion** (purple): restates the *lede* in individualized human terms



Working with the Press

1. **If politicians want “asks,” reporters typically have angles.** Research the reporter and ask about the story.
2. **Be quick to respond.** Reporters work on deadlines.
3. **Prepare the message you want to communicate:** your thesis, arguments, and even potential quotes.
4. **Offer data to back up your point.** Reporters need citations.
5. **Answer only the questions you can and feel comfortable answering.** It’s okay if you need to get back to them; it’s okay to say you have no answer.



Press (cont.)

6. Be prepared to pivot to your point. Use sentences like, “That’s a great question, but what’s really important to understand is...” “Or, that question makes me think of a related one that’s critical...”

7. Make your points—more than once. Reporters often end the interview by asking if there is anything they’re missing. Use that opportunity.

8. You may ask to check direct quotes for accuracy. You won’t likely get to change more.

Pivoting

- **Reframe context.** “That's a great question, but what's really important to know is...”
- **Correct with alternative stories or data.** “Yes, I've heard that concern, but what I see in practice is...” or “but what the data show is...”
- **Reframe the question.** “That's not in my area of expertise or I can't speak to that, but what I can tell you is...” Repeat your message.
- **Offer to get back to them.** “Can I get back to you on that?”
- **Reiterate your message.** If any question gives you an opening, answer the question and then refine it by repeating your message.

Pivots ← → “To Be Sure”

- Both are about addressing points potentially critical to your point of view, coming from opposite directions:
- “To Be Sure” You are the drafter, so you anticipate the counter-arguments.
- During a press interview, the reporter is leading the inquiry. Pivoting allows you to address misconceptions on the part of the reporter or someone they’ve quoted and return to your point.

**Workshop 2:
Role Play &
Sharing “To
Be Sure”**



Advocacy is a team sport.



Advancing the
health & human rights
of people in pain.

NATIONALPAIN.ORG



Contact me with questions,
advocacy ideas, for support,
for help with an Op-Ed at:
kate@nationalpain.org