

Big Numbers and Why Pain Counts

#TellCongressToCountPain

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Advancing Research for Chronic Pain Act S.2922/H.R.7164



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



Why Does it Matter to People with Chronic Pain?



How Did it Come About?



What Can You Do to Take Action?

What is the Advancing Research for Chronic Pain Act?

- 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



What is 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



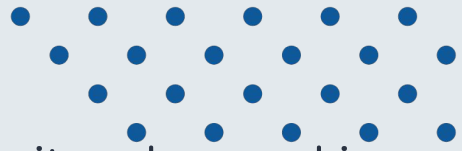
What Information Would be Required?

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 U.S.? What are their ages at onset? What is the relationship between disease progression and pain?
- ◆ How many people have chronic headache or migraine disease?
 - The widely cited 40 million prevalence number for migraine comes from one study using 2018 data, and is not a chronic headache/chronic pain number (Burch, Rizzoli & Loder, 2020); it is acute pain. *"During the past three months did you have a severe headache or migraine?"* (15.9% X 258M = 41M)
 - Only found one study from 2012 (Buse, Manack & Fanning, et al) finding .91% American adults live with chronic migraine = that is 2.3 million with chronic migraine
 - Studies are old. Do not count for Long COVID. Only counted migraine and not cluster, hemiplegic, or others. The definition of "chronic migraine" did not take into account patient views.

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

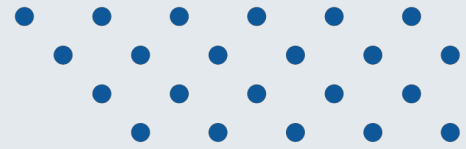
FORTUNE

The
Weather
Channel

The Washington Post

STAT

Why Does This Matter for People with Chronic Pain?

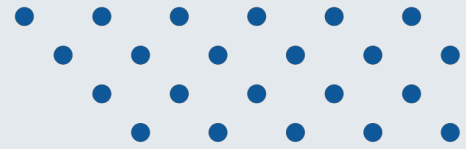


- It will identify and quantify consequences of chronic pain.
 - ◆ Consequences of chronic pain are enormous. Some examples:
 - Inability to carry out basic activities of daily living like cooking, bathing, etc.
 - Inability to concentrate
 - Inability to care for one's children and family
 - Inability 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.



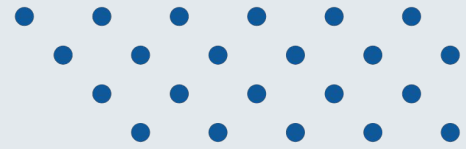
Why Does This Matter for People with Chronic Pain?



- 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 physician visits prior to diagnosis, which is costly.
- Data on the effectiveness of treatment will enable more individualized and tailored treatment plans.



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 colleague worked with me to create a first draft of the bill in 2018 for the SUPPORT Act
 - Together, with two coalitions (PCC Workgroup & PAPR), brought the bill to 18 different Hill offices in 2022
- In Feb. 2022, an aide to Sen. Casey, Kate Samuelson, expressed an interest in the bill.
 - Soon thereafter, a Research Fellow with a background in pain neuroscience, Lindsey Yessick, started working in Casey's office
 - Lindsey and Kate developed the bill with CDC and stakeholder input
 - Shared drafts with me and others for input

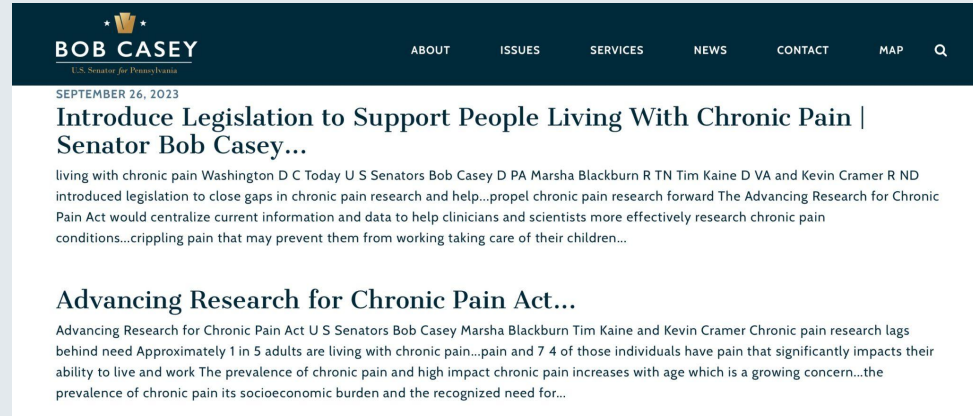


How Did it Come About?

Successful advocacy = patience + persistence + compromise

- The final bill: not everything we wanted
 - Registry for longitudinal data cut
- Kate and Lindsey sought bi-partisan co-sponsorship
- Kate asked for help finding co-sponsors
- Kate contacted me in late summer of 2023 to say they were working to introduce bill

BIG MOMENT: Bill was introduced on Sept. 26, 2023

A screenshot of a news article from the website of U.S. Senator Bob Casey. The header features the senator's name and title, along with navigation links for 'ABOUT', 'ISSUES', 'SERVICES', 'NEWS', 'CONTACT', 'MAP', and a search icon. The article is dated 'SEPTEMBER 26, 2023' and is titled 'Introduce Legislation to Support People Living With Chronic Pain | Senator Bob Casey...'. The text discusses the 'Advancing Research for Chronic Pain Act' introduced by U.S. Senators Bob Casey, Marsha Blackburn, Tim Kaine, and Kevin Cramer. It highlights the need for chronic pain research and the impact of chronic pain on individuals and society.

BOB CASEY
U.S. Senator for Pennsylvania

ABOUT ISSUES SERVICES NEWS CONTACT MAP Q

SEPTEMBER 26, 2023

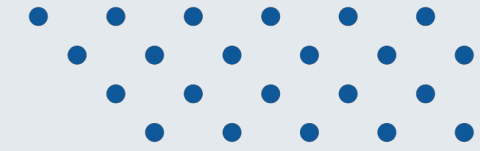
Introduce Legislation to Support People Living With Chronic Pain | Senator Bob Casey...

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...

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



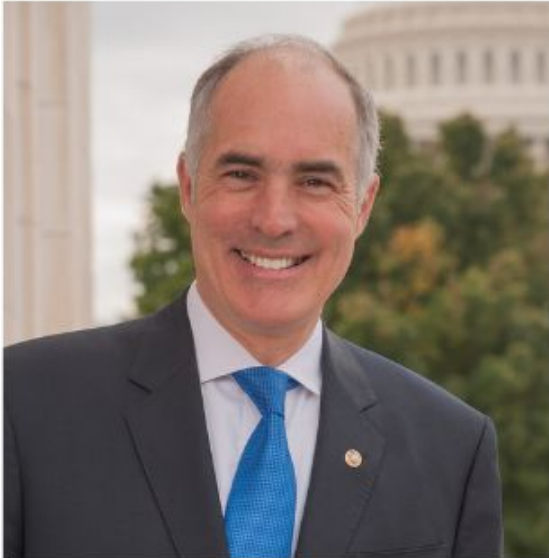
An opportunity arose when the Senate HELP Committee announced a mark-up on the SUPPORT Act Reauthorization for Dec. 12, 2023.

- 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
- Rumor circulating that Sen. Casey wasn’t going to introduce as amendment
 - Reached out to office and learned that was not the case
- 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 & reported out of HELP
 - But there are still steps to take; SUPPORT Reauthorization has not yet had a floor vote

U.S. SENATE COMMITTEE ON

Health, Education
Labor & Pensions

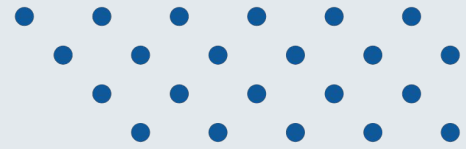
Senator Casey (D-PA) on Advancing Research for Chronic Pain Act



Senate HELP Committee Markup
December 12, 2023



What About the House of Representatives?



- House had already passed the SUPPORT Reauthorization Act
- E&C Health Subcommittee recommended favorably out of committee prior summer on July 19, 2023

- Strategy-wise, best to get our bill introduced in the House in the event SUPPORT goes to conference
 - Began looking for a House sponsor

- Soon thereafter, Kate (Samuelson from Sen. Casey's office) reached out sharing that Congresswoman Yadira Caraveo, MD (CO-08) was interested in introducing the bill in the House

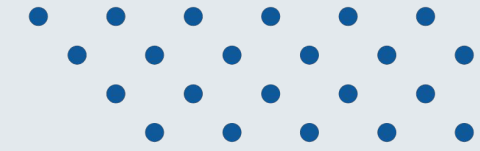


Elizabeth Tapia, MPH Health Policy Advisor Congresswoman Yadira Caraveo, MD

- ❑ Master of Public Health, and Bachelor of Science in Health Promotion & Disease Prevention
- ❑ Focuses on access to health care, drug pricing and accessibility, and investments in health research
- ❑ Certified Health Education Specialist



Advancing Research for Chronic Pain Introduced in House of Representatives




REPRESENTATIVE
YADIRA CARAVEO
COLORADO'S 8TH CONGRESSIONAL DISTRICT

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ENGLISH ESPAÑOL

CONGRESSWOMAN CARAVEO LEADS BIPARTISAN LEGISLATION TO ADVANCE CHRONIC PAIN RESEARCH



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 Can We Do to Take Action?

Two different “asks” – one for U.S. Senate and one for U.S. House

In the House:

H.R.7164 is a stand-alone bill

- Introduced after the House had already taken a vote on SUPPORT Reauthorization Act

“Ask” for your Representative:

Please co-sponsor H.R.7164, the Advancing Research for Chronic Pain Act

- Contact Elizabeth Tapia, Health Policy Advisor to Congresswoman Caraveo, to co-sponsor



What Can We Do to Take Action?

Two different “asks” – one for U.S. Senate and one for U.S. House

In the Senate:

S.2922 was included in the Senate SUPPORT Reauthorization Act (S.3393)

“Ask” for your Senators:

Please urge Senate leadership to take a full Senate vote on the SUPPORT Reauthorization Act

- If you live in New York or Kentucky, the “ask” is for Senators Chuck Schumer and Mitch McConnell to call a full vote on the SUPPORT Reauthorization Act



U.S. Pain Has Made Taking Action Easy!

You will receive an email explaining how to take action tomorrow. You also can visit uspainfoundation.org/advocacyday starting at 12:01 a.m. ET and learn how!

You can participate using any (or all three) of these actions using resources we've prepared for you:

1. Email your Senators and Representative using a template email — send with just one click
2. Call your Senators' and Representative's offices in DC with a draft script ready for you
 - a. Quick tip: follow-up the call by emailing our one-pager about the bill to them while repeating your “ask”
3. Send a pre-drafted tweet to your Senators and Representative urging them to ensure passage of the bill



We Hope You Will Take Action With Us Tomorrow!

Any
questions?



Working together, we can create meaningful change!

THANKS FOR ATTENDING

Join us tomorrow, July 23, as we
#TellCongressToCountPain and
#WhyPainCounts.

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U.S. PAIN
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