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*FasterCures*

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# **Vital Voices Webinar Series: Patient Organization Strategies to Inform CMS Access and Coverage Decisions**

## ***Part 1: Strength in Numbers: Coalitions Amplifying Patient Voices***

*August 5, 2025*

# FasterCures Programs

**Mission: To build a biomedical innovation system that is effective, efficient, and driven by a clear vision: patient needs above all else**

## R&D Environment

- ENRICH-CT (Enabling Networks of Research Infrastructure for Community Health Through Clinical Trials)
- Representation in Clinical Trials
- Future of Biomedical Innovation



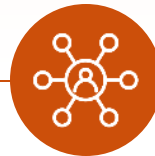
## Policy

- CMS/FDA Alignment: Accelerating Treatments to Patients
- Building Patient Engagement Capabilities at CMS
- Prevention-First Health



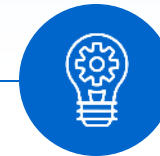
## Patient Engagement

- TRAIN (The Research Acceleration and Innovation Network)
- LeadersLink
- Patient Engagement in Medtech Development
- Vital Voices: Patient Engagement with CMS



## Innovation

- Future of Cancer Care in the US
- Cell, Gene, and RNA Therapies
- Emerging Technologies
- Data and AI



## International

- Project Prevent
- Global Cancer Care
- Anti-Microbial Resistance
- Early Warning System



# TRAIN: The Research Acceleration & Innovation Network

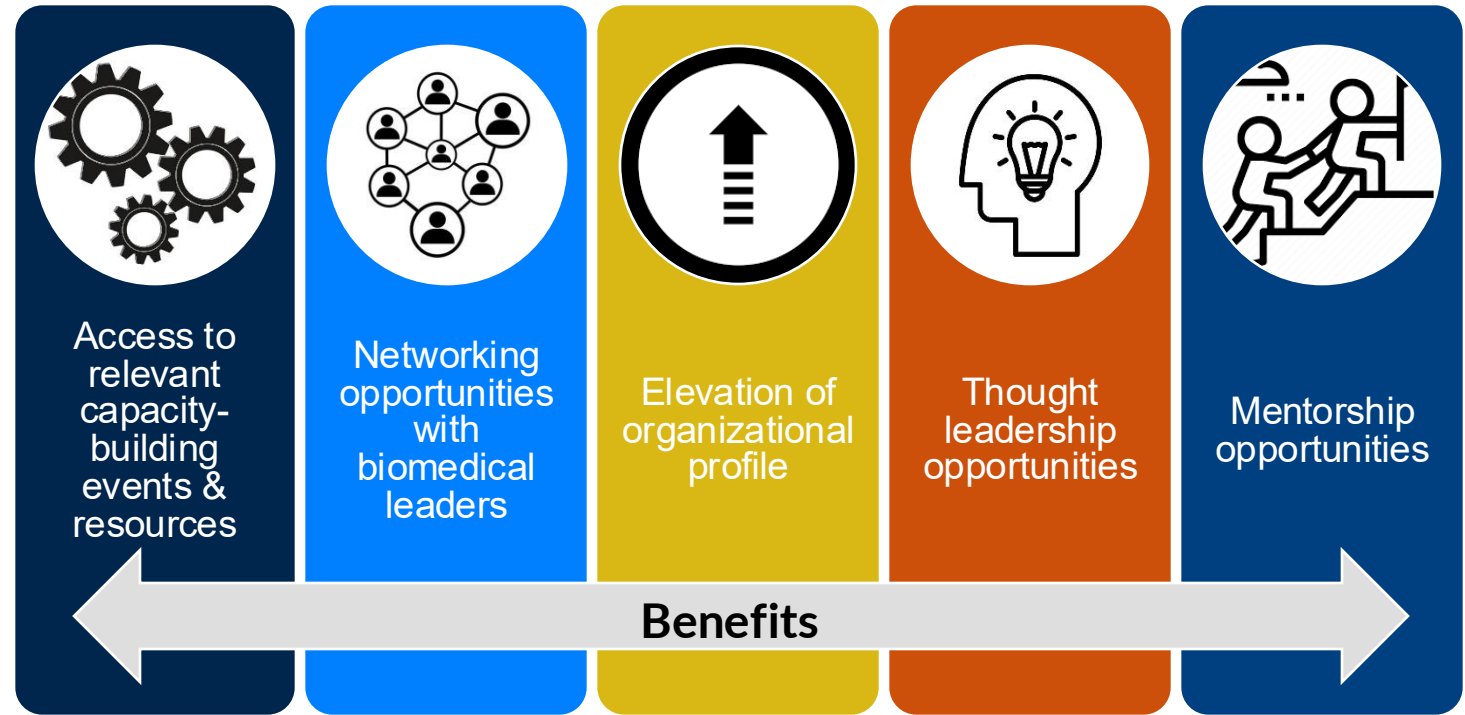


The objectives of TRAIN are to:

- To encourage more entrepreneurial philanthropy in medical research
- To build more and better networks with other R&D stakeholders
- To enhance the influence of the network

**Join TRAIN  
and/or serve  
as a mentor  
for a rare  
disease org!**

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Questions? [TRAIN@milkeninstitute.org](mailto:TRAIN@milkeninstitute.org)



# Background

- The Centers for Medicare and Medicaid Services (CMS) is the bellwether to which other payers and value assessors look for guidance and leadership.
- Patient organizations bring unique, real-world insights that can shape CMS's decisions on treatment access, yet many groups are unaware of how or when to effectively engage.
- Providing patient organizations with practical tools and peer-driven examples strengthens their ability to advocate for equitable, patient-centered care policies.

# About the Webinar Series

The FasterCures Vital Voices three-part webinar series explores how patient organizations can inform and potentially influence CMS activities and state-level coverage decisions. Each session focuses on a key strategy for engagement:

- **Part 1:** Engaging in coalitions to impact CMS decision-making (August)
- **Part 2:** Collecting and leveraging patient experience data (September)
- **Part 3:** Navigating state-level policy and coverage (November)

# Today's Webinar

- Objective: Showcase how coalitions empower patient organizations to engage with CMS more effectively by leveraging shared resources and aligning on shared priorities.
- Key topics will include:
  - The role of coalitions in amplifying patient perspectives for CMS decision-makers
  - How different organizations can align on shared priorities and speak with one voice
  - Successful tactics coalitions have used to engage CMS around coverage and payment decisions

# Speakers



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**Peter W. Thomas, JD**

Managing Partner,  
Powers Law;  
Co-Coordinator,  
Independence  
Through  
Enhancement of  
Medicare and  
Medicaid (ITEM)  
Coalition



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**Tiffany Westrich-  
Robertson**

CEO, Co-Founder, and  
Board President,  
AI Arthritis;  
Coalition Founder, Project  
Manager,  
Ensuring Access through  
Collaborative Health  
(EACH) & the Patient  
Inclusion Council (PIC)  
Coalition



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**Josie Cooper**

Executive Director,  
Alliance for Patient  
Access (AfPA)





**Peter W. Thomas, JD**  
Managing Partner, Powers Law;  
Co-Coordinator,  
Independence Through Enhancement of Medicare  
and Medicaid (ITEM) Coalition

## Strength through Coalitions: ITEM Coalition Initiative to Obtain Medicare Coverage of Seat Elevation in Powers Wheelchairs



Peter W. Thomas, JD, Managing Partner,  
Powers Law  
ITEM Coalition Co-Coordinator  
August 5, 2025



# Value of Coalitions

- . Strength in numbers
- . Consistent and consensus messaging on policies and advocacy
- . Accelerates and facilitates the legislative and regulatory processes of government
- . Demonstrates that diversity of stakeholders view priorities similarly
- . Pools resources and reduces duplication, allowing funders to conserve dollars or apply them to complementary strategies such as PR, grassroots, evidence development, economic modeling, and, if necessary, litigation

# ITEM Coalition

- . Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition
- . Mission: Access to assistive devices and technologies
- . Founded in 2003; now has 100 non-profit members comprised of patient groups, disability organizations, clinical academies, and research associations.
- . For more information, go to [www.ITEMCoalition.org](http://www.ITEMCoalition.org)
- . Developed complimentary website for seat elevation NCD initiative: [www.rise4access.org](http://www.rise4access.org)

# CASE STUDY: Seat Elevation

- Medicare sets the standard for coverage for other payers
- Medicare Coverage of Seat Elevation and Standing Systems in Power wheelchairs
- CMS looking for non-regulatory method of providing patients with mobility impairments with access to benefits not already covered
- ITEM Coalition discussed National Coverage Determination approach with former CMS Administrator and agreed on strategy
- Developed ITEM subcommittees with diversity of stakeholders
- Powers law firm drafted the NCD reconsideration request with major assistance from the Clinicians Task Force (CTF) and others
- Secured funding through ITEM Coalition members and others

# CASE STUDY: Seat Elevation (cont'd)

- Developed well-researched, evidence-based 62-page NCD Reconsideration Request for Medicare coverage of seat elevation and standing systems in power wheelchairs:
- 314 footnotes and 129 individual source documents
- NCD redline and draft LCD as appendices
- Letter of support from 60 national non-profit organizations
- Letters of support from Members of the U.S. House and Senate
- National Council on Disability prioritized coverage in its agenda and held a virtual forum to build grassroots awareness and the evidence base
- Submitted NCD Reconsideration Request in September 2020. CMS deemed it “complete” in November 2020



# CASE STUDY: Seat Elevation (cont'd)

- Multiple meetings with CMS' TCPG, CCSQ, COM, CMS Administrator's office, and HHS Communications Office to seek opening of the National Coverage Analysis (NCA)
- All stakeholders represented, including consumers using seat elevation and standing systems technology
- Direct phone and letter contact between Senator Duckworth, Congressman Langevin, and senior leadership at CMS
- Public relations efforts and social media campaign helped create pressure, including a national, virtual petition for CMS to act.
- Conclusion: CMS opened NCA on August 15, 2022 for seat elevation coverage only, bifurcating standing systems until another day.

# CASE STUDY: Seat Elevation (cont'd)

- Once opened, CMS has 9 months total to issue final NCD after publishing a draft NCD and accepting public comment two times
- ITEM Coalition orchestrated major campaign for advocates and the public to submit comments
- Massive undertaking and massive response from the rehab and disability communities
- Proposed NCD issued on February 15, 2023 for public comment. Policy was a victory but draft coverage included several harmful restrictions
- ITEM Coalition pursued a massive second public comment effort
- Over 3,000 comments submitted, including most that were “unique.”
- Final NCD announced May 15, 2025, effective immediately



# CASE STUDY: Seat Elevation (cont'd)

- CMS issued an expansive final coverage policy for seat elevation in both power *and* manual wheelchairs
- Clarified that extending one's reach to perform MRADL's was included in coverage criteria
- Clarified that Medicare coverage of mechanical lifts for home use did not bar coverage of seat elevation systems
- CMS attributed expanded coverage to strong evidence base and massive outpouring of public comment.
- Today, Medicare beneficiaries (and many covered by private plans) have access to seat elevation systems
- However, Medicare beneficiaries are **STILL WAITING** for CMS to open an NCA for standing systems.

# CASE STUDY: Seat Elevation (cont'd)

- Diversity of organizations and individuals all aligned with a consistent, consensus message. This proved dispositive
- ITEM Coalition Steering Committee coordinated the entire effort
- Patient groups were intimately involved in this effort and led the advocacy messaging
- Physicians and their societies were involved to speak eye-to-eye with CMS medical and clinical staff assessing the evidence base
- Physical and occupational therapists developed the evidence base and eloquently wrote compelling arguments for coverage
- Attorneys analyzed existing barriers to coverage and designed the strategy to allow CMS to make the right decision and get to “yes”
- Manufacturers and supplier organizations help fund this initiative





# Thank you!

Learn more about ITEM Coalition at  
[www.itemcoalition.org](http://www.itemcoalition.org)

Peter W. Thomas, J.D.  
ITEM Coalition Co-Coordinator  
(c) 202-607-5780  
[Peter.Thomas@PowersLaw.com](mailto:Peter.Thomas@PowersLaw.com)



*Independence Through  
Enhancement of  
Medicare and Medicaid*  
COALITION

**POWERS**  
POWERS PYLES SUTTER & VERVILLE PC



## **Tiffany Westrich-Robertson**

CEO, Co-Founder, and Board President,  
AI Arthritis;

Coalition Founder, Project Manager,  
Ensuring Access through Collaborative Health (EACH)  
& the Patient Inclusion Council (PIC) Coalition



# **ENSURING ACCESS THROUGH COLLABORATIVE HEALTH**

**STRENGTH IN NUMBERS: COALITIONS AMPLIFYING PATIENT  
VOICES IN CMS DECISION-MAKING**

Tiffany Westrich-Robertson  
Founder EACH/PIC - EACH Lead, PIC Assist  
AiArthritis Founder, CEO  
Person living with Axial Spondyloarthritis

<https://www.linkedin.com/in/tiffanywestrichrobertson/>





## **ENSURING ACCESS THROUGH COLLABORATIVE HEALTH**

Patient organizations & allied groups (doctors, pharmacists, etc.) who advocate for drug affordability policies that benefit patients.



## **PATIENT INCLUSION COUNCIL**

Patients & caregivers who participate in activities that ensure patient-reported needs are incorporated into drug affordability solutions.

[WWW.EACHPIC.ORG](http://WWW.EACHPIC.ORG)



# Coalition Importance and Impact



## National Network of Participants

- **CMS: “We have to accept one off meetings, this makes it very difficult for us.”**
- **Unified language, while celebrating individuality**
- **Avoid duplication of efforts, resource repository, champion others, collaborate**
- EACH – Over 80 groups, various levels of participation, range of groups (patient organizations, allied groups, other coalitions – like ASBM, LMDD, Derma Care Access Network, etc
  - Cover CMS and PDABs, coalition is needed for all types of participants:
    - In and out
    - Dedicated/involved
    - Information only/watching from the sidelines for now



## PIC – Adopted 95/5

- Peer-to-peer recruitment, education, preparation (NO TRAINING)
- PIC: Leave your opinions at the door, share your truth



## PROJECTS/OPPORTUNITIES

- Patient opportunity – affordability & unaffordability WHY. PDABs, CMS, Legislators. Data matters. PRP led/Patient Orgs/Data Scientist
- **RELEASED AUG 4TH! <https://eachpic.org/each-pic-releases-results-from-patient-led-survey-on-drug-affordability/>**



# Patient Organization/Patients

## Feedback, Opportunities, Adjustments for 2025



### We want “real” patients

- 2023: Of the 40% recruited, 40% of those had never spoken publicly
  - “We got you.” “Trust us” (peers). “We will help you **PREPARE**” - will will NOT script or train you.
  - 2025: AiArthritis 70% autoimmune drug; EACH/PIC additional 5, 2 “assists”
- Several hours day and night working on peer-to-peer recruitment, created associated **education** (“the why you should participate/what is this anyway”).



### Patient voices needed, engagement limitations/improvement

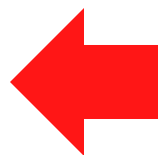
- “Check your spam!” & 4 day turnaround to people who don’t use email regularly. 24 hour follow up, repeat.
- Still left with a lot of questions (from us and the participants):
  - “What did they do with my testimony?” “Did my input do anything?”
- They did improve, but there’s work to do.



**Participating in coalitions can help overcome these challenges by amplifying collective patient voices, aligning priorities, and leveraging resources.**

**Let the PIC Help YOU!** Process - send to OUR FORM/Not Direct Link to Outside Engagement, then we connect them to opportunities (plural)

- CMS “Patient Office Hours!”
- CMS Prep Sessions:
  - April 9th, 5pm ET
  - April 12th, 11am ET
  - April 16-29: Roundtables
  - April 30-May 15: Patient Follow-up
- OR PDAB: April 1-30: Activate patients to submit info on drug subset list
- CO PDAB: April-June: Activate patients to testify on Enbrel
- MD PDAB: May-July: Activate patients to engage on Jardiance and Farxiga



PATIENT EXPERIENCES DRIVING CHANGE

## Calling All Patients and Caregivers: Share Your Perspective On Prescription Drugs

We support reducing prescription drug costs and want to ensure health reforms truly benefit patients. For that to happen, patients and caregivers need to share their experiences.

» GET STARTED





 **PIC: Patient-facing,  
EACH participants welcome**

 **National Network: Work  
together = stronger impact!**



**Your voice matters.**

**CMS Medicare Drug Pricing Negotiation  
Patient Experiences Driving Change**

**Wednesday, February 19  
6pm ET/5pm CT/3pm PT**

**PATIENT  
INCLUSION COUNCIL**



Ensuring Access through  
Collaborative Health (EACH) & the  
Patient Inclusion Council (PIC)

The PIC is part of a bigger coalition.  
PIC participants include patients  
and caregivers.

**Welcome!**



#### PATIENT INCLUSION COUNCIL

### How does the drug negotiation work?

Drug Name	Commonly Treated Conditions*	Total Gross Presc Costs 2021
Ozempic; Rybelsus; Wegovy	Type 2 diabetes; Type 2 diabetes and cardiovascular disease; Obesity/overweight and cardiovascular disease	
Trelegy Ellipta	Asthma; Chronic obstructive pulmonary disease	
Xtandi	Prostate cancer	
Pomalyst	Kaposi sarcoma; Multiple myeloma	
Ibrance	Breast cancer	
Orin	Idiopathic pulmonary fibrosis	
Linzess	Chronic idiopathic constipation; Irritable bowel syndrome with constipation	
Calquence	Chronic lymphocytic leukemia/small lymphocytic lymphoma; Mantle cell lymphoma	
Austedo; Austedo XR	Chorea in Huntington's disease; Tardive dyskinesia	
Breo Ellipta	Asthma; Chronic obstructive pulmonary disease	
Trasenda	Type 2 diabetes	
Xifaxan	Hepatic encephalopathy; Irritable bowel syndrome with diarrhea	
Vraylar	Bipolar I disorder; Major depressive disorder; Schizophrenia	
Janumet; Janumet XR	Type 2 diabetes	
Otezla	Oral ulcers in Behçet's Disease; Plaque psoriasis; Psoriatic arthritis	



CMS selects a handful of drugs that have high costs to them and starts a formal negotiation process with manufacturers. **These are not drugs identified based on patient-reported needs.**



CMS asks all groups who are part of the complex prescription drug system to submit information to them about the drug under review.

Some include drug companies, insurance/Pharmacy Benefit Managers (PBMs) who pick the drugs on your drug lists, pharmacists, doctors, patient organizations, and PATIENTS/CAREGIVERS. roundtables, and a townhall. **Currently, VERY, VERY few patients are participating in these sessions and CMS is making decisions WITHOUT OUR INPUT.**



CMS - NOW through April



Patient Inclusion Council (PIC)

## EACH COALITION

# Participate & Collaborate

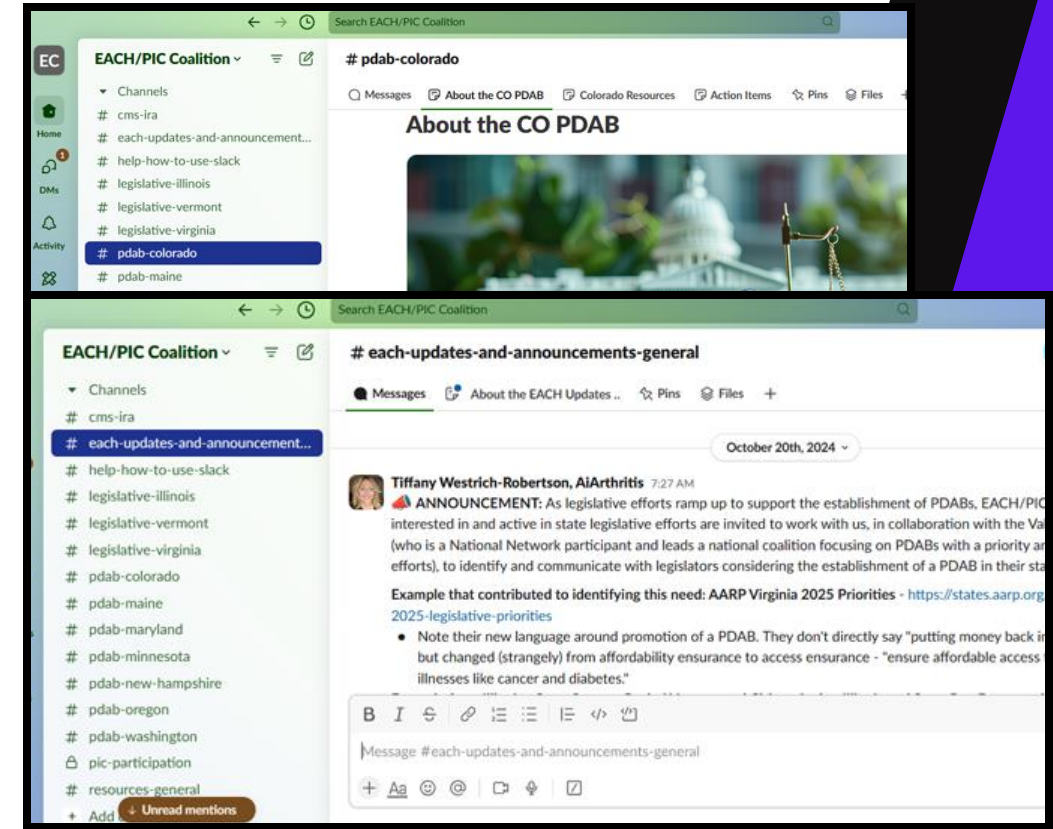


## Letter Sign Ons/Guidance Points






## EACH/PIC SLACK COMMUNITY!

- Channel for CMS, every PDAB, every legislative state thinking about a PDAB, MFP legislation channel, and NEW! #abolished - pdab- (new-hampshire)

**Participating in coalitions can help overcome these challenges by amplifying collective patient voices, aligning priorities, and leveraging resources.**



## Other Examples

-  **SLACK: Unified speaking points (in real time)**
-  **SLACK: Brainstorming off email/contained and can revisit**
-  **“PDAB” Blocking**
-  **WA PDAB: Patient-Facing Survey Involvement**  
**MD PDAB/PDAB ‘coalition’ - Patient Engagement Best Practices/streamlining the processes (“need unified voices and less one offs)**
-  **The EACH/PIC Coalition Releases Results from Patient-Led Survey on Drug Affordability (Aug 4, 2025) - the shift to patient experience data begins. (Ok, that’s just hopeful, but it’s possible TOGETHER!**





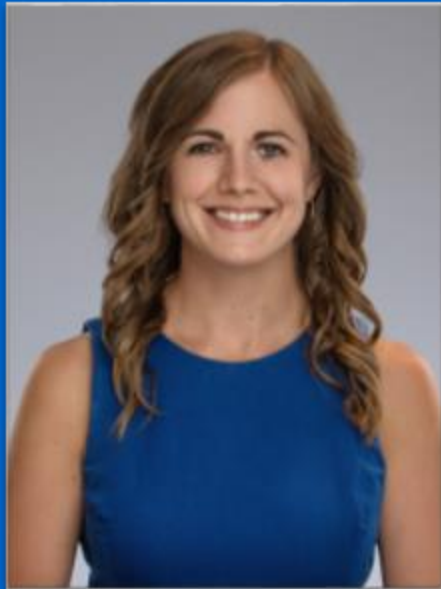
# **ENSURING ACCESS THROUGH COLLABORATIVE HEALTH**

T H A N K   Y O U !

<https://eachpic.org>



@eachpic



**Josie Cooper**  
Executive Director,  
Alliance for Patient Access (AfPA)

# Alliance for Patient Access: Empowering Stakeholder Advocacy

*Josie Cooper*  
*AfPA Executive Director*





# AfPA's Mission

**The Alliance for Patient Access (AfPA)** is a national non-profit advocacy organization dedicated to ensuring patient-centered health care policies.

AfPA accomplishes its mission through educating clinicians and other stakeholders on issues impacting patient access and empowering them to engage and inform policymakers.





# Patient-Centered Care

- Strong clinician-patient relationship
- Empowered patients engaged in shared decision making
- Patients don't benefit from one-size-fits-all/least costly alternative health care
- Policies that support therapeutic access
- Value of getting it right

# AfPA's Policy Priorities



**Patient Access**



**Patient Cost**



**Patient Choice**

# Organizing Clinicians and Partners

AfPA Working Groups & Initiatives organize **health care providers** around a common disease area, identify shared advocacy needs and opportunities, and empower providers to engage in direct advocacy.

AfPA-led coalitions organize **patient advocacy groups, medical societies and other partners** through a shared platform. Coalition members partner on educational resources and campaigns, policy events and advocacy initiatives.



**Mental Health**  
Working Group

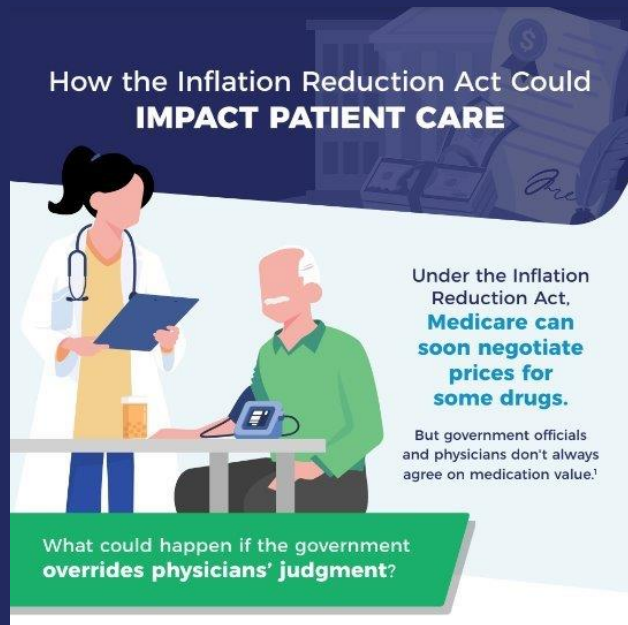


**Neurological Disease**  
Working Group



# Medicare Drug Price Negotiation Engagement

- Under the Inflation Reduction Act, signed into law in 2022, Medicare can now negotiate prescription drug prices through the Medicare Drug Price Negotiation Program



## Multi-Year Approach

- 1st Year – 10 Part D single source drugs
- 2nd Year – 15 additional Part D drugs
- 3rd Year – 15 Part B/D Drugs
- 4th Year – 20 Part B/D Drugs

# Timeline

## Medicare Drug Price Negotiation Timeline for 2026 & 2027



SOURCE: KFF analysis of section 11001 of the Inflation Reduction Act of 2022.

**KFF**

Drug Name	Commonly Treated Conditions*
Ozempic; Rybelsus; Wegovy	Type 2 diabetes; Type 2 diabetes and cardiovascular disease; Obesity/overweight and cardiovascular disease
Trelegy Ellipta	Asthma; Chronic obstructive pulmonary disease
Xtandi	Prostate cancer
Pomalyst	Kaposi sarcoma; Multiple myeloma
Ibrance	Breast cancer
Ofev	Idiopathic pulmonary fibrosis
Linzess	Chronic idiopathic constipation; Irritable bowel syndrome with constipation
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Xifaxan	Hepatic encephalopathy; Irritable bowel syndrome with diarrhea
Vraylar	Bipolar I disorder; Major depressive disorder; Schizophrenia
Janumet; Janumet XR	Type 2 diabetes
Otezla	Oral ulcers in Behçet's Disease; Plaque psoriasis; Psoriatic arthritis

## Second Round: 15 Drugs

On January 17, 2025, the Centers for Medicare & Medicaid Services (CMS) announced the list of 15 Part D drugs selected for the second round of price negotiation, after concluding the first round of negotiation for 10 Part D drugs in August 2024.

On January 31, 2025, CMS announced they would continue the process, but with improvements.



# IRA & Neurology/Mental Health

For the first time, medications that are important for the neurological disease and mental health communities are being negotiated through the drug price negotiation program:

- **Deutetrabenazine (Austedo):** an FDA-approved treatment for both tardive dyskinesia and a symptom of Huntington's disease known as chorea.
- **Cariprazine (Vraylar):** a treatment for schizophrenia, bipolar, and major depressive disorder.



Patient Access

Medicare Price Caps May Hurt Patient Access



Patient Access

Feds Target 15 More Drugs for Price Negotiations

# IRA: Unintended Consequences

- **Reduced Innovation**

- Many conditions don't yet have a cure, making innovation and the development of new medications critical for the patient community
- Research shows that IRA drug price negotiation may slow innovation, leading to fewer treatments for those who need them
- The law may incentivize the development of biologic medications over small molecule treatments

- **Decreased Access**

- Utilization management tools like prior authorization, step therapy, and non-medical switching undermine optimal care for patients
- Research has shown patients may experience more utilization management for medications that undergo Medicare price negotiation



# CMS – The IRA Input Process

- During the first round of negotiations, patients, providers, and advocacy groups raised numerous concerns about the transparency and accessibility of the input process – as a result, CMS issues new guidelines in hopes of improving the process.
- CMS provided three primary opportunities for advocates to weigh in in spring 2025.
  1. Submitting comment through the portal.
  2. Participating in a patient-focused roundtable related to each medication.
  3. Participating in a clinically oriented virtual townhall meeting.

**AfPA's Goal: Support coalition partners, clinician members and other advocates in participating through every stage of the process.**

# Timeline of Key Activities

Jan 17, 2025 - CMS published list of 15 drugs

Feb 2025 - CMS released guidelines on public comment

**Mar 1, 2025 - Deadline to submit public comment**

**Mar-Apr 2025 - CMS hosts up to 15 patient-focused roundtable events and two town hall meetings focused on clinician considerations**

Spring-November 2025 - Negotiations between CMS and manufacturers

Nov 30, 2025 - Publication of negotiated prices

Jan 1, 2027 - Availability negotiated prices for 15 selected drugs

# Engaging Stakeholders

- AfPA and our Movement Disorders Policy Coalition worked to:
  - Support AfPA clinicians and advocacy partners in submitting public comment
  - Mobilize partners through town halls and listening sessions
  - Help patient advocates share their stories with CMS and other stakeholders

## What You Can Do

### SUBMIT PUBLIC COMMENT



Patients, care partners, health care providers and others can submit comment on their perspectives with the health condition selected medications treat. Specifically, CMS is seeking input on unmet medical need and impacts to specific populations. **Submissions must be made by March 1, 2025.**

How to Submit a Comment:

1. Click here: [Medicare Drug Price Negotiation Program Public Submission Form](#).
2. Register with a valid email address
3. Check your email for access to the submission form
4. Select the drug for which you are submitting information
5. Answer the questions

► Required Sections

- I28: Respondent Information
- J: Certification of Submission of Section I

► Optional Sections

- Answer any relevant questions you wish – **you are not required to fill out every question.**

6. Save and submit your response. CMS will not review saved responses unless they are submitted.

For more information on how to submit comment – including guidance on which questions are most relevant – visit [www.movementdisorderspolicy.org/IRA](http://www.movementdisorderspolicy.org/IRA).

### SHARE YOUR STORY

If you're a patient, care partner, or patient advocacy organization, register [here](#) to speak in a patient-focused roundtable related to your medication by March 12, 2025. These virtual sessions, which will not be livestreamed, are intended to collect input related to the patient experience.

- Austedo, Austedo XR: April 16, 2025 at 10:00 AM ET
- Vraylar: April 28, 2025 at 11:00 AM ET

Selected participants will receive a confirmation email the week of March 24, 2025, and must confirm within 4 days.

### JOIN A TOWNHALL

Clinicians, researchers and others from the public may also register to participate in a clinically oriented virtual and livestreamed townhall on Wednesday, April 30, 2025. To speak, you must register [here](#) by 11:59 PM PT on March 12, 2025.

Selected participants will receive a confirmation email the week of March 24, 2025, and must confirm within 4 days.

# Engaging Stakeholders



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## Webinar on the IRA and Movement Disorders

Join the **Movement Disorders Policy Coalition** and **Alliance for Patient Access** for a conversation on the **Medicare Drug Price Negotiation Program**, its impact on those living with movement disorders and mental health conditions, and opportunities for patients, advocacy groups, clinicians and others to weigh in.

**When:** Tuesday, February 11, 11:30 am ET

[Register Now](#)


- Convened clinician and organizational stakeholders for an advocacy webinar
- Provided background on the issue, the impact and potential concerns
- Outlined available engagement opportunities and answered questions




# Engaging Stakeholders

**Navigating the Inflation Reduction Act:**  
What it Means for Movement Disorder Patients & Advocates

Advocacy Toolkit



 **MOVEMENT DISORDERS**  
POLICY COALITION

FEBRUARY 2025

## Key Messages



### 1 Movement disorders are serious, debilitating conditions.

- Many movement disorders don't have cures.
- The medications that have been selected for negotiation are valuable treatment options that must remain accessible.



### 2 Each patient needs tailored treatment.

- Movement disorders patients respond to treatments differently, making it critical to have multiple accessible treatment options.
- A one-size-fits-all approach to care will harm patients and keep them from managing their condition.



### 3 Innovation is needed for movement disorders patients.

- Price negotiations could deter companies from investing in new treatments, leaving patients with fewer options for disease management and less hope of a cure.

MOVEMENT DISORDERS POLICY COALITION

4



## Social Media Guide

### Hashtags

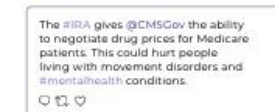
#MovementDisorders

#MentalHealth

#PatientAccess

#IRA

### Sample Posts

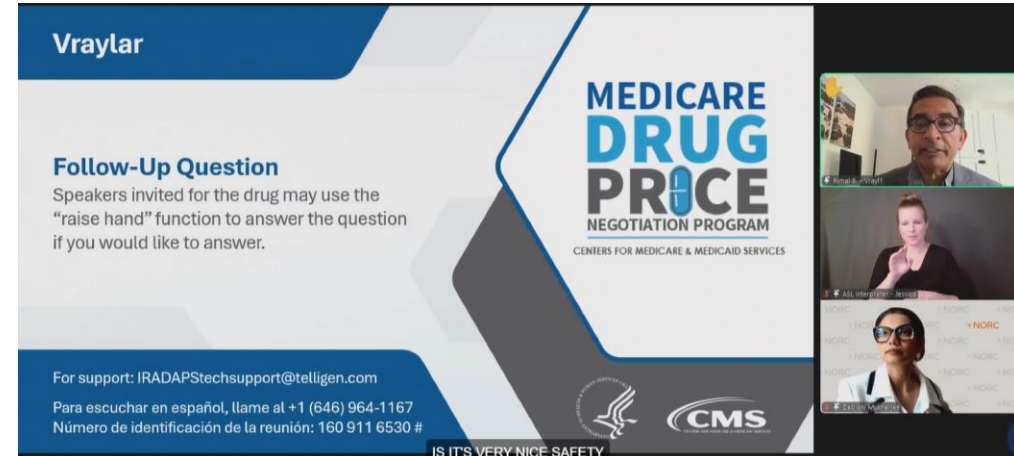


MOVEMENT DISORDERS POLICY COALITION

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# Successful Engagement in the Process

- Supported clinicians, patient advocates and other stakeholders in submitting written comment
- Worked with coalition partners on patient roundtable participation
- Mobilized AfPA clinician members to share their perspectives through clinical town hall participation







# Takeaways

- Patient and provider voices are critical in policy conversations
- Coalitions play an important role in creating capacity for advocacy organizations
- You don't have to be a policy expert to lend your voice!

# Moderated Q & A



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**Raymond Puerini**  
Director,  
FasterCures



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Managing Partner, Powers  
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**Josie Cooper**  
Executive Director,  
Alliance for Patient  
Access (AfPA)



# Thank You!

For additional questions or to learn more  
about TRAIN, please contact  
[TRAIN@milkeninstitute.org](mailto:TRAIN@milkeninstitute.org)