AiARTHRITIS
INTERNATIONAL FOUNDATION FOR AUTOIMMUNE
& AUTOINFLAMMATORY ARTHRITIS

Advocacy Report - 2025 Third Quarter

The International Foundation for Autoimmune and Autoinflammatory Arthritis (AiArthritis) focuses its efforts on a small group of diseases that are either autoimmune or autoinflammatory (of the immune system) that include inflammatory arthritis. *Through our work we empower more patients to take an active role in their healthcare and in efforts to increase global awareness, affect policy issues, and support research efforts.*

AiArthritis participated in-person at several national events during the third quarter of 2025. This included presenting before the National Council of State Legislators (NCOIL) at their summer meeting in Chicago, where **Mark Hobraczk- our Director of Public Policy and person living with Ankylosing Spondylitis** - was the sole patient representative on a panel of stakeholders impacted by Prescription Drug Affordability Boards (see below). Mark also participated in ADAP Advocacy's Health Fireside Chat on the Inflation Reduction Act in Atlanta and attended the annual Advocacy Conference for the Coalition of State Rheumatology Organizations (CSRO) in Dallas.

Tiffany Westrich-Robertson, our CEO and person living with Axial Spondyloarthritis, spoke on the Milken Institute's Vital Voices - Strength in Numbers: Coalitions Amplifying Patient Voices in CMS Decision-Making panel, Cancer Support Community (CSC) 2025 Inflation Reduction Act Stakeholder Engagement Summit, and BIO's State of Patient Access Coffee Chat on engagement with PDABs and CMS. Tiffany is also the Patient Co-Chair for ICER's Patient Council, concluding her first 3 year term in early 2026; however, she was asked to stay on as Co-Chair for another 2 years while the Council goes through a member transition. She attended the Council's annual meeting and, because of her role, also attended the annual ICER Stakeholder Council meeting.

Vanessa Lathan, Grassroots Advocacy Manager and person living with Undifferentiated Connective Tissue Disease (UCTD), represented AiArthritis across multiple advocacy and engagement activities this month. Vanessa attended the RAAP Patient Engagement meeting, joined the California Rare Disease Access Coalition meeting focused on The Rare Disease Experience in the Hospital Setting, and participated in the in-person Alternative Funding Programs (AFP) Task Force meeting. She also took part in Season 2 of the No Longer Silent podcast episode, "Racial Disparities in Healthcare Aren't Accidental," hosted by Carrie's Touch. In addition, Vanessa held an introductory meeting with the National Minority Quality Forum's Faith Health Alliance team to explore future collaboration.

During the third quarter, Mark also virtually attended the National Coalition for Autoimmune Patient Groups summer meeting and the Autoimmune Community Summit, as well as the Steering Committee meeting for the Chronic Care Policy Alliance

Mark and/or Vanessa continue to participate virtually every quarter in the ADAP Advocacy 340B Patient Advisory Committee, the ASAP 340B Quarterly Partner Meeting, and the California Rare Disease Access Coalition.

Knowledge=Empowerment Patient-Led Policy Education and Action Program

The advocacy goals for AiArthritis involve influencing policy and legislation by leveraging personal experiences of patients, fostering a supportive and collaborative network, and actively engaging in advocacy. As a lean organization who is unable to staff state or regional advocacy leads, our AiAdvocates will become our representatives in these areas. To address a recent trend in "all patient perspective participation", this program will also aim to build the pool of voices past the typical "5%" of advocates who always participate (targeting a recruitment of people who have rarely or never advocated prior.)

During Q3, AiArthritis continued to also expand our grassroots Knowledge = Empowerment project thanks you to our project sponsors: Genentech, Amgen, AbbVie, Johnson & Johnson, Bristol Myers Squibb, and Viatris - a one-of-a-kind, patient led policy education and advocacy action program. We are making steady progress on our mission to build out an army of patients and caregivers to represent AiArthritis on state-level coalitions, track our state-level bills, write letters on behalf of AiArthritis and encourage other patients to do the same, and more.

At the core of AiArthritis's mission lies a heartfelt commitment to influence policies and legislation, driven by the real-life experiences of patients. Operating under the embracing banner of or simply "AiAdvocates," we aim to amplify our community impact through a robust volunteer advocacy program. While this outline is specific to public policy, we plan to replicate this in both the Education/Awareness and Research/Research Advocacy sectors. This program, recognized as a pivotal initiative, seeks to engage and empower individuals living with autoimmune and autoinflammatory arthritis (AiArthritis) diseases, as well as caregivers transforming them into formidable champions for AiArthritis awareness, research, and policy reform.

During Q3, AiArthritis scheduled three K=E “classroom” webinars to be held in Q4 with national experts on alternative funding programs, biomarker testing, and the federal 340B drug discount program.

#WTHellth?! We also launched the breakout #WTHellth?! Program, including its own website and social media channels (more social platforms to come). This campaign encourages those frustrated with various aspects of the health care system to share their “hellish” experiences on video or written story and on social media (using the hashtag) or through the website.

This data will be shared with people (like government representatives or legislators) who can make changes to our healthcare system.

We continue looking for more sponsors of this program. If you are interested in supporting patient voices in state-level policy efforts, please contact tiffany@aiarthritis.org.

COALITIONS

In addition to our leadership of the EACH-PIC Coalition, AiArthritis continues to participate in over 35 coalitions, including the following new additions during Q3:

- Part B Access for Seniors and Physicians Coalition
- Employers Against Hospital Pricing Abuse

Policy Engagement

On behalf of the EACH/PIC Coalition, AiArthritis submitted public comments/testimony before existing prescription drug affordability boards in Colorado, Maryland, Minnesota, Oregon and Washington. AiArthritis also published and widely disseminated the findings from the EACH/PIC's patient-led survey on drug affordability demonstrating how policymakers conducting drug affordability reviews often miss the factors that make medications inaccessible to patients, including health plan design, cumulative healthcare costs, and complex personal circumstances.

AiArthritis greatly expanded the national visibility of the EACH/PIC Coalition by taking the initiative to ensure it was represented on the PDAB panel assembled by NCOIL for their annual summer meeting (see above). AiArthritis continues to pursue similar opportunities with other national groups including the National Association of Insurance Commissioners, the National Conference of State Legislators, the National Conference of Black State Legislators, and patient/provider groups seeking information/education about the adverse impacts of PDAB actions on patients.

To view the full list of EACH/PIC coalition letters submitted by AiArthritis in Q3, please view the coalition website.

During Q3, AiArthritis continued to actively engage in state and federal policymaking beyond EACH-PIC. This included the following highlights:

- Through the Partnership to Protect Coverage, Consortium for Constituents with Disabilities, and other coalitions, AiArthritis signed-on to multiple letters urging repeal/modification of the dramatic cuts to Medicaid/Affordable Care Act coverage enacted last quarter under H.R.1, as well as extending or making permanent the enhanced premium tax credits that have made Marketplace plans accessible to a record 24 million Americans. AiArthritis also signed onto PPC letters urging the U.S. Department of Health and Human Services (HHS) to reject state waivers seeking to impose burdensome and counterproductive Medicaid work reporting requirements, as well as increase premiums on the Medicaid expansion population.

- Facilitated virtual meetings between AiAdvocates from Georgia, Missouri, and North Dakota and their respective Congressional offices to urge lawmakers include the following reforms in any end-of-year spending package:
    - Extension of the enhancements to ACA premium tax credits that are slated to expire on December 31st (resulting in more than five million Americans becoming uninsured per the Congressional Budget Office).
    - Consumer protections from health plans barriers such as step therapy, copay accumulators/maximizers, and alternative funding programs.
    - Substantive pharmacy benefit manager (PBM) reform that includes "delinking" PBM compensation from the price of a drug (as proposed by S.882).
- Signed-on to Congressional letter with 29 other organizations (including ADAP Advocacy, Chronic Care Policy Alliance, and CSRO) urging the House Energy and Commerce health subcommittee to oppose the expansion of the 340B Drug Discount Program under the *340B Patients Act of 2025* and instead support passage of the *340B Access Act* (that was reintroduced in September).
- Joined 11 patient advocacy organizations (including American Cancer Society, Leukemia and Lymphoma Society, and the Epilepsy Foundation of America) signed-on to the *amici curiae* brief filed by the National Health Law Program in support of a federal injunction sought by 20 state attorneys general against Centers for Medicare and Medicaid Services (CMS) regulations that created new barriers to ACA Marketplace enrollment and will result in millions of consumers becoming uninsured.
- Joined with ADAP Advocacy to submit written comments urging the HHS to exempt certain patient populations from the CMS IRA Medicare Drug Price Negotiation Program. Signed-on with 67 other patient and caregiver groups to a letter led by the Cancer Support Community urging CMS to prioritize patient access and engagement in developing and implementing Medicare maximum fair price for CMS IRA drugs.
- Signed-on to letter to Congress led by the National Community Pharmacists Association urging passage of the full package of pending PBM reform bills that increase reporting and transparency relating to drug rebates and "delink" PBM compensation from the price of the drug. (The letter was joined by 135 community-based organizations and coalitions.)

- Joined letter from the Alliance for Transparent and Affordable Prescriptions (ATAP) urging the U.S. Department of Labor to "swiftly promulgate robust regulations reforming the practices of pharmacy benefit managers."
- Signed-on to written comments submitted by the Medicare Access for Patient Rx (MapRx) coalition supporting revisions to model documents for the Medicare Prescription Payment Plan and urging CMS to seek and incorporate greater stakeholder engagement.
- Signed-on to letter with more than 50 other patient advocacy groups (including the Autoimmune Association, Chronic Care Policy Alliance, and CSRO) urging the U.S. Department of Commerce to exempt medications from Europe or other allied countries that do not pose any threat to national security from any Section 232 tariffs.
- Joined public comments submitted by 74 other organizations representing patient, public health, caregiver, and other healthcare professionals (including the Autoimmune Association, Chronic Care Policy Alliance, and Partnership to Fight Chronic Disease) that urged the federal Advisory Committee on Immunization Practices (ACIP) to follow long-standing guidance on immunizations and reject proposals that create barriers and limit patient choice of available vaccines.
- Submitted written testimony supporting state legislation (S.214/H.419) to protect Massachusetts' consumers from medical debt.
- Signed-on to written comments led by the American Cancer Society Cancer Action Network recommending changes to Colorado Division of Insurance regulations concerning coverage of biomarker testing in state-regulated health plans.
- Joined Leukemia and Lymphoma Society comments to proposed rule from the Idaho Department of Insurance that would roll back standards for short-term limited duration health plans that do not comply with Affordable Care Act (ACA) protections.
- Submitted letter to California Governor urging signature of comprehensive PBM reform bill (S.B. 41) that prohibits PBMs from "steering" patients to pharmacies they own.

Bill Tracking

AiArthritis continued to track nearly 80 federal and state bills during Q3 related to our policy priorities. This includes bills creating (or impacting) PDABs in three remaining states, 340B reform bills in at least seven states and Congress, bills restricting copay accumulators/maximizers in at least four states and Congress, PBM reform bills in at least four states and Congress, and biomarker testing bills in Massachusetts. For a summary report of those bills, click here.

Social Media

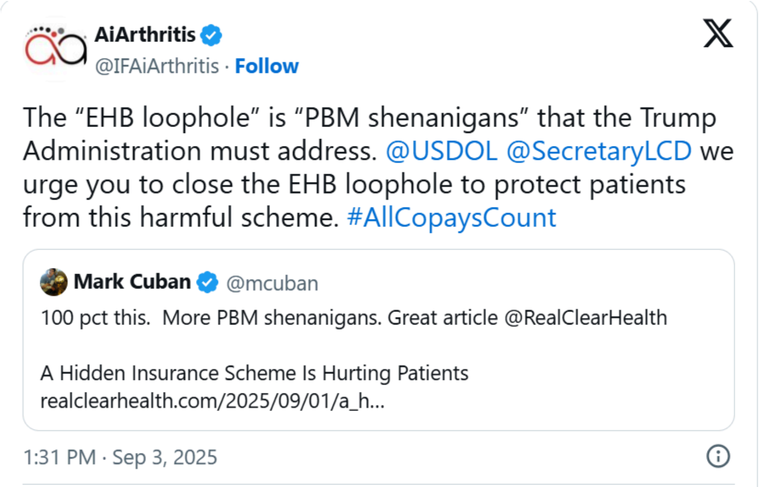
In Q3, the AiArthritis advocacy team expanded to several social media applications to post about our policy priorities. This included messaging about federal legislation protecting patients from insurance barriers like step therapy and alternative funding programs, as well as providing greater oversight and accountability for 340B drug discounts and reforming anticompetitive PBM practices. Here are a few highlights:

AiArthritis
@IFAiArthritis · Follow

@IFAiArthritis strongly supports the newest version of the #SafeStepAct in Congress, which will provide nationwide protections against step therapy protocols that allow health plans to force patients to "fail first" on inferior drug therapies.

allen.house.gov
Congressman Rick Allen Leads Colleagues in Reintroducing the Safe Step Act | U.S. Representative...

3:33 PM · Sep 23, 2025



AiArthritis
@IFAiArthritis · Follow

The “EHB loophole” is “PBM shenanigans” that the Trump Administration must address. @USDOL @SecretaryLCD we urge you to close the EHB loophole to protect patients from this harmful scheme. #AllCopaysCount

Mark Cuban @mcuban
100 pct this. More PBM shenanigans. Great article @RealClearHealth

A Hidden Insurance Scheme Is Hurting Patients
realclearhealth.com/2025/09/01/a_h...

1:31 PM · Sep 3, 2025

AiArthritis
@IFAiArthritis · Follow

@IFAiArthritis has joined with @ATAPAdvocates in urging the @USDOL to take action to reform anticompetitive PBM practices that artificially drive up drug costs for patients.

> **ATAP** @ATAPAdvocates
> PBM reform is long overdue. ATAP has joined a national coalition to ensure patients—not middlemen—come first in our health system. Details: atapadvocates.com/atap-news/2025…

6:38 PM · Sep 4, 2025

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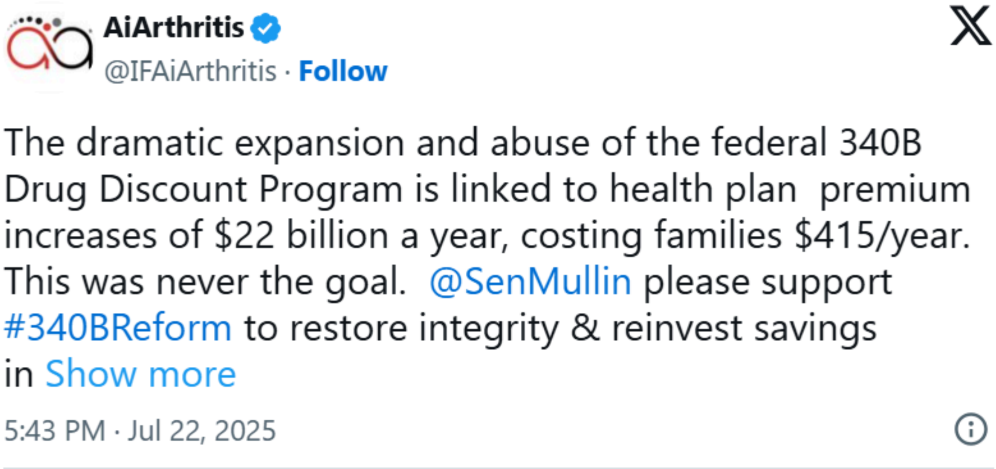
Patients are struggling now more than ever to afford the cost of healthcare, all while hospitals are using 340B revenues to add water features to their lobbies. Demand complete 340B transparency from all eligible providers. youtu.be/pxOhzEqzuQA @adapadvocacy

> youtube.com
> Is the 340B program the next 'Too Big To Fail?' - Med…
> The 340B Drug Pricing Program was designed to help poor patients access healthcare services. Yet, despite…

1:56 PM · Aug 20, 2025



AiArthritis
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The dramatic expansion and abuse of the federal 340B Drug Discount Program is linked to health plan premium increases of $22 billion a year, costing families $415/year. This was never the goal. @SenMullin please support #340BReform to restore integrity & reinvest savings in Show more

5:43 PM · Jul 22, 2025


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96% of specialist physicians surveyed are concerned that upper payment limits by #PDABs will lead to non-medical switching, restricting patient access to needed drug therapies.

Magnolia market access
a medical knowledge group company

State Prescription Drug Affordability Boards (PDAB) and Analysis of Patient Impact: A US Physician Survey Study

Specialist Physicians Are Concerned PDABs Will Limit Patient Access and Burden Providers and the Healthcare System

Executive Summary

- Endocrinologists, rheumatologists, and human immunodeficiency virus (HIV) specialists/infectious disease specialists from Colorado, Maryland, Oregon, and Washington participated in an online survey to capture insights on Prescription Drug Affordability Boards' (PDABs) impact on patient accessibility and affordability of treatments
- Almost universally, physicians (93%) report a lack of sufficient knowledge-sharing between PDABs and clinicians
- Physicians (93%) are also concerned PDABs unaffiliated with a state medical board will make decisions that may affect medication access
- Clinicians surveyed (96%) were somewhat or very concerned that UPLs may lead to non-medical

magnoliamarketaccess.com
Specialist Physicians' Perspectives on State PDABs: Access, Affordability, …
As states expand PDAB authority to set Upper Payment Limits (UPLs) on high-cost therapies, Magnolia Market Access surveyed physicians in …

3:54 PM · Jul 28, 2025