

Advocacy Report - 2025 Fourth Quarter



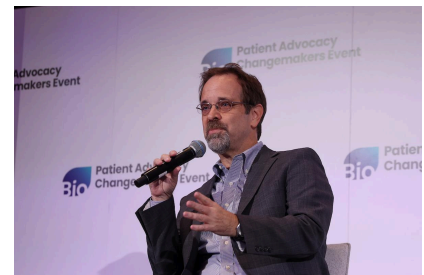
The International Foundation for **Autoimmune and Autoinflammatory Arthritis (AiArthritis)** focuses its efforts on a small group of diseases that are either autoimmune or autoinflammatory (of the immune system) that include inflammatory arthritis. *Through our work we empower more patients to take an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

their healthcare and in efforts to increase global awareness, affect policy issues, and support research efforts.

AiArthritis participated in-person and online at several national events during the fourth quarter of 2025.

Tiffany Westrich-Robertson, our CEO and person living with Axial Spondyloarthritis spoke on numerous panels specific to government drug affordability reviews (PDABs and CMS IRA) - including BIO's State of Patient Access and Patient Advocacy Coffee Chat. She was also the moderator at the 2025 Fall Policy Summit: Centering Patient Values in Drug Policy: Transparency, Value, and Access and panelist for the Value-Based Chronic Disease Collaborative (VBCDC) workshop Real-World Successes in Engaging Patients and Patient Representatives in Managed Care Pharmacy Decisions. During the 4th quarter meeting, she was also asked to renew her position as **ICER's Patient Council** Lead for another two year term.

Mark Hobraczek- our Director of Public Policy and person living with Ankylosing Spondylitis was part of a panel of stakeholders discussing patient engagement strategies at the **Patient Advocacy Changemakers Event** held by the Biotechnology Innovation Organization (BIO). Mark also joined with the **Chronic Care Policy Alliance** (CCPA) during



their visits to U.S. Senate offices to advocate for greater accountability, oversight, and transparency regarding pharmacy benefit managers (PBMs) and providers participating in the federal 340B Drug Discount Program.

Vanessa Lathan, Grassroots Advocacy Manager and person living with Undifferentiated Connective Tissue Disease (UCTD), participated in a wide range of federal and state policy strategy meetings, coalition convenings, and advocacy efforts in preparation for 2026. This included participation in ADAP’s 2026 Advocacy Policy Strategy Discussion (in person), Rare Access Action Project’s PDAB webinar “Battleground 2026”, and the in-person ASP/MFP Capitol Hill briefing examining implementation risks of the Inflation Reduction Act for Medicare Part B access. Additional engagement included the BMS Rural Health Stakeholder Policy Forum (in person) and multiple policy and advocacy workshops at ACR 2025 in Chicago. She also participated in numerous coalition activities, including the in-person Partnership to Protect Coverage annual meeting, the CSRO Advocacy Townhall and Virtual Advocacy Day, and the All Copays Coalition Virtual Hill Day. Vanessa also attended the PhRMA Alliance’s Toast to Partnership end-of-year celebration (in person).



During the fourth quarter, Mark also virtually attended webinars from the Kaiser Family Foundation on federal drug pricing proposals and from Alliance for Safe Biologic Medicines on 340B Reform.

Mark and/or Vanessa continue to virtually participate every quarter in the ADAP Advocacy 340B Patient Advisory Committee, the ASAP 340B Quarterly Partner Meeting, the California Rare Disease Access Coalition, and the steering committee for the Chronic Care Policy Alliance. Both also participated in the virtual Hill Day sponsored this fall by the All Copays Count Coalition to urge House and Senate members to support reintroduced legislation (the [HELP Copays Act](#)) to ban copay accumulator/maximizer and alternative funding programs.

AiArthritis commissioned a [new study](#) completed by the Milliman consulting firm in the fourth quarter that identifies significantly higher profit margins for autoimmune drugs at hospitals participating in the federal 340B Drug Discount Program. This research can impact the current

debate about how the 340B program needs to be reformed by federal/state policymakers to ensure the discounted drugs are benefiting patients as Congress intended when the program was created.

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 Q4, 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 Viatrix - 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 Q4, AiArthritis held three [K=E “classroom” webinars](#) with national experts on alternative funding programs, biomarker testing, and the federal 340B drug discount program.

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](#).

Policy Engagement

On behalf of the EACH/PIC Coalition, AiArthritis submitted public comments and/or in-person testimony during the fourth quarter before existing prescription drug affordability boards in Colorado, Maryland, Minnesota, Oregon and Washington. AiArthritis also sent letters to House and Senate members serving on health committees in Colorado opposing the first upper payment limit (UPL) set by the state's PDAB and urging lawmakers to enact legislative guardrails to protect patients from unintended and adverse consequences of UPLs, as well as letters to other state legislatures considering UPLs.

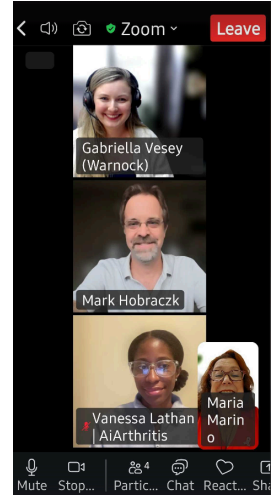
Additionally, AiArthritis sent letters on behalf of EACH/PIC urging members of Congress to “implement patient safeguards and reforms that will ensure that patient access to existing and future cures is not comprised” under the initial CMS IRA price caps for 2026, as well as “firmly oppose efforts to import foreign referencing pricing into the American drug market.” The letters advocated for alternative reforms such as increasing transparency/oversight over anti-competitive PBM practices and “delinking” PBM compensation from the price of a drug.

[*To view the full list of EACH/PIC coalition letters submitted by AiArthritis in Q4, please view the coalition website.*](#)

During Q4, AiArthritis also continued to actively engage in state and federal policymaking beyond EACH-PIC. This includes the following highlights:

- Signed onto coalition letter to Virginia lawmakers from the Rare Access Action Project opposing the imminent reintroduction of legislation to create a PDAB with authority to set upper payment limits.
- Joined [amicus brief](#) led by the HIV+Hepatitis Policy Institute in support of federal litigation to block alternative funding programs from forcing patients to use illegally imported drugs.
- Facilitated virtual meetings between AiAdvocates and their respective Congressional offices to urge lawmakers include the following reforms in any federal spending package for FY2026:

- Extension of the enhancements to ACA premium tax credits that expired on December 31st.
- 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](#) and other Congressional bills).
- Participated in meetings of state coalitions supporting legislation to protect patients from copay accumulator/maximizer programs in both Missouri and Wisconsin.
- Signed onto Aimed Alliance letter urging the Ohio Attorney General to investigate alternative funding programs as unfair and deceptive trade practices under state law.
- Signed onto Modern Medicaid Alliance letter to the federal Centers for Medicare and Medicaid Services (CMS) urging the agency to implement “streamlined and efficient processes for states to help to avoid inappropriate coverage losses” as a result of the Medicaid work reporting requirements mandated last summer by H.R.1.
- Joined Partnership to Protect Coverage (PPC) [letter](#) urging Congress to find “an immediate solution to the expiration of the enhanced advanced premium tax credits” on December 31st that are forcing millions of patients in ACA plans to pay dramatically higher premiums for 2026 or become uninsured. Also joined [PPC letters](#) opposing the Administration’s attempts to undermine the authority/funding for the federal Consumer Financial Protection Bureau, finalize regulations that deny lawful immigration status to persons in need of public assistance, relax standards for limited benefit or “junk” health plans, and protect against improper coverage losses in states implementing Medicaid work reporting requirements.
- Signed onto letters from the [Alliance for 340B Reform](#) urging members of the House Energy and Commerce, Ways and Means, and Appropriations committees to support the 340B Access Act that was reintroduced in September.
- Signed onto [Alliance for Transparent and Affordable Prescriptions](#) letter urging Congress to pass meaningful and comprehensive PBM reform in 2025, including delinking PBM compensation from the price of the drug.



- Signed onto [Chronic Care Policy Alliance letter](#) urging Congress to permanently reinstate COVID-era telehealth flexibilities under Medicare that expired October 1st.
- Joined with nearly 120 patient groups and stakeholders onto a letter led by the [Alliance for Regenerative Medicine](#) urging Congress to pass bipartisan bills to support life-saving treatments for rare diseases (the *Give Kids a Chance Act* and *Accelerating Kids' Access to Care Act*) into a year-end legislative package.
- Joined with more than 60 patient, caregiver, and healthcare worker groups from the [Alliance for Aging Research](#) urging the CDC's Advisory Committee on Immunization Practices (ACIP) not to amend long-standing guidance and limit coverage/access to vaccines for all adults and children that need them.

Bill Tracking

AiArthritis continued to track nearly 100 federal and state bills during Q4 related to our policy priorities. This includes the following:

- At least eight Congressional bills to expand/modify the Medicare Drug Price Negotiation Program or require some form of international reference pricing.
- Bills creating (or impacting) PDABs in three states (including draft legislation in Virginia for 2026).
- Bills reforming the 340B Drug Discount Program in at least nine states and Congress.
- Bills restricting copay accumulators/maximizers in at least four states (including New Jersey, where A.5217 unanimously passed both chambers) as well as the [HELP Copays Act](#) in Congress.
- Bills reforming PBM practices in at least four states (including California where [S.B. 41](#) was enacted), as well as Congress.
- Bills putting guardrails on step therapy in at least three states, as well as the Safe Step Act in Congress.

For a summary report of those bills, click [here](#).

Social Media

In Q4, the **Ai**Arthritis advocacy team expanded to several social media applications to post about our policy priorities.

Here are a few highlights:

AiArthritis @IFAiArthritis · Nov 18, 2025

@IFAiArthritis joined with 35 non-partisan patient advocacy orgs urging Congress to pass a clean, three-year extension of premium tax credit enhancements that have made ACA health coverage accessible to a record 24 million Americans. Congress must act by Dec 15 to ensure millions don't start losing coverage for 2026! protectcoverage.org/siteFiles/5190...

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AiArthritis @IFAiArthritis · Dec 5, 2025

Costs for the federal 340B Drug Pricing Program have skyrocketed from \$6.6B in 2010 to \$43.9B in 2021 but patients are missing the savings. We need accountability, transparency and reform to support patients in need. @SenMullin, Congress must pass #340BReform now. [Show more](#)

Year	Cost (Billions of Dollars)
2010	6.6
2011	7.5
2012	8.5
2013	9.5
2014	11.5
2015	14.5
2016	18.5
2017	22.5
2018	28.5
2019	34.5
2020	40.5
2021	43.9

From cbo.gov

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AiArthritis @IFAiArthritis

Promote

Thank you to @RepBuddyCarter and @RepHarshbarger for reintroducing the 340B Access Act in Congress, which would provide critically-needed oversight and transparency to ensure consumers benefit as intended from the federal 340B Drug Discount Program.

buddycarter.house.gov
Carter, Harshbarger Introduce Legislation to Ensure Acces...
Rep. Buddy Carter, Serving Georgia's 1st District

1:46 PM · Oct 17, 2025 · 60 Views

View post engagements

AiArthritis @IFAIArthritis · Dec 17, 2025 Promote

Thank you @GOPDoctors for endorsing the PBM Reform Act (H.R. 4317) to "delink" pharmacy benefit manager revenue from drug rebates. Per @USCSchaeffer, this single reform would reduce net annual drug spending by nearly 15% and be far more effective than artificial price caps.



Delinking PBM Compensation From Drug List Prices Could Unleash Major Savi...

From schaeffer.usc.edu

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AiArthritis @IFAIArthritis · Dec 5, 2025

@IFAIArthritis strongly supports Congressional passage of the #HELPCopaysAct. This bipartisan legislation had more than 165 cosponsors last session and would provide all health plan consumers with critical protections against copay diversion programs. #AllCopaysCount

Congressman Tom Kean @CongressmanKean · Dec 4, 2025

Today I introduced the bipartisan HELP Copays Act alongside @RepBarragan, @RepMMM, @RepAuchincloss, @RepBrianFitz, and @RepBonnie.

For too long, health insurers and PBMs have been pocketing copay ... [Show more](#)





Post



AiArthritis
@IFAiArthritis



AiArthritis urges [@WisSenGOP](#) [@WISenateDems](#) to pass [#SB203](#) to protect health plan consumers from copay diversion programs and make [#AllCopaysCount](#). Join 25 states (including Illinois, Indiana, Iowa) and preserve access to the lifeline that copay assistance provides. [@WI4Patients](#)

11:47 AM · Oct 10, 2025 · **60** Views

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