

Advocacy Report - 2025 Second 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.



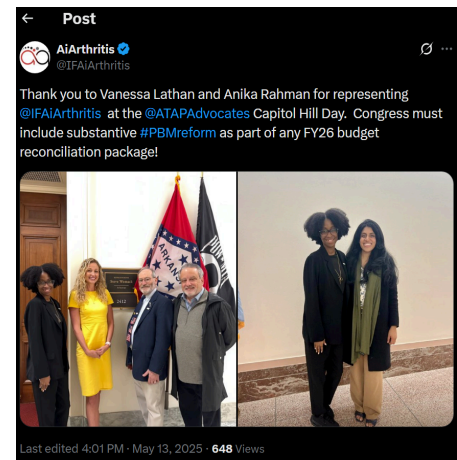
AiArthritis further expanded our policy and advocacy team during the second quarter of 2025 after hiring Vanessa Lathan as the Grassroots Advocacy Manager. Vanessa is a person living with undifferentiated connective tissue disease who will focus on building out our network of AiAdvocates and also serve as the lead for the Patient Inclusion Council (PIC) for patients, caregivers, and patient organizations.

Vanessa brings over 15 years of experience in public health program management, policy, and advocacy across government and nonprofit sectors, primarily focused on HIV. She is deeply passionate about advancing health equity, civil rights, and disability rights/justice public policy. A proud double alumna of Morgan State University, a Historically Black College and University (HBCU), Vanessa holds a Master of Public Health and a Bachelor of Science in Social Work degrees. She also spent a year and a half as a full-time caregiver for her grandmother until her passing in January 2023. This experience profoundly shaped her perspective by giving her firsthand insight into what it means to be both a patient and a caregiver.

Drawing from her lived experiences and professional background, Vanessa's goals as Grassroots Advocacy Manager and Patient Inclusion Council (PIC) Lead include expanding diverse patient

engagement through intentional education and advocacy initiatives, bridging the gap between patients and policymakers, and ensuring that lived experience directly informs and drives state and federal policy decisions. Additionally, she aims to strengthen coalition partnerships and elevate the voices of underrepresented communities to promote equitable, inclusive health policy reforms.

Based in northern Virginia, Vanessa regularly participates in-person for coalition meetings and advocacy events in the DC area, including the Capitol Hill Advocacy Day last May for the Alliance for Transparent and Affordable Prescriptions, where she and Anika Rahman (our Legislative Liaison and Policy Consultant) met with Congressional offices to urge for passage of the [PBM Reform Act](#).



Tiffany was a panelist in several webinars and meetings including:

- FasterCures D.C. workshop for increasing engagement with CMS
- ISPOR PDAB Panel with Andy York from MD PDAB and Genentech representative.
- Coalition for State Rheumatology

Organizations (CSRO) webinar to explain to physicians the concerns around PDABs and access.

(Pictured above): Tiffany participated in a panel discussion on Access & Affordability: Advancing Patient Centered Policy Solutions for Women in Government in St. Louis, MO. The discussion centered on 340b and Prescription Drug Affordability Boards (PDABs). It did not appear that any of the legislators knew what PDABs were and the audience seemed genuinely surprised when we explained how they are not fit for purpose.

Both Tiffany and Vanessa participated in CANNs PDAB Summit, a 60 person roundtable discussion in D.C. Mark participated in Chronic Care Policy Alliance's Forecast 2025 in Columbus, OH and presented on legislative initiatives related to PDABs.

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 Q2, AiArthritis continued to also expand our grassroots [Knowledge = Empowerment project \(thank you to our sponsors: Amgen, AbbVie, Genentech, Bristol Myers Squibb, J & J\), 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.

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 [nearly 25 coalitions](#), including the following new additions during Q2:

Modern Medicaid Alliance

AiArthritis joined the [Modern Medicaid Alliance](#) (MMA), a coalition of nearly 200 patient advocacy organizations, health care systems, and health insurers educating policymakers and the public about the critical and positive role that state Medicaid programs play in terms of cost savings, health outcomes, and societal impact.

Coalition for Health Funding

AiArthritis joined the [Coalition for Health Funding](#) to advocate against severe federal budget cuts to the Food and Drug Administration, Centers for Disease Control and Prevention, National Institutes of Health, and other critical agencies with the Department of Health and Human Services. The Coalition of over 90 patient advocacy organizations is the nation's oldest and largest nonprofit alliance working to preserve public health investments.

Bleeding Disorders Substance Use and Mental Health Access Coalition (BDSUMHAC)

AiArthritis was asked to join the expanded [BDSUMHAC](#) to bring attention to an emerging access issue for patients who are frequently denied admission to inpatient rehabilitation care solely because they require infusion drug therapies despite disability discrimination laws prohibition broad disease-specific exclusions.

Policy Engagement

Through our leadership of the EACH/PIC Coalition, **Ai**Arthritis submitted public comments/testimony before existing prescription drug affordability boards in Colorado, Maryland, Minnesota, Oregon and Washington. **[Any others?]**

AiArthritis also submitted letters on behalf of the EACH/PIC Coalition opposing legislation to create PDABs in Massachusetts and Michigan, as well as supporting legislation that ultimately repealed the New Hampshire PDAB for failing to demonstrate any savings since its creation. Though the EACH/PIC, **Ai**Arthritis also vigorously opposed legislation in Delaware, Rhode Island and Nevada that would cap select drug prices at the Medicare maximum fair price (MFP) under the

CMS IRA as an alternative to creating a PDAB (successfully urging the Nevada governor to veto the MFP bill).

AiArthritis continued to successfully engage PIC patients to participate in CMS roundtables and provide input on drugs selected for Medicare price negotiation. Through the EACH/PIC, AiArthritis urged CMS to take concrete steps to boost meaningful patient engagement and preserve patient access to critical medications. AiArthritis also signed onto letters from other coalitions urging CMS prioritize patient engagement in the CMS IRA process.

[To view the full list of EACH/PIC coalition letters submitted by AiArthritis in Q2, please view the coalition website.](#)

During Q2, AiArthritis continued to actively engage in state and federal policymaking beyond EACH-PIC. This included the following victories and highlights:

- Through the [Partnership to Protect Coverage](#), [Modern Medicaid Alliance](#), [Consortium for Citizens with Disabilities](#), and other coalitions, AiArthritis signed-on to multiple letters to Congress, press releases, and other public statements condemning the massive cuts to Medicaid, the Affordable Care Act, and other safety net programs enacted under the *One Big Beautiful Bill Act* (H.R. 1) that are projected by the Congressional Budget Office to result in at least ten million Americans losing critical health insurance coverage.
- Facilitated virtual meetings with AiAdvocates and their respective members of Congress to oppose the severity of Medicaid/ACA cuts in H.R.1 but urge the ultimately **successful inclusion of Orphan CURES Act language**, which fixes a flaw in the Inflation Reduction Act limiting the orphan drug exemption under Medicare price drug negotiation only to a single FDA-approved indication.
- Signed-on to letter to members of Congress submitted by the Alliance for Transparent and Affordable Prescriptions (ATAP) successfully urging against the inclusion of the Administration's "Most Favored Nation" drug pricing proposal in the OBBA (H.R.1). Also joined coalition letters urging Congressional delegations for California and Kansas
- Signed-on to letters led by the [Autoimmune Association](#), National Coalition of Autoimmune Patient Groups (NCAPG) and [Chronic Care Policy Alliance](#) opposing (or urging changes to) the Administration's imposition of tariffs on imported medications.

- Joined with more than 530 patient and provider organizations in [Coalition for Health Funding letter](#) opposing “dangerous and devastating” budget cuts to all Department of Health and Human Services (HHS). Also signed-on to letters from NCAPG and other coalitions opposing broad cuts to specific HHS agencies like NIH.
- Joined [Congressional resolution](#) (along with 30 other patient advocacy organizations) and other coalition press release/public comments urging HHS to reverse its decision to significantly limit public notice and comments for most agency actions.
- Submitted letters/testimony supporting legislation to prohibit copay accumulator/diversion programs in Massachusetts, North Dakota, and Wisconsin. Worked with the All Copays Count Coalition (ACCC) on **successful legislation in Indiana, Iowa, Maryland, and North Dakota** that brought the total number of states with copay accumulator protections to 25 (as well as DC and Puerto Rico).
- Signed-on to letters led by the National Organization for Rare Disorders (NORD) urging the successful creation of Rare Disease Advisory Councils (RDACs) in **Arizona, Montana, and Rhode Island** (bringing the total of RDAC states to 33). Also joined letters supporting pending legislation to make the RDAC in New York permanent and oppose provisions in an Ohio budget bill to repeal that state’s RDAC.
- Signed-on to multiple letters through Partnership to Protect Coverage coalition urging CMS not to approve waivers allowing states like [Arkansas](#) and [Ohio](#) to impose Medicaid work reporting requirements that have resulted in mass coverage losses due solely to delays in submitting proper paperwork. This includes public comments urging HHS not to extend [Georgia’s failed experiment](#) with work reporting requirements.
- Signed-on to coalition letters supporting state 340B reform bills (including Minnesota, New York, and Texas).
- Signed-on to letter with nearly 30 other national and state patient advocacy organizations successfully opposing legislation in California (A.B. 1460) that failed to adequately reform the 340B Drug Discount Program to ensure it operates as intended for the benefit of patients.
- Signed-on to public comments submitted by the Alliance for Transparent and Affordable Prescriptions (ATAP) to the Federal Trade Commission (FTC) supporting agency efforts to

reform anticompetitive PBM practices in Medicare, Affordable Care Act Marketplaces, and other federal programs.

- Submitted or signed onto coalition letters supporting federal and state pharmacy benefit manager reforms (including specific bills in Arkansas, California, Colorado, Iowa, Louisiana, and Nevada).
- Signed-on to letters led by CSRO and the Nevada Chronic Care Collaborative urging Congress to fix the “pill penalty” in the IRA via the *EPIC Act*.
- Joined Leukemia and Lymphoma Society letter supporting Ohio legislation to protect consumers from medical debt collections.
- Signed onto coalition letters supporting bills mandating health plan coverage of biomarker testing in Connecticut, New Jersey, and at least five other states.
- Signed onto public comments submitted by the Medicare Access for Patient Rx (MapRx) coalition.



Bill Tracking


AiArthritis continued to track over 150 federal and state bills during Q2 related to our policy priorities. This includes creating PDABs (or defaulting to Medicare maximum fair price) in at least 10 states, 340B reform bills in at least 17 states and Congress, bills restricting copay accumulators/maximizers in at least 14 states (four of which were enacted) and Congress, PBM reform bills in at least 11 states and Congress, and biomarker testing bills in at least seven states. For a summary report of those bills, click [here](#).

Social Media

In Q2, the **Ai**Arthritis advocacy team expanded to several social media applications to post about our policy priorities. This included messaging about the federal legislation to dramatically cut spending for Medicaid, the Affordable Care Act and other safety net programs that dominated much of the news cycle. However, we also focused on getting out the word on drugs selected for PDAB affordability reviews or Medicare price negotiation, legislation to protect consumers from copay diversion programs, and developments related to PBM and 340B reform. Here are a few highlights:

← Post

 **AiArthritis** 
@IFAiArthritis



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@IFAiArthritis joins over 30 patient organizations in condemning today's Senate passage of [#HR1](#) that guts Medicaid, dismantles key parts of the Affordable Care Act, destabilizes the health insurance market, and is a "dangerous setback" for all patients. protectcoverage.org/siteFiles/5122

...

2:32 PM · Jul 1, 2025 · 56 Views

← Post

 **AiArthritis** 
@IFAiArthritis

 ...

@IFAiArthritis joins with the Save Rare Treatments Task Force (saveraretreatments.org) in urging the Senate to keep the [#ORPHANCuresAct](#) as part of the mega budget reconciliation bill ([#HR1](#)). Orphan drugs should be exempt from Medicare drug price negotiation for more than a single indication.

