

Advocacy Report - 2025 First 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 significantly expanded our policy and advocacy work during the first quarter of 2025 after hiring Mark Hobraczk, JD, MPA as the Director of Public Policy in late 2024. Mark is a person living with ankylosing spondylitis who spent the past 20 years with advocacy groups representing persons with bleeding disorders, and previously directed advocacy efforts for two national trade associations, supervised the reimbursement department for a medical device manufacturer, and managed institutional reimbursement programs for Wyoming Medicaid.



Mark's wealth of experience enabled AiArthritis to broaden its participation in national and state level coalitions as well as increase our focus on reforms ensuring patients properly benefit from 340B drug discounts and are protected from copay diversion programs, step therapy, non-medical switching, and other harmful health insurance practices.

Mark also serves as the legislative lead for the Ensuring Access through Collaborative Health (EACH) coalition for patient organizations and allied groups, as well as the novel Patient Inclusion Council (PIC), for patients, caregivers, and patient organizations. Through our leadership of this unique coalition, AiArthritis continues to be recognized as a national leader in increasing patient

awareness, engagement, and opposition to Prescription Drug Affordability Boards and Medicare drug price negotiations.

AiArthritis expects to further expand our advocacy team in Q2 with the addition of a Grassroots Advocacy Manager.

During Q1, 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.

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.

Knowledge=Empowerment Elevated Experience: AiAdvocates!

*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.)*

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.

COALITIONS

In addition to our leadership of the EACH-PIC Coalition, AiArthritis continues to participate in [more than 20 coalitions](#), including two new additions during Q1:

Partnership to Protect Coverage

AiArthritis was formally admitted as a member organization in the national [Partnership to Protect Coverage](#) coalition in Q1. Initially formed in 2017 to protect against efforts to repeal consumer protections under the Affordable Care Act, the PPC now represents nearly 50 of the nation’s leading patient and consumer advocacy organizations who advance our shared goal of ensuring affordable and equitable access to quality healthcare coverage.

Through PPC, AiArthritis signed onto nearly ten coalition letters in Q1 including those urging Congress to [extend the enhanced premium tax credits](#) that have greatly increased the affordability of ACA Marketplace coverage since 2022, as well as urging the new Administration to continue defending the [ACA’s mandate for no-cost preventive services](#) before the U.S. Supreme Court. At the federal level these letters also opposed the [unprecedented cuts to state Medicaid programs](#) being proposed in Congress, as well as U.S Department of Health and Human Services regulations proposing to [eliminate public notice and comment](#) on most agency rulemaking. At the state level, AiArthritis signed onto letters opposing bills that allow greater use of limited benefit or “junk” plans that do not comply with the ACA, as well as supporting state waivers that ensure continuity of Medicaid coverage for children and justice-involved populations.

340B Reforms

AiArthritis continued to increase our focus on reforming the federal 340B Drug Pricing Program in Q1, joining the [Ryan White Grantee 340B Patient Advisory Committee](#) (in addition to our continued participation in the [ASAP340B coalition](#).)

Policy Engagement

Through our leadership of the EACH-PIC Coalition, AiArthritis helped secure a successful veto of Virginia legislation to create a PDAB, amended Maryland legislation expanding the PDAB's upper payment limit (UPL) authority to allow for greater patient engagement, and forestalled expected PDAB and/or UPL bills in Maine and Oregon. The Coalition also successfully engaged patients to participate in CMS roundtables and provide input on drugs selected for Medicare price negotiation.

[To view the full list of EACH/PIC coalition letters submitted by AiArthritis in Q1, please view the coalition website.](#)

During Q1, AiArthritis also greatly expanded its active engagement in state and federal policymaking beyond EACH-PIC. This included the following highlights:

- AiArthritis Patient Advocacy Manager Brian DuVal testified before the Tennessee House Insurance Committee in support of legislation that would have strengthened the state's 2021 ban on copay accumulators to include other copay diversion tactics such as copay maximizers and alternative funding programs.
- Submitted letters/testimony supporting legislation to prohibit copay accumulator/diversion programs in Florida, Maryland, Missouri, New Hampshire, New Jersey, North Dakota, and Rhode Island.
 - Signed onto [All Copays Count Coalition](#) letters supporting copay accumulator/diversion legislation in Nebraska and Tennessee, and the reintroduction of the [HELP Copays Act](#) (S.864) in Congress (prohibiting copay accumulators/maximizers in state and federally-regulated plans).
- Signed onto National Organization for Rare Disease (NORD) letters supporting legislation creating a permanent Rare Disease Advisory Council in Arizona, New York, Oklahoma, Oregon, and Vermont.
- Submitted or signed onto coalition letters supporting federal and state pharmacy benefit manager reforms (including specific bills in California and Nevada).



- Submitted letter supporting California legislation ensuring access to plasma for life-saving treatments.
- Submitted letter urging members of Congress to reintroduce 340B Access Act legislation from last session and signed onto coalition letters supporting state 340B reform bills (including California, Kentucky, and Illinois.)
- Signed onto American Lung Association letter urging Congress not to pass legislation that would delay or block critical public health protections in regulations issued by the U.S. Department of Health and Human Services.
- Signed onto Cancer Support Community letter urging Congress to pass the EPIC Act, which would equalize the time period for which small molecule and biologic drugs remain exempt from Medicare drug price negotiations under the Inflation Reduction Act.
- Signed onto coalition letter urging the Centers for Medicare and Medicaid Services to [freeze implementation](#) of the Medicare drug price negotiation program.
- Signed onto coalition letters supporting bills mandating health plan coverage of biomarker testing in Connecticut, New Jersey, Ohio, and Tennessee. and legislation in Texas restricting non-medical switching.
- Signed onto public comments submitted by the Medicare Access for Patient Rx (MapRx) coalition in response to proposed changes to Medicare Advantage and Part D drug plans.

Bill Tracking

AiArthritis tracked well over 200 federal and state bills during Q1 related to our policy priorities. This includes PDAB bills in at least 15 states, 340B reform bills in at least 26 states (and Congress), copay accumulator/maximizer bills in at least 18 states (and Congress), and PBM reform bills in at least 12 states (and Congress). For a full report of those bills that are still active, click [here](#). (This list does not include bills not introduced until Q2).

Social Media

In Q1, the **Ai**Arthritis advocacy team expanded to several social media applications to post about our policy priorities. This included messaging about drugs selected for PDAB affordability reviews or Medicare price negotiation and legislation to protect consumers from copay diversion programs,

reform PBM and 340B practices and otherwise ensure equitable access to affordable, quality care. Here are a few highlights:

