AiARTHRITIS
INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS

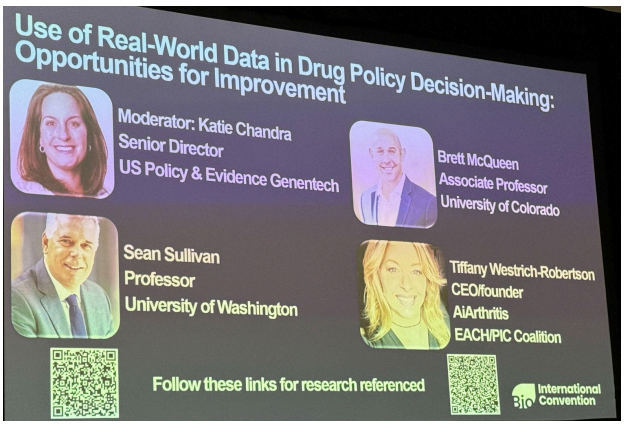
Advocacy Report - 2026 Second Quarter

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 participated in-person and online at several national (and international) events during the second quarter of 2026.

Tiffany Westrich-Robertson, our CEO and person living with non-radiographic Axial Spondyloarthritis primarily leads the organization's research to drive public policy initiatives, so attending research conferences is a high priority for her work. In June she attended the EULAR Congress in London where in addition she learned about the latest innovation in therapies, she also reported a strong focus on the consideration of affordability and access to those treatments as part of many presentations. AiArthritis was also invited in 2023 to be one of the first of six patient organizations to be founding delegates for iPARE (international People with Arthritis and Rheumatism in Europe), as the only patient organization representing North America. This working group focuses on uniting patient groups worldwide to identify patient needs that exist regardless of location, then design collaborative projects to address these needs.

AiArthritis hopes to tap into this network as we expand our public policy efforts internationally in the future.



Also in June - while battling severe laryngitis - Tiffany headed to San Diego for BIO International, where she spoke on a panel regarding the importance of incorporating patient experiences and associated data into policy decisions impacting pharmaceutical drug affordability reviews. Citing the research she spearheaded in association with the Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC) coalition - a two part, disease agnostic coalition led by AiArthritis - Tiffany spoke about the necessary, but often missing data, in drug affordability reviews.

Mark Hobraczk- our Director of Public Policy and person living with Ankylosing Spondylitis presented on PDAB legislation at the Forecast 2026 roundtable for the Chronic Care Policy Alliance. He also testified before the Nevada Joint Interim Commerce and Labor Committee in support of reforming pharmacy benefit manager (PBM) practices and the 340B Drug Discount Program. Mark also attended the annual Florida Voices for Health summit to ensure the patient perspective was presented during a panel session promoting PDABs.

Vanessa Lathan, Grassroots Advocacy Manager and a person living with Undifferentiated Connective Tissue Disease (UCTD), met with members of Congress as part of the Alliance for Transparent and Affordable Prescriptions (ATAP) annual legislative day on Capitol Hill to advocate for pharmacy benefit manager (PBM) reforms. She also continued state and federal advocacy through EACH/PIC, including preparing a patient for CMS roundtables and providing public comment at the

New Jersey Drug Affordability Council's June meeting on medication affordability and patient access.

Vanessa also continued expanding AiArthritis' focus and presence in the rare disease policy space, which is particularly important given that many of the autoimmune and autoinflammatory conditions represented by AiArthritis are rare or affect smaller patient populations, and Vanessa lives with a rare autoimmune condition herself. She attended the Rare Access Action Project (RAAP) Federal Briefing and the Save Rare Treatments Task Force policy meeting on the state of rare disease policy to learn more about federal and state rare disease priorities, emerging policy challenges, and opportunities to advance patient access.

Additionally, Vanessa participated in several primarily in-person events focused on patient engagement, access, and affordability, including the BIO Women's Health Task Force & Stakeholder Discussion, which sought to increase the focus on women in health policy and research; a lunch discussion featuring patient advocate Annabelle Gurwitch and her book, The End of My Life Is Killing Me: The Unexpected Joys of a Cancer Slacker, which included discussion around copay accumulators; the BMS Q2 Stakeholder Policy Forum, focused on keeping patient affordability and access at the center of ongoing federal healthcare reforms; and the 2026 Maryland State of Reform Health Policy Conference, where she brought a patient advocacy perspective to drug affordability discussions and connected with organizations in Maryland, a key state for PDAB advocacy. Vanessa also joined a BIO discussion on the 340B Drug Pricing Program, including the importance of patient engagement and patient perspectives in this policy conversation.

Through these engagements, Vanessa continued to elevate patient and grassroots perspectives across state and federal policy discussions, expand AiArthritis' presence in policy spaces affecting rare, autoimmune, and autoinflammatory disease communities, and bring a health equity lens to conversations about access, affordability, and healthcare policy.

Kaylee Harper, Public Policy Assistant

In May, Kaylee attended the California Rare Disease Access Coalition Summer Meeting virtually to discuss the progression of various bills focused on lowering out-of-pocket costs for patients and protecting patient access to essential medications. She also attended PBMs at an Inflection Point: An Opportunity for a Candid Conversation, a virtual webinar hosted by Patients Rising in

collaboration with Pharmaceutical Care Management Association (PCMA). This event allowed for patients and patient advocates to ask questions seeking transparency and accountability about the role of PBMs and how they impact patient access and out-of-pocket costs for medications. Kaylee also learned how to better engage with legislators when advocating for bills that protect patients and equitable access to therapies necessary for daily life after attending Effective Lawmaker Engagement for Rare Disease Advocates in June.

Public Policy Department

Mark, Vanessa, and Kaylee all participated in the inaugural virtual advocacy day for the California Rare Disease Access Coalition, meeting with state legislative offices to urge support for legislation protecting consumers from copay diversion programs and burdensome utilization management for rare disease drugs.

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.

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 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.

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

In January, the EACH/PIC Coalition released the results of version 2.0 of the Patient Experience Survey: Prescription Drug Affordability and Unaffordability, which proved to be a very effective advocacy and recruiting tool over the first quarter. The results demonstrated why upper payment

limits (UPLs) are the wrong tool to address drug unaffordability as the survey of more than 520 patients revealed that affordability was overwhelmingly dictated by health plan design and barriers, and not the list price of a drug. This is the same report Tiffany spoke about at BIO International in June and continues to talk about to Prescription Drug Affordability Boards and legislators so they understand what solutions will matter most to patients.

On behalf of EACH/PIC, AiArthritis remains actively engaged in opposing drug affordability reviews at the federal and state level and seeking needed changes to ensure the patient voice was heard throughout the process.

At the state level, AiArthritis submitted public comments and/or in-person testimony on behalf of EACH/PIC during Q2 before PDABs in Colorado, Maryland, Minnesota, Oregon, and Washington. In addition, AiArthritis submitted sign-on letters from 22 organizations to the Maryland PDAB regarding their affordability criteria and from 25 organizations to the Colorado PDAB opposing the UPL set for Cosentyx.

AiArthritis actively engaged in opposing stalled legislation in Illinois and vetoed legislation in Virginia that would have created a PDAB with authority to set UPLs at the Medicare maximum fair price (MFP) for CMS IRA drugs. AiArthritis also submitted multiple letters opposing enacted legislation in Louisiana creating a PDAB, but without authority to set UPLs (S.B. 401).

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

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

- Joined coalition letters from the Rare Access Action Project and the Global Coalition on Aging urging Virginia Governor Abigail Spanberger (D) to veto legislation creating a PDAB with authority to set upper payment limits (UPLs).
- Joined numerous Partnership to Protect Coverage (PPC) coalition letters, including those opposing CMS' interim final rule that made it more difficult than Congress intended for Medicaid enrollees to meet the medically frail exemption to new work reporting requirements and urging Congress not to consider a rumored budget reconciliation package that would make additional Medicaid/Affordable Care Act cuts beyond those enacted last year under H.R. 1. Also joined PPC's written comments on CMS' regulations relating to prior authorization requests, which urged the agency to require all qualified health plans to respond within 24 hours.
- Joined with nearly 360 members of the Disability and Aging Collaborative and Consortium for Citizens with Disabilities urging Congress not to pursue additional proposed cuts to Medicaid beyond those already imposed last year under H.R. 1.
- Submitted written comments in support of legislation banning copay accumulators, maximizers, and alternative funding programs in Michigan and South Carolina. Signed onto coalition letters/one-pagers supporting similar legislation in Minnesota and Ohio.
- Joined with 16 other patient groups onto a letter led by Aimed Alliance urging the Texas Attorney General to promptly issue a legal opinion recognizing the illegality of alternative funding programs.
- Resubmitted written comments supporting California bills to protect consumers from copay diversion programs (S.B. 1199) and burdensome utilization management for rare disease

drugs (A.B. 1887) as the bills moved to their opposing chambers. Also submitted written comments supporting A.B. 2009, which would modernize California laws relating to source plasma donation centers.

- Submitted letter to the U.S. House Ways and Means committee urging their support for reforms that increase accountability, transparency, and oversight for the federal 340B Drug Discount Program, including the rebate model pilot proposed by the U.S. Department of Health and Human Services (HHS).
- Submitted written comments to the Health Resources and Services Administration supporting their proposed revisions to the rebate model pilot for 340B.
- Joined letter with over 30 patient, provider, and business groups opposing Illinois legislation (H.B. 2371) mandating unlimited expansion of contract pharmacies under the federal 340B Drug Discount Program.
- Submitted multiple letters to Minnesota lawmakers in opposition to House and Senate bills (H.F.3609/S.F.3769) that would repeal the sunset of 340B mandate legislation.
- Joined coalition letter led by the Lupus Foundation of America urging Congress to pass the *Protecting Patient Access to Cancer and Complex Therapies Act* (H.R. 4299) to ensure that life-saving medications covered under Medicare Part B remain available in the communities where patients live, work and go to school.
- Joined written comments from the MAPRx Coalition opposing proposed CMS regulations that weaken prior authorization protections for those enrolled in Medicare Part D drug plans.
- Signed onto a letter led by the Partnership for Part D Access opposing CMS' proposed GUARD model for Medicare Part D and urging the agency to preserve the six protected drug classes under Part D.
- Joined California Chronic Care Coalition letter opposing S.B. 1094 legislation that would allow pharmacists to substitute biosimilar medications not prescribed by a patient's physician.
- Joined with more than 530 organizations on to letter led by the Coalition for Health Funding urging Congress to oppose the Administration's proposed cuts to Labor-HHS-Education appropriations for fiscal year 2027.
- Signed onto a letter to Congress led by the ERISA Industry Committee supporting the *PBM Kickback Prohibition Act* (H.R. 7895).

- Joined coalition letter led by the Autoimmune Association to urge the U.S. Trade Representative to negotiate agreements with foreign countries that increase spending and reimbursement for critical drug therapies and exempt them from tariffs.
- Joined coalition letter led by the American Lung Association urging CMS to approve California's requested renewal of its federal waiver to provide Medicaid coverage for incarcerated individuals up to 90 days before their release, as well as provide employment-supports benefits to Medicaid enrollees subject to new federally-mandated work reporting requirements.
- Submitted written comments to the U.S, Department of Labor supporting proposed PBM rule for health plans governed by federal ERISA law.
- Joined written comments submitted by the Alliance for Aging Research supporting FDA approval of mRNA vaccine options for influenza.
- Signed onto a coalition letter led by the Partnership to Fight Infectious Diseases opposing the U.S. Department of Health and Human Services' proposed overhaul of the Vaccine Injury Compensation Program.
- Signed onto a coalition letter urging Governor Bill Lee (R) to sign legislation making Tennessee the 24th state to require health plans to cover biomarker testing.
- Joined coalition letter led by the National Organization for Rare Disorders urging Governor Phil Scott (R) to make Vermont the 34th to create a Rare Disease Advisory Council.

Bill Tracking

AiArthritis tracked at least 170 federal and state bills during Q2 related to our policy priorities. This includes the following:

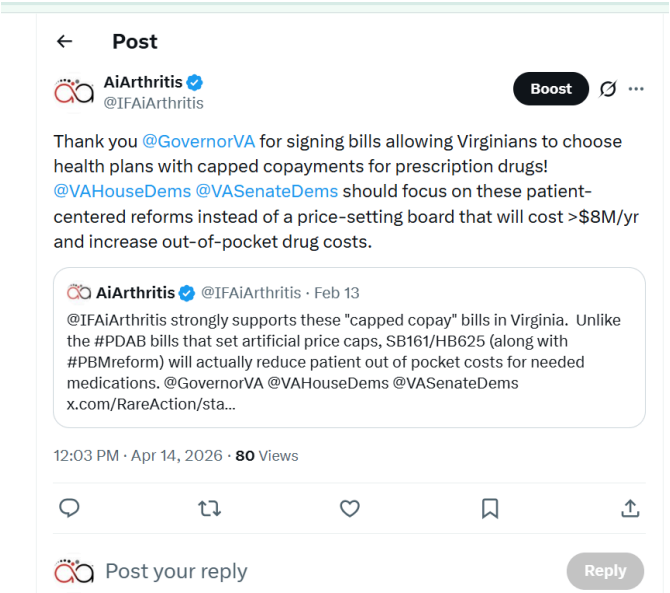
- At least eight Congressional bills to expand/modify the Medicare Drug Price Negotiation Program or require some form of international reference pricing.
- Bills relating to PDABs in ten states (including enacted legislation in Louisiana and vetoed legislation in Virginia).
- Bills reforming the 340B Drug Discount Program in at least ten states and Congress.
- Bills restricting copay accumulators/maximizers in at least ten states (including California, Michigan, Missouri, Ohio, Pennsylvania, and Wisconsin) as well as the *HELP Copays Act* in Congress.

- Bills reforming anti-competitive PBM practices in at least 20 states (as well as Congress) including enacted legislation in Louisiana that "delinks" PBM revenue from the price of a drug.
- Bills extending or making permanent Rare Disease Advisory Councils in New York, North Carolina, and Vermont, as well as eliminating the RDAC in West Virginia (H.B. 5364).
- Bills expanding coverage for biomarker testing in seven states including Tennessee (where H.B. 484 was signed by the Governor).
- Bills putting guardrails on step therapy in at least six states, as well as the Safe Step Act in Congress.

For a summary report of those bills, click here.

Social Media

In Q2, the AiArthritis advocacy team posted about our policy priorities and/or engagement on several social media applications. Here are a few highlights:



Post

AiArthritis
@IFAiArthritis

@IFAiArthritis thanks @GovBillLee for signing legislation to make Tennessee the 24th state requiring health plans cover #biomarkertesting.

5:10 PM · May 8, 2026 · **42** Views

Post your reply

Reply

Post

AiArthritis
@IFAiArthritis

@IFAiArthritis is disappointed that Congress continues to skirt long-needed reforms to bring accountability and oversight for the #340B Drug Discount Program and ensure it works as intended to benefit low-income or uninsured patients.

> Victoria Knight @victoriaregisk · May 18
> NEW: House Ways & Means Committee is planning a Thursday mark-up that includes health bills on fraud, Medicare doc fee schedule.
>
> But, the panel axed consideration of a bill that would've increased reporting for non-profit hospitals on 340B/charity care....

3:45 PM · May 18, 2026 · **94** Views

2 3

Post

AiArthritis
@IFAiArthritis

The U.S. House Appropriations Committee is calling on @CMSgov to protect patients from harmful #copayaccumulator programs that deny them access to copay assistance. CMS must finally take action to ensure that #AllCopaysCount. Read more: bit.ly/3S8I6yS.

10:00 AM · Jun 17, 2026 · **56** Views

1 2

Post

AiArthritis
@IFAiArthritis

@IFAiArthritis joined with 48 other patient groups to oppose new rulemaking from @HHSGov that will make it dramatically harder for Medicaid enrollees with severe or complex conditions to qualify for medical exemptions from new Medicaid work reporting requirements. These changes put millions at risk of inappropriately losing coverage if they fail to comply with massive paperwork burdens every month. lung.org/media/press-re...

lung.org
48 Patient Organizations Warn of Massive Coverage Losse...
Today 48 non-profit, non-partisan patient organizations issued a statement in response to the interim final rule ...

9:45 AM · Jun 4, 2026 · **36** Views

3 2

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