Advocacy Report - 2026 First Quarter

The International Foundation foFINr 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 welcomed Kaylee Harper in Q1 as our new Public Policy Assistant for the advocacy team.

Kaylee is deeply passionate about understanding how health conditions affect diverse communities and using research and policy engagement to expand fair and inclusive healthcare access and improve outcomes for those most impacted. Her commitment to health equity is reflected through her primary research experiences at North Carolina Agricultural & Technical State University, UC Berkeley, and Harvard Business School, where she examined how social, behavioral, and organizational factors influence health outcomes and broader access to opportunity. She has also collaborated with various nonprofit organizations to further develop her understanding of policy advocacy and strategies that strengthen inclusive healthcare systems.With a strong commitment to patient-centered advocacy, Kaylee is excited to contribute her research and advocacy experience to support individuals and communities impacted

by autoimmune and autoinflammatory conditions. She also has supported her grandmother with Rheumatoid Arthritis.

Kaylee will be the lead member of the advocacy team reporting on federal and state policies impacting patient access to needed vaccines/immunizations. This is a new policy priority that AiArthritis established this quarter based on input from our AiAdvocates.

AiArthritis participated in-person and online at several national events during the first quarter of 2026.

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 Engaging Patients in Medicare Drug Price Negotiations with CMS: What's Next and How to Participate (hosted by NHC), BIO Patient Advocacy Coffee Chat — Drug Pricing & Patient Access, and Cardiovascular Leadership Speaker Series: What Patients Say About Prescription Drug Affordability. She also participated in a private meeting with CMS - invited by NHC and Cancer Support Community - to encourage better patient focused outcomes and transparency in patient experience data usage in the negotiations. She actively participated in Advisory Councils for ISPOR (international health economics and outcomes research coalition), Innovation Value Institute, Patient-Focused Medicines Development (PFMD), and was invited to serve another two-year term as the Patient Co-Chair for ICER's Patient Council.

Mark Hobraczk- our Director of Public Policy and person living with Ankylosing Spondylitis participated in a national panel for the ASAP 340B coalition detailing the results from the Milliman study commissioned last year by AiArthritis that found significantly higher profit margins for autoimmune drugs at hospitals participating in the federal 340B Drug Discount Program. Mark also met in-person with Florida lawmakers and the Governor's office to oppose state legislation setting drug price caps based on international reference prices, as well as

virtually with Illinois Rep. Grasse to provide support for her concerns about adverse patient impact from PDAB legislation in her committee (see below).

Mark also participated in the first ever Patient and Consumer Forum held by the California Office of Health Care Affordability, an event spearheaded by advocacy from the California Rare Disease Access Coalition (in which AiArthritis participates).

Vanessa Lathan, Grassroots Advocacy Manager and person living with Undifferentiated Connective Tissue Disease (UCTD) testified on behalf of the EACH/PIC Coalition before the Maryland Senate Finance Committee in support of legislation to exempt drugs subject to upper payment limits from utilization management protocols.

Vanessa also participated in the Rare Access Action Project's advocacy day at the Virginia Capitol to directly urge lawmakers not to support legislation creating a Prescription Drug Affordability Board with authority to set upper payment limits (at the Medicare maximum fair price).

Additionally, Vanessa attended several other in-person policy meetings and conferences this quarter, focused on patient access, affordability, rare disease advocacy, and healthcare policy reform. These included the 2026 BMS Policy Forum, which brought together patient advocates, policy leaders, and healthcare experts to discuss key policy and payment issues impacting patient access to care; a Bipartisan Rural Health Caucus briefing focused on improving access to care, technology, and workforce development across rural communities; and Collaborating for Care+ (C4C+), which explored patient- and provider-centered policy in an AI healthcare environment.

Vanessa also participated in Rare Disease Week on Capitol Hill, including congressional meetings where she highlighted the needs of patients living with rare and smaller autoimmune and autoinflammatory arthritis diseases, an issue especially meaningful as someone living with a rare autoimmune condition herself. During the week, she also met with leadership from the Rare & Ready Coalition to discuss shared priorities around patient engagement in state-level advocacy within the rare disease community.

Additional meetings included the 2026 Amgen Policy Summit..

Tiffany and Vanessa also led the Patient Inclusion Council's February 24th webinar with Centers for Medicare and Medicaid Services (CMS) officials that educated patients how they can best engage in CMS roundtables related to drugs selected for Medicare drug price negotiation.

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 Q1, 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 Q1, AiArthritis held the first of four K=E "classroom" webinars for 2026 entitled "Research Advocacy 101: Your Voice Matters in Healthcare Policy."

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.

On behalf of EACH/PIC, AiArthritis remained 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. In addition to convening the PIC patient engagement webinar with CMS officials (see above), AiArthritis submitted comments to CMS on the 15 drugs selected for the Medicare Negotiation Program for IPAY 2028 (which includes Part B drugs for the first time) as well as comments on the involuntary GUARD model CMS proposed in December, which would apply "most favored nation" prices from other countries to Medicare Part D drugs.

At the state level, AiArthritis submitted public comments and/or in-person testimony on behalf of EACH/PIC during the first quarter before existing prescription drug affordability boards in Colorado, Maryland, Oregon, and Washington. In addition, AiArthritis actively engaged in opposing legislation in Hawaii, Illinois, and Virginia that would have created a PDAB with authority to set UPLs at the Medicare maximum fair price (MFP) for CMS IRA drugs as well as legislation in Louisiana and Rhode Island that would either create a PDAB or simply default to Medicare MFP.

AiArthritis also held several in-person meetings in Florida with the Governor's office, House health committee chair, and Senate leadership to oppose the MFN legislation in that state.

Representatives from AiArthritis met directly with the Governor's office in Virginia to successfully advocate for amendments that would delay legislative authorization for UPLs until a preliminary study demonstrated "evidence of effectiveness." AiArthritis urged the Governor to veto the entire bill after her changes were rebuffed by the Legislature.

In addition, AiArthritis met virtually with Illinois Rep. Nicolle Grasse regarding her concerns about PDAB legislation in her committee, testified before the Maryland Senate Finance Committee in support of legislation exempting drugs assigned UPLs from utilization management protocols by health plans, and joined the Senate sponsors of Colorado legislation to exempt rare disease drugs from UPLs in their meeting with the Department of Insurance.

To view the full list of EACH/PIC coalition letters submitted by AiArthritis in Q4, please view the coalition website.

During Q1, AiArthritis also continued to actively engage in state and federal policymaking beyond EACH-PIC. This includes the following highlights:

- Signed onto multiple letters from the Global Coalition for Aging and Rare Access Action Project successfully urging the Virginia Governor to seek amendments to legislation creating a PDAB with UPL authority until a preliminary study can fully evaluate the adverse impact on patient access.
- Signed onto a coalition letter led by Community Access National Network opposing Louisiana legislation creating a PDAB or defaulting to Medicare drug pricing, while supporting bills to reform anti-competitive pharmacy benefit manager (PBM) practices.
- Signed onto Rare and Ready coalition letter supporting Colorado legislation that would exempt rare disease drugs from UPLs set by the state PDAB.
- Participated in meetings of state coalitions supporting legislation to protect patients from copay accumulator/maximizer programs in California, Florida, Missouri, Nebraska, and Wisconsin (in addition to bi-weekly meetings for the All Copays Count Coalition state working group).
- Submitted written comments supporting California bills to ban copay accumulator adjuster programs (S.B. 1199), exempt drugs approved by FDA to treat rare diseases from utilization management protocols by state-regulated plans (A.B. 1887), and modernize regulations for plasma donation centers (A.B. 2009).
- Submitted written comments in support of legislation banning copay accumulators, maximizers, and alternative funding programs in Florida, Missouri, and South Carolina. Signed onto coalition letters supporting copay accumulator bans in Minnesota, Nebraska, and Ohio.
- Joined Fair Health VA coalition letter led by Blood Cancer United urging Virginia lawmakers to pass legislation (S.B. 161/H.B. 625) ultimately signed by the Governor that allows consumers to select health plans with fixed copayments.
- 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.
- Signed onto letters urging lawmakers in Michigan, Virginia, and Puerto Rico to seek reforms increasing transparency and reporting requirements for providers participating in the 340B Drug Discount Program.
- Submitted letter to House Energy and Commerce health subcommittee urging them to focus on 340B reform for March 18 hearing.

- Joined with the Alliance for Transparent and Affordable Prescriptions (ATAP) in applauding Congress for passing landmark PBM reform legislation "delinking" PBM revenue from drug prices under Medicare Part D.
- Joined written comments from ATAP urging CMS to reconsider mandatory GLOBE and GUARD models that would apply international reference prices to Medicare Part B and Part D drugs.
- Joined written comments from the PBM Accountability Project supporting proposed regulations from the U.S. Department of Labor that increased PBM transparency requirements for ERISA (large group and self-funded) plans and urged further action.
- Joined with 70 patient organizations on the Alliance for Aging Research press statement supporting the American Academy of Pediatrics lawsuit opposing federal changes to the long-standing childhood immunization schedule–changes that were temporarily blocked by a lower court.
- Joined National Organization for Rare Disorders (NORD) letter opposing West Virginia legislation (H.B. 5364/S.B. 894) that sought to repeal the state Rare Disease Advisory Council.
- Signed onto a coalition letter led by Blood Cancer United urging the Oregon Governor to veto legislation (H.B. 4040) increasing the presumptive eligibility requirements for hospital charity care.
- Joined with a dozen patient organizations onto letter led by Looms for Lupus urging Senator Padilla and other California Congressional members to cosponsor the *Small Biotech Innovation Act* (S.1930), which extends the small biotech exemption from Medicare drug price negotiation beyond 2029.
- Joined letter with 52 other patient organizations led by United For Cures urging Congress to increase funding for the National Institutes of Health (NIH) funding for medical research.
- Signed onto a coalition letter led by American Lung Association urging Mississippi Governor to veto legislation (S.B. 2704) that would allow access to limited benefit association health plans that need not comply with consumer protections in the ACA.
- Joined written comments led by the MAPRx Coalition opposing the mandatory GUARD Model proposed by the Centers for Medicare and Medicaid Services (CMS) that would apply "most favored nation" prices from other countries to Medicare Part D drugs.

- Joined written comments led by the MAPRx Coalition urging changes to proposed CMS regulations that fail to provide adequate protections for consumers in Medicare Part D and Medicare Advantage plans.
- Joined with nearly 40 employers, insurers, and patient advocacy organizations on letter urging federal agencies to reform the Independent Dispute Resolution process that Congress created under the No Surprises Act, as the lack of transparency and oversight is failing to adequately protect patients from surprise medical bills for out-of-network services furnished at in-network providers.
- Joined more than 20 patient organizations on letter successfully urging Congress to include provisions of the *Increasing Transparency in Generic Drug Applications Act* (S. 1302/H.R. 1843) in federal funding legislation, which will increase patient access to generic drugs by accelerating FDA approval of complex generic drug approvals.
- Joined numerous Partnership to Protect Coverage (PPC) coalition letters, including those urging Congress to extend enhanced premium tax credits for ACA plans and reject other efforts to undermine ACA coverage.
- Joined PPC coalition letters urging CMS to mitigate against coverage losses in their implementation of Medicaid work reporting requirements imposed last year by Congress under H.R.1 and opposing Nebraska regulations implementing those requirements before Congress' deadline.
- Joined PPC coalition letter opposing U.S. Department of Health and Human Services annual Marketplace standards rule that weaken consumer protections in the ACA and "erect burdensome administrative barriers" for consumers trying to enroll in Marketplace coverage.

Bill Tracking

AiArthritis tracked nearly 290 federal and state bills during Q1 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 legislation in Illinois, Hawaii, Louisiana, Massachusetts, Michigan, Virginia that would create a new PDAB).
- Bills reforming the 340B Drug Discount Program in at least 13 states and Congress.

- Bills restricting copay accumulators/maximizers in at least 15 states (including California, Michigan, Missouri, Ohio, Pennsylvania, and Wisconsin) as well as the *HELP Copays Act* in Congress.
- Bills allowing for alternative funding programs in Colorado and specifically prohibiting them in Tennessee.
- Bills reforming anti-competitive PBM practices in at least 20 states (as well as Congress) including legislation in Louisiana, New Hampshire, and Virginia that sought to "delink" PBM revenue from the price of a drug.
- Bills extending or making permanent Rare Disease Advisory Councils in Mississippi, New York, Utah, and Vermont, as well as eliminating the RDAC in West Virginia (H.B. 5364).
- Bills expanding coverage for biomarker testing in ten states including Mississippi (where H.B. 565 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 Q1, 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

Thank you Virginia Senator @lashrecseaird for meeting with @IFAiArthritis and @AccessRare to discuss concerns about how artificial drug price caps may limit patient access to care. Please vote to delay any upper payment limits under #SB271 until this impact is studied by the legislature.

Post

AiArthritis
@IFAiArthritis

Promote

New patient survey results from @EACHPIC challenge Virginia lawmakers to rethink upper payment limits for prescription drugs. eachpic.org/if-patients-ar... @SpanbergerForVA @KarrieKDelaney @CreighDeeds @SenDaveMarsden @VASenateDems @VAHouseDems @VaBlackCaucus

From eachpic.org

6:27 PM · Feb 5, 2026 · **55** Views

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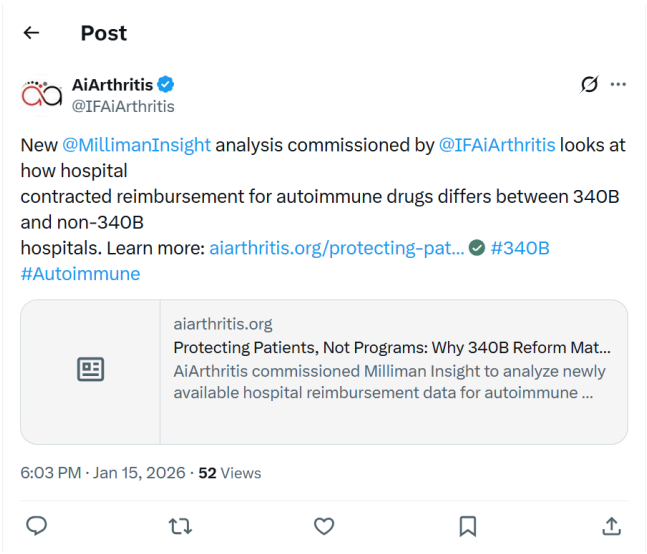
Post
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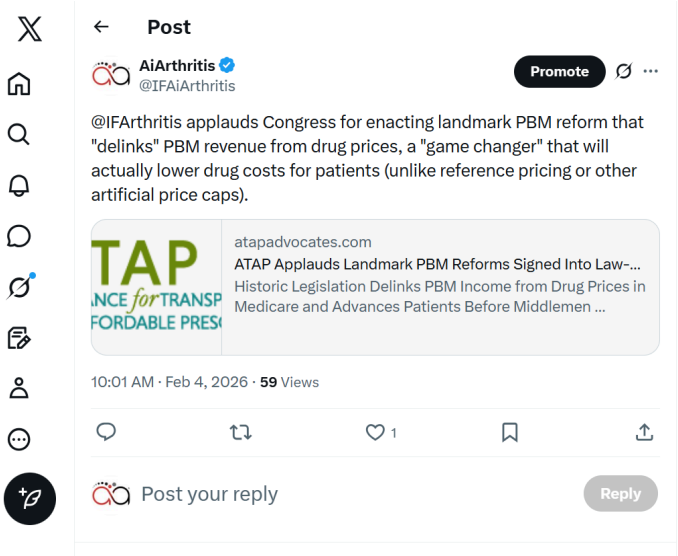
New @MillimanInsight analysis commissioned by @IFAiArthritis looks at how hospital
contracted reimbursement for autoimmune drugs differs between 340B and non-340B
hospitals. Learn more: aiarthritis.org/protecting-pat... #340B #Autoimmune
aiarthritis.org
Protecting Patients, Not Programs: Why 340B Reform Mat...
AiArthritis commissioned Milliman Insight to analyze newly available hospital reimbursement data for autoimmune ...
6:03 PM · Jan 15, 2026 · 52 Views


Post
AiArthritis
@IFAiArthritis
#OhioSB207 would stop health insurers from diverting copay assistance and protect patients from crushing out-of-pocket costs.
@OhioSenateGOP and @OhioSenateDems need to follow the lead of 26 states that nearly unanimously acted to ban #copayaccumulators and make #allcopayscount! bit.ly/49BwiKy
2:38 PM · Jan 15, 2026 · 51 Views
Post your reply
Reply


Post
AiArthritis
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Promote
@IFArthritis applauds Congress for enacting landmark PBM reform that "delinks" PBM revenue from drug prices, a "game changer" that will actually lower drug costs for patients (unlike reference pricing or other artificial price caps).
atapadvocates.com
ATAP Applauds Landmark PBM Reforms Signed Into Law-...
Historic Legislation Delinks PBM Income from Drug Prices in Medicare and Advances Patients Before Middlemen ...
10:01 AM · Feb 4, 2026 · 59 Views
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