

Advocacy Report - 2023 Quarter Two



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.

In the Second Quarter of 2023, **AiArthritis** has continued to excel in our work in public policy particularly with regard to Precision Medicine/Biomarker Testing Coverage and Copay Diversion Programs - while continuing our work in other important areas like utilization management, PBM transparency, Health Technology Assessments/Value Assessments, and data that influences policy (Research Advocacy).

Conferences, In Person Meetings Webinars, and Events

Highlights:

- **Lindsey was honored to be asked to speak on Prior Authorization at the Cardiometabolic Leadership Institute in Washington, DC in May.** She presented alongside Alisa Casavant from the Arthritis Foundation, Dr. Madelaine Feldman from CSRO, and Stephanie Hengst from the AIDS Institute. They collectively presented on Utilization Management to an eager group of new advocates in the cardiometabolic space.
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- She was also asked to present in an American Cancer Society Cancer Action Network Webinar regarding Biomarker Testing: ***Biomarker Testing: The Key to Unlocking Precision Medicine in New York and Beyond***. She spoke about how important Biomarker Testing Coverage might be to the AiArthritis community in the near future, and how legislation might support its use.
- **Lindsey also attended the California Chronic Care Coalition's annual advocacy day and served as team leader for patient advocates from across the state.** Experienced advocates were assigned teams of patient advocates and met with legislators - they did an amazing job advocating for several California bills including an Accumulator bill and a PBM bill!
- **Clinical Trial Transformation Initiative (CTTI) - Modeling & Simulation Working Group:** AiArthritis is the only Patient Organization in this group, which is no surprise given we are the non-cancer leaders in all things Precision Medicine. Tiffany attended ([meeting agenda/summary](#)). Disease progression modeling in clinical trials - as a means to collect data on subgroups - was the focus.
 - **However, in a room with mostly clinicians, some pharma, and researchers, Tiffany and one other attendee, President of the Critical Path Institute, bonded over recognizing the bigger picture to get patient orgs involved in blueprints for these procedures so thought of end use (Utilization Management & Value Assessments) is always considered in the design.** AiArthritis & C-Path have signed a collaboration agreement to begin identifying missing gaps in autoimmunity and the R & D continuum through regulatory and policy implementation to advance medical innovation. **Sponsorships/support pending. Please contact Tiffany to discuss if interested.**

See all Conferences, Webinars, and Events AiArthritis attended in Q2: [SEE FULL TRACKER](#).

Coalitions

We currently participate in over 2 dozen coalitions worldwide, over 75% of which are related to public policy.

NEW COALITIONS THIS QUARTER:

- Health Technology Assessment International: HTAi - <https://htai.org/>
- Patient Focused Medicine's Development/PFMD - <https://patientfocusedmedicine.org/>
- Patient Pocket Protector Coalition - [Patient Pocket Protector](#)

[*View all the Coalitions we belong to here.*](#)

Communications with Legislators and Public Comments

In the second quarter, AiArthritis continued to advocate for patients. While many state legislatures wound down in the past couple of months, we still kept busy communicating with legislators, HTA, and regulatory bodies.

Highlights:

- As part of our [Knowledge = Empowerment patient-led policy project](#) “elevated experiences”, patient program participants from around the USA were invited to join AiArthritis to write our Public Comments 2023 ICER Value Assessment Framework (VAF) and Processes for Conducting Value Assessments - Proposed Changes.
 - See our submission to ICER [HERE](#)
 - See a summary document of patient perspectives (incorporated into our final comments) [HERE](#)

- Special thank you to our Gold Level Sponsors of the Knowledge = Empowerment program, whose support enables us to perform these types of elevated experiences! **Amgen, Lilly, Genentech**
- We sent letters and written testimony on a variety of important topics, including coverage for biomarker testing, efforts to ban the use of copay accumulators and other harmful copay diversion programs, PBM reform, and supporting coverage of biomarker testing for AiArthritis diseases.
- We signed on to more than two dozen additional letters - to both State and Federal legislators and to several Regulatory Agencies. Here's some of what we signed on to:
 - PBM Reform
 - Urging CMS to consider rare disease patients in the implementation of the IRA
 - Urging Congress to reconsider harmful Part B cuts in the IRA
 - Asking the Wisconsin Group Insurance Board to refrain from adding an accumulator/maximizer program
 - and more!
- We sent comments to the Centers for Medicare and Medicaid Services regarding drug price negotiations under the IRA. We focused our comments on patient-centeredness, access to innovative treatments with regard to rare disease, transparency in drug price negotiations, the use of the QALY in any price setting, and the consideration of precision medicine. We subsequently connected with CMS personally to discuss our comments further. We are looking forward to continuing the conversation. Read our comments [HERE](#).

[HERE](#) is a PDF of the letters we sent and [HERE](#) is a PDF of the letters we signed on to.

Fast Democracy is making our legislative tracking so much more streamlined! It's much easier to manage than the google sheets tracker and also allows us to see news articles and tweets regarding the legislation.

[HERE](#) you'll find a PDF of the bills we are tracking in 2023, along with notes on the letters and testimony we prepared.

Social Media

In the second quarter, AiArthritis used our Twitter platform to tweet about legislative issues, totaling over 32,000 impressions and over 40 new followers! We tweeted about telehealth, accumulator programs, drug pricing policies, access to pharmacists, and the IRA implementation. Here are a few highlights!



JUN 2023 SUMMARY

Tweets	Tweet impressions
39	9,362
Profile visits	Mentions
1,054	18
New followers	
18	

11:59

LTE 74%



Tweet



Telehealth Access for America
@TAforAmerica

ICYMI: By integrating #telehealth into #arthritis treatment, clinical visits can be reduced by 69.9 percent.

This #ArthritisAwarenessMonth, learn how #virtualcare reduces costs by eliminating travel expenses and providing more budget-friendly care options ↓ @IFAiArthritis



telehealthaccessforamerica.org
ICYMI: Telehealth Is A Valuable Resource For Arthritis Patients, ...

10:45 AM · 5/3/23 from Earth · 28 Views



Tweet your reply



International Foundation for AiArthritis @IFAiArthritis · Jun 7

An Xcenda study released by @ChronicCarePA showed copay accumulator adjustment shows significantly increased the cost to patients with rheumatoid arthritis. Learn more about the study here: bit.ly/3IL5PNZ
#AllCopaysCount #RheumatoidArthritis

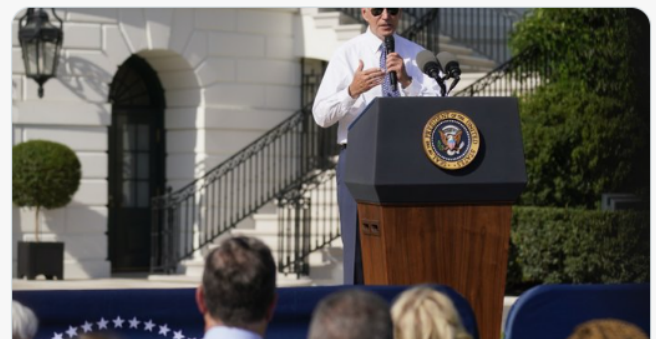


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International Foundation for AiArthritis @IFAiArthritis · May 19

Host regional roundtables. Request written comments on draft guidance. Engage patient communities in determining MFP for price setting. These are the ways @CMSgov can commit to patients as they implement IRA. #CMSPutPatientsFirst @ChronicCarePA



realclearhealth.com
Washington Must Heed Patient Recommendations as Policymakers I...
We have reached an inflection point in efforts to improve patients access to innovative medicines. In recent years, we have seen ...

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