

Advocacy Report - 2023 Quarter One



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 First Quarter of 2023, **AiArthritis** has continued to elevate our work in public policy especially with regard to Precision Medicine/Biomarkers and Copay Accumulator 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).

Highlights:

- **Lindsey gave her first live testimony** in the [Maryland State Senate Committee on Health and Government Operations](#) in early March. The testimony was in favor of HB 1217, coverage for biomarkers. We'll be continuing to provide live and written testimony throughout the legislative session in any states that we can.
- **ICER - HTA Health Equity Initiative:** AiArthritis CEO, Tiffany Westrich-Robertson, was one of 7 Senior Advisors, [final paper published March, 2023](#)
- **Knowledge = Empowerment Patient-Led Policy Program is underway!** See first round of patient-led education videos (Step Therapy, Copay Accumulator, : <https://bit.ly/KEVideos>
 - [View Infographic showing outline of video library \(Value Assessments\) strategy.](#)

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- Thank you to our [program sponsors](#) - Amgen, Lilly, Pfizer, AbbVie, Genentech/Biogen. **More Sponsors needed, contact Tiffany to discuss!**
 - **Chronic Care Policy Alliance event *Forecast 2023: The State of Access to Quality, Affordable Health Care* in Tempe, Arizona.** Lindsey Viscarra, AiArthritis Public Policy Manager, was asked to participate in the We were one of approximately 15 groups from across the country invited to participate.
 - **Lindsey was also asked to join the steering committee of the Alliance.** She was honored to accept.
 - **Rare Disease Week:** Lindsey also attended Rare Disease Week in Washington, DC, in early February/early March. It was a full 3 days and while she was there, she had the opportunity to meet with staff in 3 key legislative offices: Congressman Eric Swalwell, co-chair of the Personalized Medicine Caucus, Congresswoman Debbie Dingell, chair of the Arthritis Caucus, and Senator Krysten Sinema, co-chair of the Personalized Medicine Caucus. We are looking forward to building these relationships.
 - **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.**
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Coalitions

We currently participate in over 2 dozen coalitions worldwide, over 75% of which are related to public policy. [View all the Coalitions we belong to here.](#)

- In the first quarter of 2023, we joined 3 new coalitions:
 - Alliance for a Stronger FDA
 - Patients for Prescription Access
 - Global Advocacy Alliance

Conferences, In Person Meetings Webinars, and Events

In addition to attendance mentioned earlier in this report, AiArthritis participated in many Conferences, Webinars, and Events [SEE FULL TRACKER.](#)

Communications with Legislators

In the first quarter, AiArthritis continued to advocate for patients and it was a busy quarter!

Highlights:

- We sent 19 letters to legislators in 13 states on a variety of important topics, including coverage for biomarker testing, efforts to ban the use of copay accumulators, PBM reform, and to increase access to affordable prescriptions.
- We sent written testimony on 6 bills and gave live testimony on 1 more. Our testimony was overwhelmingly in support of biomarker testing.

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- We signed on to 33 letters - to legislators in 13 states and to several Regulatory Agencies.
 - Establishing Rare Disease Advisory Councils
 - Prohibitions on White-Bagging
 - Step Therapy reform
 - Many letters to Centers for Medicare & Medicaid Services (CMS) regarding the NBPP 2024 proposed rule
 - An amicus brief was filed in support of a lawsuit brought by the HIV + Hepatitis Institute in opposition to copay accumulators. We were proud to be included.
 - [HERE](#) is a PDF of the letters we sent and signed on to.

We are excited that this is the first quarter we're using FastDemocracy to track legislation. Gone is the google sheets tracker and [HERE](#) you'll find a PDF of the bills we are tracking in 2023, along with notes on the letters and testimony we prepared.

FastDemocracy also allows us to create pre-written letters for anyone who wants to communicate with their legislators. For the first quarter, we had 2 campaigns active - one for the Safe Step Act, and one for the HELP Copays Act. We'll be adding more in the second quarter!

Social Media

In the first quarter, AiArthritis mainly used our Twitter platform to tweet about legislative issues, totaling nearly 17,000 impressions and 112 mentions. We tweeted about access to pharmacists, PMB reform, Telehealth, the Inflation Reduction Act, Copay Assistance and Accumulator programs, and many more topics. Here are a few highlights!

International Foundation AiArthritis @IFAIArthritis · Feb 22

AiArthritis is proud to be a member of the Personalized Medicine Coalition. Looking forward to advancing this important work in 2023!

PMC @permedcoalition · Feb 22

Today, a new PMC report shows personalized medicines accounted for at least 25% of new FDA drug approvals for each of the last eight years. Despite high development costs and reimbursement headwinds, industry executives remain committed to the field. More: tinyurl.com/mufy953p

Personalized Medicines Accounted for More Than 25% of FDA Approvals for Each of the Last Eight Years

Year	Percentage
2015	28%
2016	27%
2017	34%
2018	42%
2019	25%
2020	39%
2021	35%
2022	34%

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International Foundation AiArthritis @IFAIArthritis · Feb 28

Today is **#RareDiseaseDay**! Our Public Policy Manager Lindsay is at the **#NIH** event learning more about **#RareDiseases**, their effects, and new ways they are being treated. **#RDDNIH**

Lindsay Viscarra
International Foundation for Autoimmune & Autoinflammatory Arthritis

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International Foundation AiArthritis @IFAIArthritis · Mar 9

Today, insurers and PBMs pocket billions in discounts and rebates from drug manufacturers - instead of lowering costs for patients. Join advocates in Oklahoma on March 22 to reduce drug prices and **#ShareTheSavings**. Register here: patientpocketprotector.org/lobby-day-marc...

MAKE A DIFFERENCE IN OKLAHOMA

CALLING ALL ADVOCATES: TELL OKLAHOMA LAWMAKERS TO PROTECT PATIENTS' POCKETS

DATE: WEDNESDAY, MARCH 22 **TIME:** 8:30 AM

MEET: NAMI Oklahoma Office
3812 N. Santa Fe Avenue, Suite 305
Oklahoma City, OK 73118

AGENDA:
8:30am Coffee and Training
9am Bus to Capitol
9:30am Legislator Meetings
12:45pm Bus Returns to NAMI Office
1pm Recap and Box Lunch

SHOW UP AND SHARE YOUR SUPPORT FOR HB 2853 AND SB 549

RSVP & MORE INFO: ECALLAHAN@DIABETESPAAC.ORG

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International Foundation AiArthritis @IFAIArthritis · Mar 3

We are calling on **#mnleg** to pass SF1948 so more MNs can get the right treatment at the right time. Biomarker testing is an important step to accessing **#PrecisionMedicine** treatments that can lead to better survivorship & quality of life for patients. **#precisionmattersmn**

THE RIGHT TREATMENT AT THE RIGHT TIME.

#PRECISIONMATTERSMN

Support SF1948 (Seeberger) and HF1978 (Reyer)

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