

Advocacy Report - 2022 Quarter Four



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. AiArthritis is not only patient-led, we are the only organization global in scope and whose

leaders are part of the community with our peers, participating daily in online communities and disease-related groups. We are respected leaders, teachers, mentors, and friends to our peers. 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. We do this through a 6-step problem-solving process that aims to bring as many patient voices to the table as possible (not only the same people every time), alongside other stakeholders - as equals - so together we can solve issues that impact education, advocacy, and research.

In the Fourth Quarter of 2022, AiArthritis has continued to elevate our work in public policy especially with regard to Health Technology Assessments/Value Assessments, Precision Medicine/Biomarkers, and Biosimilars - while continuing our work in other important areas like utilization management, accumulator, PBM transparency, and data that influences policy (Research Advocacy).

Highlights:

• **Speaker**: AiArthritis CEO, Tiffany Westrich-Robertson, was invited to speak as part of the Congressional Personalized Medicine Caucus panel (December 5), stressing the importance of autoimmune disease consideration in biomarker policy.

- Speaker: She also was invited to wrap up the Innovation and Value Initiative (IVI) public
 event to explore challenges and emerging solutions involving value assessments and HTA's,
 providing a summary of high points from the day and suggesting recommendations for
 community next steps. Stakeholders present included organizations, employer-purchaser
 and payers, policymakers, and ICER representatives.
- AiArthritis has been invited to take a seat on RheumPAC for 2023, an American College of Rheumatology committee that focuses on raising funds to support candidates who advocate for patient access and issues important to our community.
- International Advocacy: AiArthritis was invited to take part in EULAR PARE (patient organization country representatives of Europe) in Brussels, Belgium as the sole representative for North America.
- AiArthritis continued to raise our Public Policy/Advocacy voice with the continued work of a
 Public Policy Manager who we introduced in Q3, and will continue this important work into
 2023.

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.*

View our Coalition meeting tracker <u>HERE</u>.

Conferences, Webinars, and Events

In addition to attendance mentioned earlier in this report, AiArthritis participated in many Conferences, Webinars, and Events <u>SEE FULL TRACKER</u>.

Communications with Legislators

In the fourth quarter, AiArthritis continued to advocate for patients:

Highlights:

- Called Governor Baker of Massachusetts and signed on to a letter to urge him to sign
 H 4929, an act related to Step Therapy. We're thrilled that he did sign the bill!
- Letter written to Governor Hochul of New York urging her signature on A1741A, an act related to Copay Accumulators. We're pleased that she signed the bill!
- We also signed on to quite a few letters:
 - Urging the leaders of the HELP and Energy and Commerce committees to resume negotiations to develop a comprehensive FDA User Fee package
 - Commenting on the Oregon HERC Options for continued consideration of QALYs as part of their determinations related to the Medicaid prioritized list of services
 - Urging CMS to support the proposed rule to streamline Medicaid/CHiP enrollment and eligibility
 - Urging the Committee on Appropriations to pass a final appropriations bill
 that includes the Office of Autoimmunity under NIH
 - Encouraging CMS to include medically necessary dental coverage for autoimmune disease under Medicare

VIEW ALL

TO VIEW OUR FULL Q4 POLICY TRACKER, <u>CLICK HERE.</u>

We are excited to announce that this is the last quarter we are using this tracker! We've begun working in Fast Democracy, a platform that will allow far easier tracking of legislation, our efforts, and allow our volunteers and followers to weigh in on legislation as well. More on this in the first quarter 2023 report!

Social Media

In the fourth quarter, AiArthritis mainly used our Twitter platform to tweet about legislative issues, totaling more than 24,000 impressions and 187 mentions. We tweeted about Telehealth, Accumulator programs, Antimicrobial Resistance, Clinical Trials, Step Therapy, and many more topics. Here are a few highlights!

