

Advocacy Report - 2023 Quarter three



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 Third Quarter of 2023, AiArthritis has continued to excel in our work in public policy particularly with the **addition of Anika Rahman, our new advocacy staff!**



It's a pleasure to announce that Anika Rahman joined the AiArthritis team as the International Advocacy & Policy Director just three weeks ago! You'll find her sharing her extensive knowledge and over 12 years of deep-rooted experience in government affairs, policy, legislative tracking, grassroots advocacy, campaigns, and organizing within the realms of social justice, public affairs, and foreign policy.

Possessing linguistic fluency in five languages, namely English, French, Bangla, Hindi, and Urdu, Anika has worked on a slew of advocacy projects, both on the Hill and in the Virginia General Assembly, demonstrating mastery in navigating distinct federal and state legislative

processes. Her accomplishments are highlighted by leading successful Democratic Senate and State Delegate races/campaigns.

Anika's forte lies in crafting and executing effective advocacy strategies, extending to the organization and facilitation of numerous meetings, briefings, fundraisers, and events with highly-regarded leaders and advocates across varying sectors.

Focusing on Anika's engagement at **AiArthritis**, her personal connection with the cause resonates deeply as her mother suffers from an undiagnosed autoimmune disease. Anika's role is not just representing the patient voice; she is the patient voice! With a passion for patient care and advocacy, Anika aims to fortify **AiArthritis'** advocacy and policy mission. She appreciates the guidance given by Tiffany and is excited about the learning experience. As we look ahead, Anika's primary focus elements include:

- [The Knowledge is Empowerment \(K=E\) program](#), where regular policy update shares are aligned with the expansion of advocacy through this grassroots (volunteer) program.
- International outreach with iPARE, intending to collaborate globally among patient organizations for the benefit of individuals with rheumatic and musculoskeletal diseases (RMDs). As EULAR iPARE's chosen representative for North America, Anika is honored to participate in their event scheduled in Brussels, Belgium this November.
- Promoting increased patient involvement through a national network (coalition) focused on price setting - stay tuned for more details!

Moreover, she'll be engaged in various daily activities and many more ventures, making a significant contribution to **AiArthritis**. We're thrilled to have her on board and look forward to the journey ahead!

Conferences, In Person Meetings Webinars, and Events

Highlights:

- Anika and Tiffany Westrich-Robertson, CEO and person living with axial spondyloarthritis, spent a week and a half together in Washington DC in late September. Needless to say, Anika had a whirlwind first couple of weeks! While there they attended:

- Innovation and Value Initiative meeting, [focusing on Value Assessments and learning about the new model that could one day take the place of the QALY.](#)
- The same week, the Colorado Prescription Drug Affordability Board (CO PDAB) online sessions for Enbrel, Cosentyx, and Stelara started. AiArthritis worked with the Arthritis Foundation and the National Psoriasis Foundation to recruit patients and mentor them to prepare for speaking. Tiffany participated as a patient on Cosentyx. **AiArthritis was the only nonprofit organization to have representation at all three listening sessions.**
 - She is helping create a coalition to highlight the need for better GPS and patient voices.
 - Also while in D.C., Tiffany participated in the Clinical Trial Transformation Initiative (CTTI) meeting (which ties data into policy), and attended Hill visits with the American College of Rheumatology (ACR) to advocate for the Safe Step Act and PBM transparency and reform.

See all Conferences, Webinars, and Events AiArthritis attended in Q3: [SEE FULL TRACKER.](#)

Coalitions

BIG NEWS!!! We are gearing up to CO-LEAD our FIRST NATIONAL COALITION to facilitate productive discussions with the Prescription Drug Affordability Board (PDAB) and Centers for Medicare and Medicaid Services (CMS) regarding the affordability of prescription drugs and **Government Price Setting (GPS)**. Stay tuned...

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

Communications with Legislators and Public Comments

Highlights:

We signed on to and wrote several letters that reflect the following;

- Advocated for the rights of patients and healthcare providers alongside All Copays Count Coalition.

- Took a stand against the abusive practices of PBM's and health insurers.
- Sent a collective letter requesting a reduction in patient co-pays and immediate financial relief for those affected by complex, chronic, and rare diseases.
- Placed an emphasis on PBM reforms as a vital aspect of the advocacy.
- Worked on expanding access for historically underserved populations to COVID-19 antivirals.
- Engaged with the CO Prescription Drug Affordability Board (PDAB), providing them with guidance and urging them to adopt a more person-centered approach in decision-making.
- Submitted comments to the Centers for Medicare and Medicaid Services (CMS) regarding proposed policy changes for diagnostic radiopharmaceuticals payments under the HOPPS.

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

AiArthritis supports and follows a range of legislation. Below is the link to access a list of these bills, explore their objectives, and track their progress. Engaging in this process is an excellent way to remain informed about crucial federal policies under consideration. [HERE](#) you'll find a PDF of the bills we are tracking in 2023, along with notes on the letters and testimony we prepared.

Advocacy Related Projects and Programs Update

- **Knowledge = Empowerment Patient-Led Public Policy Education and Action grassroots program.** First, thank you to our current project supporters: Amgen, AbbVie, Lilly, Genentech, and Pfizer. Because of your support, we were able to successfully build and launch this pilot program (starting with four topics: Step Therapy, Accumulator, Value Assessments, and Precision Medicine).
 - We launched the first classes in September, beginning with Precision Medicine (Class Speaker was ACS-CAN, leader of the biomarkers legislation coalition) and Step Therapy (Class Speaker was from National Psoriasis Foundation, co-lead for the Safe Step Act coalition).
 - We successfully launched an over 30 patient-led Video Library!

- We recruited several Library Collaborators, including the groups mentioned above, Arthritis Foundation, and more. Together we are stronger!
- Given the success of the program, we will move forward in 2024 and the program will include ALL of our advocacy priority areas! We do need additional support to grow this program, so if you are reading this, we know you may be interested in getting involved. Please contact tiffany@aiarthritis.org for more information.
- View the class here: <https://www.aiarthritis.org/knowledge-empowerment-classroom>
- **Biosimilars Education project.** Thanks to Amgen and Boehringer Ingelheim, we launched our patient-led biosimilars project, aimed at helping patients understand biosimilars and what to do when and if they are switched to one. In addition to hosting the Biosimilars Hotline, we worked with leaders from the Alliance for Safe Biologic Medicines (ASBM) for an [AiArthritis Voices 360 Talk Show episode](#), which to date is the most downloaded episode this year.
 - As recent as September 2023, we continued to ask our peers their thoughts about biosimilars. Initially to our surprise, so many still do not understand what they are, if they are safe, and largely feel upset if they are forced to use them. When we delved into how patients still are ill-informed, given the abundance of patient education available, the overwhelming response was, “I guess it doesn’t affect me now so until it does I don’t really care/haven’t paid attention.” This tells us there will be a LOT of work to do as patients start to get switched more often.
- **The AiArthritis Research Database is finally here!** Thanks to FORWARD: National Databank for Rheumatic Diseases, who built and will house our own research database, we have a way to collect real world evidence to help expedite diagnosis, understand therapy responses, study subgroups, and collect data to drive policy decisions. Tiffany, who manages our research department, and who leads all things Research Advocacy (research that impacts legislation and associated policy efforts), will be running this initiative.

A monthly newsletter is distributed to nearly 2000 subscribers to provide updates on advocacy and policy. It keeps community members and patients informed about activities such as trips, work updates, legislative changes, and classroom sessions. To access an example of the newsletter, please click on this link: [HERE](#). To subscribe, click [HERE](#).

Social Media

In the third quarter, AiArthritis used our Twitter platform to tweet about legislative issues, totaling over 37,000 impressions and over 40 new followers! We tweeted about telehealth, accumulator programs, step therapy, drug pricing policies, access to pharmacists, and the IRA implementation. Here are a few highlights!





International Foundation for AiArthritis @IFAiArthritis · Sep 11

Accumulator adjustment programs force patients to pay high medical costs OR stop successful treatment - learn more: tinyurl.com/2p8sexr9
Join @CSROAdvocacy to raise awareness with policy makers on this issue during a Day of Action on 9/15! #RDAM #RDAMAdvocacyIsAwareness

SEPTEMBER RHEUMATIC DISEASE AWARENESS MONTH

DID YOU KNOW?

Accumulator Adjustment Programs are a utilization management tool used by insurers and Pharmacy Benefit Managers that DO NOT count co-pay assistance toward patients' out-of-pocket maximum or deductible.

CSRO Advocacy = Awareness



International Foundation for AiArthritis @IFAiArthritis · Sep 11

We applaud @SenJohnThune and @MarkWarner for championing #S2477 to ensure senior access to prompt and essential pharmacist services. We stand ready to work with you on this critical patient effort. bit.ly/Enact-S2477

S. 2477: Equitable Community Access to Pharmacist Services Act

Bipartisan legislation to ensure seniors maintain access to essential pharmacist services.

FUTURE OF PHARMACY CARE COALITION





International Foundation for AiArthritis @IFAIArthritis · Aug 7

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A new episode of the AiArthritis Voices 360 Talk Show is live! Learn what is important re: [#biosimilars](#) and [#access](#) to treatments. What is interchangeable? Automatic substitution? Non-medical switching? Listen or watch: [aiarthritis.org/talkshow-ep88](https://www.aiarthritis.org/talkshow-ep88) @SAFEbiologics @GlobalCRC

NEW EPISODE

ep 88

TIFFANY

ANDREW SPIEGEL

DR. RALPH MCKIBBIN

MICHAEL REILLY

BIOSIMILARS: INTERCHANGEABILITY & SWITCHING 2023

aiarthritisvoices **360**

Official Talk Show of the International Foundation for Autoimmune & Inflammatory Arthritis (iArthritis)

<https://www.aiarthritis.org/talkshow-ep79>

