

# 2018 Upcoming Activities & Accomplishments

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Approved language: talking about our initiatives

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### 2018 ORGANIZATIONAL PRIORITIES

#### Ensuring Access Through the Voice of People With Arthritis

The Arthritis Foundation amplifies the voice of people with arthritis, so they are heard and listened to at the federal and state levels. We are there at every step – reaching out to patients, talking with policymakers and industry leaders, sharing information with our constituents and providing resources and support.

##### **Legislative Action**

The Arthritis Foundation pushes for policies and laws that make health care more accessible and works with the administration to find policy solutions that reduce patient out-of-pocket costs.

##### Medicare Part D Guidance

The Foundation released an [advocacy statement](#) in response to the administration's announcement of new guidance to Medicare Part D prescription drug coverage plans. This proposal would place further restraints on the already narrow treatment options available for patients with inflammatory forms of arthritis. (Aug. 30)

##### Legislation Bans Gag Clauses

Congress passed two pieces of [legislation that would ban the use of gag clauses](#), which prohibits pharmacists from telling patients whether they could save money by paying cash for their medication instead of using health insurance. The Foundation led the charge by building support in Congress among other patient and provider organizations. (Oct. 10)

##### **Arthritis Industry Forum**

On May 16, the Foundation convened a forum of stakeholders – pharmaceutical, biotech, academic and government institutions and members of the arthritis patient community – to discuss emerging and timely policy and legislative issues that affect the arthritis community.

##### **Patient Voice Access Project**

The Foundation developed a white paper for industry partners that outlines recommendations to help patients better navigate health care options and afford medication. We engaged 600 Foundation constituents through surveys and held focus groups on how affordability challenges affect patients. We are now launching the next phase of this project, educating stakeholders and developing resources to help patients. (Feb. 28)

### Advocacy Events

Through the Arthritis Foundation's network of committed Advocates and events like our Advocacy Summit and Platinum Ambassador Assembly, we fight to address key policy issues and make positive changes on Capitol Hill.

#### Advocacy Summit

The [2019 Advocacy Summit](#) will take place March 11-12 in Arlington, VA. This conference brings together engaged advocacy volunteers who want to hone their skills, meet other advocates and learn how to use their voice. Attendees will have the opportunity to meet their members of Congress. ([Oct. 19](#))

#### Platinum Ambassador Assembly

The Foundation hosted its first ever Platinum Ambassador Assembly in Washington, DC on March 12-13. In place of a traditional Advocacy Summit, this event featured specialized trainings for our top grassroots volunteers, our [Platinum Ambassadors](#). Our social media activation garnered more than 11 million impressions using the hashtag #AdvocateforArthritis. ([March 12](#))

### Ambassador's Legislative Wins

Twenty-three members of Congress signed arthritis funding support letters and two lawmakers joined the Arthritis Caucus because of the 137 Capitol Hill meetings held during the Platinum Ambassador Assembly. ([April 26](#))

### Advocacy Chats

To provide a platform for discussion on timely advocacy issues, the Arthritis Foundation has hosted several Twitter chats.

#### #CopaysCount Chat

With 3.4 million impressions, the Foundation led a successful #CopaysCount Twitter chat focused on changes to co-payment assistance programs and the affects to patients. ([July 18](#))

#### #Rheum Chat

We co-hosted a Twitter chat with the American College of Rheumatology to raise awareness around health care issues patients should know, with more than 1.5 million impressions of #RheumChat. ([Jan. 25](#))

### Hill Briefing

We hosted a Capitol Hill briefing with the American College of Rheumatology and half a dozen other organizations, highlighting the growing physical and economic burden of arthritis and urging lawmakers to increase funding to government funded arthritis programs. ([Feb. 1](#))

### State Legislative Activity

We tackle the big issues – raising our collective voice to secure one victory after another, state after state and on Capitol Hill. In September, the Arthritis

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Foundation secured our 100<sup>th</sup> state legislative victory since 2014. Our victories occurred in 47 states plus Washington, DC, impacting more than 50 million people with arthritis. In 2018, we have supported 26 legislative wins in 20 states. [\(Oct. 1\)](#)

### Biosimilars

We advocate for biosimilar substitution legislation, enhancing patient access to new innovative medications while ensuring pharmacists are communicating critical and up-to-date medical information about patients to physicians.

Nine states (AK, CT, MI, SD, VT, WY, WV, WI) have signed biosimilar substitution bills into law so far in 2018, impacting more than 5.3 million residents with doctor-diagnosed arthritis. [\(Oct. 15\)](#)

### Mid-Year Formulary Changes

We support legislation that keeps insurance coverage consistent and affordable during a plan year.

**Illinois** signed HB 4146 into law, protecting patients from mid-year prescription coverage reductions, impacting more than 2.3 million residents with doctor-diagnosed arthritis. [\(Aug. 23\)](#)

### State Implementation Program

To help ensure state laws are implemented fully and that patients know their rights, we are developing resources that explain the issue, the law and what it means to patients. In 2018, we are focusing efforts in 10 states with laws focused on step therapy (CO, IL, IA, MO, NY, TX, WV) prior authorization (IN, OH) and out-of-pocket costs (DC).

We launched an [Action Center](#) where volunteers can contact elected officials at the state and federal levels and share their stories. [\(June 4\)](#)

### Capitol Days

We've held 13 local Capitol Days focusing on topics that include limiting step therapy and legislation related to out-of-pocket health care costs, resulting in more than 272 legislative visits. [\(Oct. 15\)](#)

### Step Therapy

The Arthritis Foundation advocates to reform step therapy, the process that forces patients to try drugs that insurance companies choose before the patient has access to the medicine that their doctor originally prescribed.

Two states (MN, NV) have passed legislation to curb step therapy, increasing access to care for more than 1.2 million people with arthritis. [\(Oct. 15\)](#)

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### Prior Authorization

The Arthritis Foundation backs measures to streamline the prior authorization process.

**Indiana** signed prior authorization bill, HB 1143, into law, strengthening the 2017 bill and impacting more than 1.3 million residents with doctor-diagnosed arthritis. (Oct. 15)

### Prescription Drug Clawbacks

We advocate for the disclosure of information that helps consumers make informed health care choices including the prohibition of gag orders preventing patients from knowing the lowest cost payment options for their medications.

Thirteen states (AK, AZ, CO, FL, KY, MD, NY, SD, UT, VA, WV, WY) have signed legislation prohibiting clawbacks, impacting more than 15,761,000 residents with doctor-diagnosed arthritis. (Oct. 15)

## Shaping Health Outcomes

We're working to build a national network that elevates the patient's role in their care, improves dialogue between the doctor and patient, and results in more control of inflammation and fewer flare-ups.

### **Improving Quality of Care**

To enhance communication between patients and health care teams and provide a wholistic picture of a patient's condition, the Foundation has launched the [Rheumatology Learning Health System](#) (RLHS). This project combines existing arthritis patient registries, electronic patient health records and information entered by patients themselves. So far, three pediatric sites have been selected: Hackensack Meridian Health (NJ), Stanford Health Care (CA) and Wake Forest Baptist Health -Brenner Children's Hospital (NC).

The RLHS has been created in collaboration with the Childhood Arthritis and Rheumatology Research Alliance (CARRA), the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN), Understanding Childhood Arthritis Network – Canadian/Dutch Collaboration (UCAN, CAN-DU), and the Dartmouth Institute for Health Policy & Clinical Practice. (March 14)

### **Cultivating a New Generation of Rheumatologists**

To close the gap on the shortage of rheumatologists, we have expanded the number of fellowship opportunities for rheumatologists, focusing on communities with the greatest need. Our patient-centered approach allows doctors to get to know their community and what their patients really need, including Foundation resources that can help them.

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The Arthritis Foundation [awarded the following institutions](#) \$150,000 to expand their established fellowship programs: University of Washington (Seattle), University of California (San Francisco), University of Alabama at Birmingham (Birmingham, Ala.), Grant Riley Hospital for Children at Indiana University Health (Indianapolis) and the David Geffen School of Medicine, UCLA (L.A.). (May 25)

### Patient Engagement

The Arthritis Foundation incorporates patient insights into everything we do, using what we learn to help shape our efforts and impact the overall research and health care system. We lead the patient engagement movement by helping patients partner with their health care providers on treatment decisions and calling on highly-engaged patients to impact research as partners, advisors and contributors.

#### Patient Leadership Council

People with arthritis are at the center of our work. To ensure our programs and work include the patient voice, we launched the [Patient Leadership Council](#) and trained 173 patients in roles that will influence the health care system and our organization's efforts. (Feb. 2017)

#### ACR/ARHP Annual Meeting

The Arthritis Foundation led the online conversation during the ACR/ARHP Annual Meeting, with 69.9 million impressions of [#ACR17](#), 9 million impressions of #ACR17 from @ArthritisFdn, 264 tweets and 592 retweets. We also piloted a patient representative program, bringing a cadre of ten highly involved, engaged patients who weighed in during [ACR sessions](#). This year's meeting is scheduled from Oct. 19-24 in Chicago. (Nov. 2017)

### Peer and Community Connections

To combat the isolation of arthritis, we connect thousands of people together who understand the challenges of living with arthritis to share ideas, hope and communal knowledge. We offer support groups nationwide for adults with arthritis, a mentoring program for teens, plus recreational and educational activities, kids' camps and more.

#### Arthritis Support Network

The [Arthritis Support Network](#) is a tremendous support network for people with arthritis and has grown from 30 to 57 groups across the country. These groups provide personalized help and support by building a community of support through educational and social activities. In 2017, we tripled our ASN participants and almost doubled the number of ASN leaders (from 37 to 67). In 2018, we will grow to 100 ASN groups, including piloting groups for JA parents. (March 28)

### **Arthritis United**

The Foundation hosted its 11<sup>th</sup> annual [Arthritis United Conference](#) (formerly the Gathering Conference) in Washington, DC from March 9-11, and engaged 156 in-person and nearly 70 virtual attendees. Sessions led by medical experts and volunteers covered a variety of topics for adults with arthritis as well as loved ones. Survey responses showed a 50 percent decrease in the number of people who report feeling down, depressed or hopeless after attending the event.

(March 9)

### **Serving Kids with JA**

Last year, family days, JA camps and JA Conference connected close to 12,000 families together. Each year, the JA Conference touches the lives of thousands of participants. We host families and young adults in two locations and provide travel awards to offset travel expenses, making it possible for families to join us. This fall, we launched our first JA Parent Support Group. (Sept. 21)

### JA Conference

In 2018, our [National JA Conference](#) was held in Seattle from June 28-July 1 and in Washington, DC from Aug. 2-5. These events hosted 1,761 attendees, including 431 families. Conference survey results showed that 81 percent of attendees felt more connected and 52 percent were attending for the first time. (Aug. 5)

### **Helping Teens Transition from Childhood to Adulthood**

In partnership with The Hospital for Sick Children, we launched the [iPeer2Peer mentorship pilot program](#) to support teens with JA and other rheumatic diseases. During the initial pilot period, we matched 12 mentors (young adults) and mentee (teens) in 2017.

### iPeer2Peer

We trained 13 new iPeer2Peer mentors in April and now have 24 active mentors across the country. Our 2018 goal is to impact at least 100 teens through iPeer2Peer. We have created A Guide for Teens to Living Well with Arthritis to include in the JA Power Pack. (May 18)

### Winterhoff Arthritis Scholarship Program

Eleven college students have been awarded the 2018-2019 [Winterhoff Arthritis Scholarship](#). Started with a donation from the late Walter J. and Kathryn M. Winterhoff, the program was the first to offer college scholarships to students with rheumatic diseases. Until 2017, the program served the Pacific Southwest, when it expanded into a nationwide opportunity. (June 28)

## **Personalized Support**

The Arthritis Foundation makes a difference in people's lives through personalized attention and expert guidance – whenever and wherever people need us. We empower millions of people to live their best life with tools, tips and expert

guidance to navigate conversations with health care providers and continue to do what they love with less pain.

### **Live Yes! Arthritis Network**

The Arthritis Foundation launched the [Live Yes! Arthritis Network](#) on World Arthritis Day, highlighting how we are making connections possible both in person and online to empower people to live their best life. We inspired conversation – our #WorldArthritisDay and #WeLiveYes posts were seen 166,519 times and reached 77,931 people. (Oct. 12)

### Live Yes! Online Community

The [Live Yes! Arthritis Network online community](#) includes five forums – RA, OA, PsA, JA and one for other types of arthritis – providing an interactive platform for peers and experts to discuss topics, including pain management medications, emotional self-care, school solutions and physical activity. (Oct. 12)

### **Living Made Easier**

[Living Made Easier](#) is a local event series that helps people with arthritis find ways to overcome daily obstacles and say Yes more than No. In 2017, our pilot program Living Made Easier: Cooking allowed attendees to learn tips and tricks in the kitchen to help make cooking easier. In 2018, we are expanding the series to 16 cities and new topics, including daily living and gardening. (March 28)

### **Living Your Yes with RA**

[Living Your Yes with RA](#) is a free personalized goal-setting event, with 70 events offered in 54 cities across the country. Three different events (101, 201 and 301) cover topics from basic disease information to small group discussions. Led by local rheumatologists, attendees get expert advice on setting goals to help people with RA live full lives. Participants report a 25 percent increase in tracking progress toward their goals after attending; and nearly a third report that management of their RA has improved since the event. (March 28)

### **Walk With Ease**

Our [Walk with Ease](#) program has proven to reduce the pain of arthritis and improve the overall health of people who participate. People can either participate in the six-week walking program with a group of walkers or do program activities on their own. Earlier this year, we expanded our partnership with Optum Fitness Advantage/UnitedHealthCare via partnerships with LA Fitness, Gold's Gym and others to reach more participants. (Jan. 22)

## **Pursuing a Cure**

The Arthritis Foundation is boldly pursuing a cure for America's # 1 cause of disability, creating the next generation of diagnostic and treatment solutions for arthritis, bringing them to market faster to get earlier, more accurate diagnoses

and treatments. We have invested more than \$500 million in arthritis research over the past seven decades.

### **Increasing Participation in Trials**

Clinical trials help test how well new medical approaches work in patients and ultimately lead to better outcomes for patients. One of the most challenging aspects of the drug approval process is finding people to participate in clinical trials. We are committed to creating resources that help accelerate the development of new treatments.

#### Arthritis Trial Finder

To build awareness and increase participation in arthritis-related clinical trials, the Foundation has launched the [Arthritis Trial Finder](#), which allows patients to find trials near them. (Sept. 10)

### **Advancing OA Treatment**

Osteoarthritis (OA) affects 27 million adults in the U.S., causing chronic pain, serious disability and diminished quality of life. There are currently no approved disease-modifying treatments that halt the progression of OA, only therapies that temporarily relieve symptoms. We are determined to find out more about this devastating disease and aid in the development of new and novel treatments.

#### FDA Guidance Helps Accelerate OA Interventions

The Food and Drug Administration (FDA) published [draft guidance](#) for developing OA drugs, devices and treatments, which the Arthritis Foundation has been urging. This is important because there is no cure for the disease and most medicines offer only modest relief. This milestone was made possible in partnership with many patients and other key stakeholders. (Aug. 22)

#### OA COE Fellows in Training Bootcamp (FIT)

**\*Upcoming\*** *Getting OA on TRACK<sup>SM</sup>* with FIT is the Arthritis Foundation's new annual total immersion conference for post-doctoral fellows, sports medicine fellows, early-stage scientists and MD/PHD candidates, and patients, interested in early OA research.

This meeting will bring together the brightest, most dedicated and passionate people to accelerate science and transform the future of osteoarthritis. They will participate in interactive workgroups, panel discussions, breakout sessions and open scientific debate.

#### OA Center of Excellence

The Arthritis Foundation has set the goal of [Advancing OA treatments](#) as one of its highest priorities. To do this, we have created the OA Center of Excellence (COE), where researchers from around the country can join the Clinical Trial Network to work together to accelerate the development of new OA therapies.

The OA COE has invested in six research institutions that will determine identifiable biomarkers for each stage of OA. (March 2017)

### OA PFDD Meeting

Our groundbreaking [Osteoarthritis Patient-Focused Drug Development meeting](#) provided patients the opportunity to share their experiences and concerns, which will help inform the benefit/risk framework of the Food and Drug Administration. [The Voice of the Patient Report](#) is the culmination of our efforts to engage patients in all aspects of treatment development for arthritis patients. (March 2017)

### **Pursuing a Cure for JA**

In the U.S., an estimated 300,000 children have JA or other rheumatic conditions. The Foundation is committed to meeting the unique and urgent needs of JA families, giving them a platform for sharing their experiences, while we work toward a cure and personalized treatment plans for each diagnosis.

### JIA PFDD

JA families had the opportunity to share their perspectives with industry leaders, FDA staff, academic personnel and members of the media about the ongoing impact of treatment approaches as part of the [Juvenile Idiopathic Arthritis Patient-Focused Drug Development](#) meeting held Aug. 2 in Washington, DC. (Aug. 23)

### **CARRA**

Finding the best treatments for JA and other rheumatic conditions is challenging. Through our partnership with CARRA, the Childhood Arthritis and Rheumatology Research Alliance, we've invested \$23.5 million over five years to collaborate on treatment plans and research to positively impact families living with JA.

### Consensus Treatment Plans

A [CARRA report](#) recommends that consensus treatment plans (CTPs) will help doctors, patients and their families choose one treatment option over another. This new approach will make it possible to compare treatment options in a new way. Studies are underway to look at treatment options for systemic juvenile idiopathic arthritis (JIA) and polyarticular JIA. (March 31)

### **Building PARTNERS**

In 2017, we launched [PARTNERS](#) (Patients, Advocates and Rheumatology Network for Research and Service) registration with 200 JA community patients. Two surveys were distributed in September. One survey prioritized research supported by PARTNERS and the other focused on patient and parent perspectives on mental health needs in rheumatology. (March 11)

### **Identifying Cardiovascular Risk in RA Patients**

The Arthritis Foundation is one of several partner organizations in a study to identify biomarkers in the blood that will measure the risk of cardiovascular disease in RA patients. Biomarkers capable of identifying cardiovascular disease risk in RA patients with minimal symptoms, such as those used in the [TARGET Biomarkers Study](#), will help improve the design of clinical trials, develop new treatments and will be used to reduce mortality among RA patients. (July 2017)

### Snapshot of our [2017 Annual Report](#)

In 2017, the Arthritis Foundation...

**Demanded that people with arthritis be heard in legislative decisions.**

- Together with our Advocates and Ambassadors, we were actively involved in more than 160 policies in 39 states.
- As health care repeal and replace debates were underway, we were there at every turn – in contact with patients, having dialogue with policymakers, keeping our constituents informed and offering guidance.

**Empowered millions of people to live their best life with tools, tips and expert guidance to navigate conversations with health care providers and continue to do what they love with less pain.**

- With more than 1,700 callers, the Arthritis Foundation Helpline provided people with real-time support.
- More than 657,000 constituents learned self-management skills with our online powerful tools.
- With over 4 million readers, Arthritis Today provided trusted advice from the world's top doctors and medical experts.

**Connected thousands of people together who understand the challenges of living with arthritis to share ideas, hope and communal knowledge.**

- The Arthritis Support Network expanded to 54 communities, offering volunteer-driven personal support.
- Living Your Yes with RA grew to 38 communities; Living Made Easier launched in five communities, offering tips for living a life of YES.
- Across the country, family days, nearly 50 JA camps and a JA conference in two locations connected close to 12,000 families together.

**Transformed the course of treatment for osteoarthritis and forged a path towards conquering all types of the disease.**

- Our groundbreaking OA Patient-Focused Drug Development meeting gave patients the opportunity to share their point of view to help inform the Food and Drug Administration.
- The Arthritis Foundation OA Center of Excellence was formed to improve clinical trials with a collaborative network and is investing in research that will determine identifiable biomarkers for each stage of OA. Five institutions have been awarded grants.
- We expanded the CARRA registry to include lupus, JDM, and scleroderma and increased participation in research by launching [PARTNERS](#) registration with 200 JA patients.