2019 Organizational Priorities & Accomplishments

How we talk about our initiatives

Arthritis Foundation®

INDEX

2019 ORGANIZATIONAL PRIORITIES

REMOVING BARRIERS TO IMPROVE ACCESS

Federal + National Legislative Wins
Increasing Visibility and Support
Advocacy Chats + Social Reach

IMPROVING OUTCOMES IN A MEDICAL SETTING

Patient-Reported Outcomes
Better Experience of Care
Cultivating a New Generation of Rheumatologists

PEER + COMMUNITY CONNECTIONS

Peers Supporting Peers
Serving Kids and Families

PURSUING A CURE

Childhood Arthritis and Rheumatology Research Alliance
Osteoarthritis Center of Excellence
FDA Guidance Helps Accelerate OA Interventions

FUNDING THE MISSION + ATTRACTING SUPPORTERS

Major Gifts Be the One Campaign
Special Events

2019 ORGANIZATIONAL PRIORITIES

REMOVING BARRIERS TO IMPROVE ACCESS

The Arthritis Foundation empowers volunteers to help lead the fight against barriers to care, high costs of treatment and scarcity of specialists. Through our committed advocacy network of more than 150,000 members, we work to address key issues on both the state and federal levels with lawmakers, insurers and regulators.

Federal + National Legislative Wins

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.

Since 2014, we have secured more than 115 state legislative victories in 49 states, plus Washington, DC, and in 2018 helped pass 37 new pieces of legislation in 29 states. The Congressional Arthritis Caucus grew to 146 members in the 115th Congress. (March 22)

Two states (OH, VA) have passed legislation to curb step therapy this legislative session, bringing the total number of state-level step therapy victories to 22. (March 22)

Serving Military Members With Arthritis

Dozens of Capitol Hill staffers joined the Arthritis Foundation and other patient organizations for a special Arthritis 101 briefing on arthritis and the military. Attendees were urged to tell their members of Congress to prioritize a letter to request an arthritis research program for $20 million through the Department of Defense Congressionally Directed Medical Research Program. (Feb. 21)

Increasing Visibility and Support

As the cause leader on behalf of the 54 million people living with arthritis, we build support from legislators, corporations and alliances with nonprofit organizations. Advocates and Ambassadors power our mission. In 2018, they sent more than 5,000 letters to policymakers through our Action Center.

Advocacy Summit

The 2019 Advocacy Summit took place March 11-12 in Arlington, VA, bringing together more than 300 engaged advocacy volunteers to hone their skills, meet other advocates and learn how to use their voice. Attendees had the opportunity to meet their members of Congress at some 215 meetings. (March 12)

State Legislative Days

We've held seven State Legislative Days focusing on topics including step therapy reform and out-of-pocket health care costs. In 2018, we held 10 State Legislative

Days across the nation. (March 22)

Advocacy Chats + Social Reach
To provide a platform for discussion on timely advocacy issues, the Arthritis Foundation hosts several Twitter chats each year.

IMPROVING OUTCOMES IN A MEDICAL SETTING

The Arthritis Foundation works to elevate the patient's role in their care, improve communication between patients and health care teams, and results in fewer flare-ups and better management of inflammation.

Patient-Reported Outcomes
The Arthritis Foundation puts volunteers and patients at the center of everything we do, from developing meaningful resources that help them live a fuller life to ensuring their voices are heard in matters that affect their health and well-being.

Live Yes! Insights Program
In 2018, the Arthritis Foundation launched a confidential dashboard of patient-recorded outcomes (PRO), which enables people with arthritis to better understand and track their health over time, allows the Foundation to tailor programming to meet the specific needs of communities and helps researchers understand patient health trends, ultimately leading to more effective treatments. (March 1)

Osteoarthritis Patient-Focused Drug Development Meeting
Our groundbreaking OA PFDD meeting provided patients the opportunity to share their experiences and concerns, which will help inform the benefit and 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 our efforts to engage patients in all aspects of treatment development for arthritis patients.
(March 8, 2017)

JIA Patient-Focused Drug Development Meeting
Hundreds of patients and their families, FDA staff, industry leaders and researchers convened in Washington, DC, to participate in the JIA Patient-Focused Drug Development meeting on Aug. 2, 2018. A written report will be published in 2019.
(Aug. 23, 2018)

Better Experience of Care
The Arthritis Foundation puts patients at the center of everything we do. We partner with patients to help improve health care outcomes by shaping the research and health care system that serves them.

Rheumatology Learning Health System
To Improve the quality of care for people with arthritis, we are building 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 INJ), Stanford Health Care (CA), and Wake Forest Baptist Health-Brenner Children's Hospital (NC). (Feb. 9, 2018)

Cultivating a New Generation of Rheumatologists
The Arthritis Foundation awarded the following institutions $150,000 to expand their established fellowship programs. University of Washington, University of California, University of Alabama, Grant Riley Hospital for Children at Indiana University Health and the David Geffen School of Medicine, UCLA. (June 8, 2018)

PEER + COMMUNITY CONNECTIONS

To combat the isolation of arthritis, we connect thousands of people who understand the challenges of living with arthritis to share ideas, hope and knowledge. We offer support groups for adults, mentoring for teens, and activities and camps for kids and families.

Peers Supporting Peers
We create opportunities for people with arthritis to connect with and support each other, both in-person and online. More than 80 active Live Yes! Connect Groups offer support group meetings for adults and JA parents in communities across the country. (Feb. 11)

Expert moderators guide online community discussions for nearly 1,000 users. (March 1)

Each year, we connect thousands of families through JA Days and JA Conference, offering a way for them to network, share their stories and meet others going through similar challenges. In 2017, we launched iPeer2Peer, which matches young adult mentors and teens with JA.

Serving Kids and Families
In the U.S., an estimated 300,000 children have JA or other rheumatic conditions. For seven decades, the Arthritis Foundation has upheld our unwavering promise to assist them and their caregivers. We're boldly leading the JA fight, ensuring easy access to vital resources, community and care. In 2018, the Arthritis Foundation connected 6,621 JA families through JA Days, more than 40 JA Camps and JA Conference. We distributed 1,356 JA Power Pack backpacks. (March 1)

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. This year's JA Conference will be held in Houston from July 18-21 and Minneapolis from Aug. 1-4. (March 1)

Welcome to Campus

The Foundation is partnering with Alpha Omicron Pi (AOII) to launch the Welcome to Campus program on 144 college campuses in 2019. Last year, we hosted focus groups and interviews with students to provide input for the program, which will provide support for college students with arthritis. (Dec. 8, 2018)

Winterhoff Arthritis Scholarship

Eleven college students were 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. (June 28, 2018)

PURSUING A CURE

The Arthritis Foundation continues to lead and fund cutting-edge scientific investigation to bring new treatments to market faster and to discover more about arthritis and what can keep it from developing in the first place.

Childhood Arthritis and Rheumatology Research Alliance

Finding the best treatments for JA is challenging. Through our partnership with CARRA, we've invested $23.5 million over five years to collaborate on treatment plans and research to support families living with JA.

STOP-JIA Study

The STOP-JIA project (Start Time Optimization of Biologic Therapy in Poly-JIA) will compare outcomes of newly diagnosed children with polyarticular juvenile idiopathic arthritis, resulting in recommended strategies for personalized treatment plans when the study ends in 2019. CARRA has enrolled 403 children with poly-JIA since 2016, making this study the largest of its kind. (Dec. 14, 2018)

CARRA Registry Enrollment Pilot

Initial results from the research coordinator program funded by the Foundation to drive CARRA Registry enrollment show a 200 percent overall increase among the eight selected sites. (Oct. 31, 2018)

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, 2018)

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)

Osteoarthritis 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)

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, 2018)

FUNDING THE MISSION + ATTRACTING SUPPORTERS

The Arthritis Foundation brings communities together through events, educational opportunities and social media – to give people a platform for sharing their struggles and stories Yes. Our volunteer leaders take on important roles that truly make a difference, raising funds and bringing in volunteers and donors to help us make a stand against arthritis.

Major Gifts Be the One Campaign

Through the Be the One campaign, donors pledged more than $ 8 million since 2017. The Jane Wyman Trust match helped the Foundation raise more than $1.2 million since launching in 2018, making it the largest match in our history. (Dec. 31, 2018)

Special Events

As people connect in person at events, we can engage them in meaningful programming and create a powerful network of support, helping participants to gain confidence in themselves and, in turn, help others.

Walk to Cure Arthritis is our flagship fundraising event and the largest arthritis gathering in the world. The Foundation holds WTCA events throughout the country, engaging thousands of Warriors. Jingle Bell Run is the original festive race for charity, bringing people from all walks of life together to champion arthritis research and resources.