

Juvenile Arthritis – 75 Years of Progress

Kids Get Arthritis, Too.

Over 300,000 children in the U.S. live with juvenile arthritis (JA), a debilitating, painful disease that can impact the entire family. The condition can affect kids as young as just a few months old. There is currently no cure.

Despite a growing number of treatment options, there is a growing shortage of pediatric rheumatologists. Only 25% of children with juvenile arthritis have access to a pediatric rheumatologist, and they must travel an average of 57 miles to reach one.

This is a significant barrier to care and is an important issue the Arthritis Foundation is addressing. Access to pediatric rheumatologists is critical, as current treatments do not work the same way with children as they do with adults.

<u>Science</u>

When the Arthritis Foundation was founded in 1948, juvenile arthritis treatments were crude (e.g., aspirin, cod liver oil, iodide of iron) and patients were nearly guaranteed to experience deformity and loss of function. Many were wheelchair-bound.

Since the end of the 20th century, research from the Arthritis Foundation has supported an explosion of therapies for JA. Treatment options have grown from "aspirin" to the use of sophisticated therapies including biologics and biosimilars.

The Arthritis Foundation is addressing the urgent need for more pediatric rheumatologists through pediatric rheumatology <u>fellowships</u> and other workforce development programs.

Since 2002, the Arthritis Foundation has partnered with the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and invested over \$35 million in <u>research</u> aimed at improving outcomes in childhood rheumatic diseases.

<u>Advocacy</u>

To combat the pediatric rheumatology shortage — particularly in rural areas — the Foundation fought for the Pediatric Subspecialty Loan Repayment Program for over 10 years. In 2022, the Foundation helped secure funding for the first time at a combined \$15M for two years. This opens the door to future funding of more pediatric rheumatologists.



JA Patient Resources

JA Parents Connect Groups provide supportive social connections for parents/guardians of children. <u>Virtual Connect Groups</u> exist for parents of elementary, middle and high school kids with arthritis.

JA Power Packs equip newly diagnosed JA families with tools to help them battle arthritis together. Packs include informational brochures for parents, an age-appropriate book and more. <u>JA Power Packs</u> are available in Child, Pre-teen and Teen versions.

Medically supervised <u>JA camps</u> help kids with JA make lifelong friends, gain a greater understanding of their disease, increase independence and self-confidence, and discover new skills and interests. This year, 11 camps are offered in 10 states along with a national virtual camp.

JA Family Summit

The first National Juvenile Arthritis Conference (now JA Family Summit) kicked off in **1984**, bringing together children with JA and their families to learn, exchange tips, make new friends and have fun.

The Arthritis Foundation was a key player in passing the federal Children's Health Act of 2000, which focused research on juvenile arthritis and began closing the gap in the pediatric rheumatology shortage.

Parent Perspectives

In 2022, the Foundation issued our <u>first-ever report</u> on juvenile arthritis based on a collection of data provided by parents and guardians of JA patients. The report highlights the challenges of diagnosing childhood rheumatic diseases and the impact they have on children and their entire families.