Wins + Roundup

Winter 2019 Impact Report

Arthritis Foundation®

A Mandate for Action

A First Look at the Arthritis Foundation's Live Yes! INSIGHTS Findings

Arthritis Foundation®

Live Yes! INSIGHTS

A First Look at the Data

The Arthritis Foundation, with input from leading scientists, developed and executed a first-of-its-kind, patient-centered approach to select scientific assessment tools that were meaningful to patients.

This innovative selection process incorporated input from 110 patients, health care providers and measurement experts, and resulted in a research tool that uniquely puts relevant and meaningful data into the hands of national and community decision makers.

This report reflects the more than 18,000 Live Yes! INSIGHTS adult assessments collected through October 2019. This study, from across the country, provides an inaugural baseline of patient-reported outcomes and represents the **largest** effort of data collection in the Arthritis Foundation's history.

The Eye-Opening Realities of Arthritis

What we have always known is this: More than 54 million people have arthritis in America, making it the number one cause of disability. And that number is rising, with conservative estimates showing an increase to 78.4 million by 2040. The toll of this disease is summed up with more than $304 billion annually from total medical costs and earning losses as of 2013.

While these statistics give us plenty to be alarmed about, they tell us very little about the lives of those 54 million. People with arthritis deserve more; they deserve to be heard, understood, acknowledged and for action to be taken by legislators, product designers, care providers, key stakeholders and their families. As the largest organization dedicated to changing the lives of people with arthritis, it is our mandate to do that work.

In 2018, we began cataloging the real-world, real-time reporting from arthritis patients, collecting details about mood, pain intensity, sleep and experience of care. In the inaugural year of this ongoing, cross-sectional analysis, we received 18,000 assessments, making the INSIGHTS program the largest collection of data in our 70-year history and one of the largest in the world.

Fight for change with me,

Ann M. Palmer

Ann M. Palmer
President & CEO
Arthritis Foundation

PAIN CAN'T BE IGNORED. IT IS AN INTENSE AND CONSTANT PRESENCE.

of patient responders REPORTED PAIN over the last seven days — **with an average pain score of 5 on a 10-point scale.**

What a "5" on the Pain Scale Means

Moderately strong pain. It can't be ignored for more than a few minutes, but with effort you still can manage to work or participate in some social activities.*

92%

of patients reported that pain interfered with their day-to-day activities.

PATIENTS HAVE TROUBLE WORKING.

reported having trouble doing all usual work.
(including work at home)

Psoriatic Arthritis
patients are more impacted at 79%.

People in
Mississippi
are impacted even more at 84%.

American Indians or Alaska Natives
are impacted more than any other race at 81%.

THERE ARE UNMET NEEDS AND DISPARITIES IN CARE.

93% of patients reported that it is extremely important to get the help they need at their health care professional's appointment.

YET ONLY

57%

surveyed reported they got the help they needed.

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* Richards KL. The Pain Scale Chart: What It Really Means. ProHealth. Updated May 18, 2019. Retrieved from https://www.prohealth.com/library/what-the-pain-scale-really-means-34982

Thought Leadership

Taking CBD for Arthritis

Cannabidiol, or CBD, has grown in popularity over the last year as a potential remedy for everything from depression and sleeplessness to pain from chronic conditions. However, there has been no guidance on how to use CBD safely, until the Arthritis Foundation stepped up to develop the first – and only – guidance for patients.*

With more people turning to marijuana and CBD to manage their pain, it's critical that researchers study their effects on arthritis patients. This is one of the reasons why the Arthritis Foundation released guidelines for people with arthritis who want to try CBD – the first such guidance on using a cannabinoid-based ingredient from any major health-related organization.

"I think there's a lot of promise for CBD to be helpful for people with arthritis, and the more we view it in a thoughtful and judicious way, as a tool opposed to a panacea, the better," Kevin Boehnke, PhD, shared on the Live Yes! With Arthritis podcast.

ARTHRITIS FOUNDATION BOLDLY DRAFTS FIRST CBD GUIDELINES FOR PATIENTS

Cindy McDaniel, senior vice president of consumer health and impact, talks about the Arthritis Foundation's decision to release guidelines for using CBD to treat arthritis.

The Arthritis Foundation conducted a survey about CBD use last year. Did the results impact the organization's decision to create the CBD guidelines?

Yes, the survey results from last July did. But also, we listen to patients and what matters to them. We've been hearing questions about CBD for the last year. We've also started to hear it a lot from the doctors we work with, who were asking for guidance on how to answer their patients' questions about CBD. So, it was kind of a combination that caused us to say, "If someone's going to do something, it needs to be us."

> "The Arthritis Foundation is the first official organization to release guidelines… There hasn't been enough education on how to safely prescribe CBD for medicinal purposes and yet these same health care providers are getting asked by their patients for this product."
>
> \- Today Show

What were the key takeaways from the survey?

The biggest takeaway was the number of people who are either using or considering using CBD, which was 79%. When we asked what they used it for, treating pain was the top answer, along with anxiety and sleep.

Importantly, the survey told us what we already know: that people are using CBD whether they have firm guidance or not. As an organization, we felt an obligation to work with some experts who are doing research on CBD and step up and provide as much guidance as we could.

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*The leading experts are Kevin Boehnke, PhD, Daniel Clauw, MD, and Mary Ann Fitzcharles, MD.

The Arthritis Foundation doesn't endorse the use of CBD or dismiss the use of it. What are you hearing from patients about the guidance?
The guidelines very intentionally don't say, "Use this." What they say is, "If you are going to try it, here's how to do it safely." There isn't a cure for arthritis. In some cases, there aren't even great treatments. We want to give people living with chronic pain options.

The guidelines suggest that patients talk to their physicians to see if they are a good candidate for CBD. Do you think most physicians are informed about the risks of CBD?
There still is a knowledge gap. Our hope is a doctor will check the patient's other medications because they may have contraindications with CBD. Hopefully, the patient and doctor will work together to adjust dosages to best manage pain. We're also putting together a patient-oriented handout that physicians may want to give to their patients.

DRIVING ENGAGEMENT AROUND CBD

The Arthritis Foundation is the cause leader for people with arthritis. With the publication of our CBD Guidance, in just one week the Arthritis Foundation was mentioned by Today, Today.com, NBC Nightly News, Forbes and Healio.com, as well as hundreds of local media outlets.

433.9+ million
total impressions

64,271 **reached via social media posts mentioning Arthritis Foundation and CBD.**

1.8+ million
people on social media

CBD content on arthritis.org netted

24,000 page views
with an average time on page of 6 minutes.

What Are People Saying?

"I appreciate that the Arthritis Foundation is the first patient advocacy group to create guidelines for CBD usage. We need more forward thinking like this!"

FACTS

- CBD products became widely available with the passing of the 2018 Farm Bill, legislation that legalizes hemp, a variety of the cannabis plant. Since then, the task of regulating CBD products has fallen on the Food and Drug Administration, but so far the agency has not done so.
- Recent studies suggest that CBD could play a role in managing arthritis pain. Some people use CBD oil to relieve pain and inflammation associated with chronic conditions like arthritis. Currently, the FDA has approved CBD oil only for use in people with rare, severe forms of epilepsy.

Advocacy

Advocating for People With Arthritis

2019 was a landmark year for our advocacy work. From securing 26 new pieces of legislation in 20 states to supporting the introduction of the Safe Step Act, a bipartisan bill, positioning arthritis as a health care priority. We helped secure more than 135 state legislative victories in all 50 states, plus Washington, DC, since 2014.

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. See the progress our network of 150,000 Advocates and 1,400 Ambassadors made last year:

- The Congressional Arthritis Caucus grew to 146 members in the 116th Congress.
- Advocates sent more than 5,000 letters to policymakers, which is important because this is one of the most influential ways to amplify our voice.
- We held 16 State Legislative Days across the country. Through these events, more than 250 Advocates shared their stories with elected officials.

We urged legislators to curb step therapy. Because of our efforts, eight states (DE, GA, ME, OH, OK, VA, WA, WI) passed legislation to curb step therapy in 2019, bringing the total number of state-level step therapy victories to 28.

The Safe Step Act, which will reform step therapy protocols nationwide, has been introduced in both the House and Senate. H.R. 2279 and S. 2546 will ensure patients are at the center of policy. Combined, these two important pieces of legislation have 110 co-sponsors.

> We pushed for legislation to protect patients. The Arthritis Foundation joined 26 other industry leaders in issuing a statement in response to an announcement that a bipartisan, bicameral deal has been reached to hold patients and individuals harmless from surprise medical bills.

The bipartisan agreement reached by the Senate Committee on Health, Education, Labor and Pensions (HELP) and the House Committee on Energy and Commerce to protect patients and consumers from surprise medical bills is greatly welcomed. As patient and consumer organizations representing millions of individuals facing serious, acute and chronic health conditions, we have been advocating for legislation to protect the people we represent from the potential of massive medical debt caused by these surprise medical bills.

Representative Ami Bera, MD, met with representatives from the patient community, including the Arthritis Foundation, the Alzheimer's Association and the California Chronic Care Coalition, about co-sponsoring H.R. 2279, which relates to step therapy reform.

Arthritis Foundation Announces

New Podcast

To help people with arthritis manage everyday challenges and better understand their diagnosis, the Arthritis Foundation introduced the Live Yes! With Arthritis podcast during the American College of Rheumatology Annual Meeting in November. This one-of-a-kind podcast offers tips, tools and expert advice and is hosted by Arthritis Foundation staff members Rebecca Gillett, MS OTR/L, health messaging strategist, and Julie Eller, director of patient-centered strategies, both of whom are arthritis patients. Subscribe to the podcast and see more information on upcoming episodes, including topics like physical activity, reframing pain and workplace challenges.

Community Support

Tools and Resources

ARTHRITIS TODAY MAGAZINE

For the past 35 years, our award-winning magazine has helped make living with arthritis easier for more than 4 million readers. Here's a behind-the-scenes look at the Winter 2019-20 edition of *Arthritis Today*, which featured Eugenia Esquivel, a yoga instructor and RA patient.

Eugenia first felt unexpected soreness in the joints of her toes and balls of her feet about 19 years ago. Then her knuckles swelled, her fingers became hot and tight and she struggled to hold even a toothbrush. She was diagnosed with RA and ulcerative colitis, both autoimmune diseases.

"The hardest thing for me was not being in control of my body," she says. When working out in the gym became too hard, she discovered yoga. "I just fell in love with it," she says. She's continued ever since and enrolled in yoga teacher training.

The physical practice of yoga improves Eugenia's strength and mobility, while its mindful breathing and principles for living help her avoid stress-related flares.

"Yoga is for every body. It doesn't have limits of age or size," she says. "It's a practice that is for any- and everybody, any ability."

Thought Leadership

Leading Conversation at ACR Annual Meeting

The Arthritis Foundation had a strong presence at the 2019 American College of Rheumatology (ACR) Annual Meeting in Atlanta (Nov. 8-13, 2019), connecting with the more than 16,000 rheumatology professionals from more than 100 countries about the latest research in rheumatology.

DEVELOPING OA PATIENT-CENTERED GUIDELINES

Throughout the meeting, the Arthritis Foundation elevated the importance of the patient voice. As part of the gathering, the ACR and the Arthritis Foundation proudly presented new guidelines for the management of osteoarthritis (OA) of the hand, knee and hip. The guidelines were developed with input from OA patients to ensure that patients' experiences are considered during new drug development.

"Traditionally, the patient voice has been invoked, but not always present as guidelines are developed," said Guy Eakin, senior vice president of scientific strategy for the Arthritis Foundation. "Through our partnership, we were able to marry the ACR rheumatology expertise with the Live Yes! patient community to pioneer a process assuring guidelines that reflect the unique perspectives of the patients who will receive them."

The guidelines include recommendations, for which there is strong evidence of benefits, including weight loss, exercise, use of medical devices and aids and topical nonsteroidal, anti-inflammatory drugs.

"It's important as patients that we are able to provide input on these types of guidelines, since we're the ones living with the daily pain," stated Raquel Masco, a patient partner of the Arthritis Foundation who was present during the announcement.

REPRESENTING THE PATIENT VOICE

As part of the Arthritis Foundation's Patient Partners program at the ACR meeting, patient advocates were active with 10 influencer patients blogging, reporting live via social channels and presenting during the Patient Perspectives Poster Session. Patient partner Shannon O'Hara-Levi presented her poster titled "The Practice of Reiki and Meditation in Maintaining Medical Compliance and Decreased Anxiety in an Adult With Juvenile Rheumatoid Arthritis," which explored her experience of introducing Reiki and meditation to her care plan in addition to medication treatments and surgical interventions, enabling her to be more present in the care of her illness and work better with her medical team. This helps her stay more compliant with medications and medical appointments as her anxiety has decreased regarding the major parts of her life.

"It's truly powerful as a patient to attend this event and tell my story. Including patients in the conversation as a norm is a powerful way to improve outcomes and influence the direction of research, treatment guidelines and resource development," shared O'Hara-Levi.

Patient partner Nick Steen, who is also a military veteran, OA patient and JA dad, gave an inspiring presentation about his arthritis journey.

"In sharing my experience with my daughter, my partner in this journey, I have come to learn that this disease is not a sign of weakness," said Steen. "This disease does not care who you are or what you've done. It attacks us all – and so we all must take a stand against it together."

IMPROVING PATIENT OUTCOMES

During the ACR meeting, the Arthritis Foundation's efforts around patient engagement and scientific discovery were featured in oral presentations and presented posters. Guy

Eakin spoke about how the Arthritis Foundation, CARRA and the pediatric rheumatology community are working together to drive better patient outcomes. Four Arthritis Foundation-funded researchers presented poster abstracts, including:

- **Bruce N. Cronstein:** Adenosine A2A Receptor (A2AR) Stimulation Mitigates Mitochondrial Inflammaging, Enhances Mitochondrial Metabolism and Reduces Reactive Oxygen Species-Mediated Mitochondrial Injury In Vitro and In Vivo in Osteoarthritis
- **C. Michael Stein and Michelle J. Ormseth:** The Endogenous Plasma Small RNAome of Rheumatoid Arthritis and Gut Dysbiosis Is Associated With Measures of Early Vascular Dysfunction in Patients With Rheumatoid Arthritis
- **Xiaojuan Li:** Multi-vendor Multi-site T1p and T2 Quantification of Knee Cartilage
- **OA Center of Excellence:** Global Management of Patients With Knee Osteoarthritis Begins With Quality of Life Assessment: A Systematic Review
- **Martin Kriegel** presented sessions titled: ACR Basic Research Conference, Session II, I and ACR Gut Check Session.

Several projects were financially supported by the Arthritis Foundation through a partnership with CARRA:

- New Medications Are Needed for Children With Juvenile Idiopathic Arthritis
- Patterns of Ambulatory Health Care Utilization and Medication Adherence Among Transition-Age Youth With SLE
- Baseline Clinical and Serological Findings in Pediatric-Onset Discoid Lupus Erythematosus: Analysis of a Multicenter Retrospective Cohort Study
- (STOP-JIA) The Childhood Arthritis and Rheumatology Research Alliance Start Time Optimization of Biologic Therapy in Polyarticular JIA Study: Patient Characteristics, Patient-Reported Outcomes and Consensus Treatment Plan Choices
- Health-related Social Media Uses by Parents of Children With Rheumatic Diseases

LIVE FROM THE ACR ANNUAL MEETING

Throughout the conference, the Arthritis Foundation team shared key takeaways from sessions, posters and more.

We earned

119,411 impressions

during our ACR coverage across social media channels.

Hosting some 200 conference attendees at a "Welcome to our Hometown" reception at the Fox Theatre, the Arthritis Foundation's event included a keynote address from NBC National Media Correspondent and Assistant Professor of Rheumatology at NYU Langone, Natalie Azar.

According to Dr. Azar, "Often, patients don't feel like they are being heard by their health care providers, but they are the experts in how they feel and what's most important to them."

Key takeaways from Dr. Azar's presentation include:

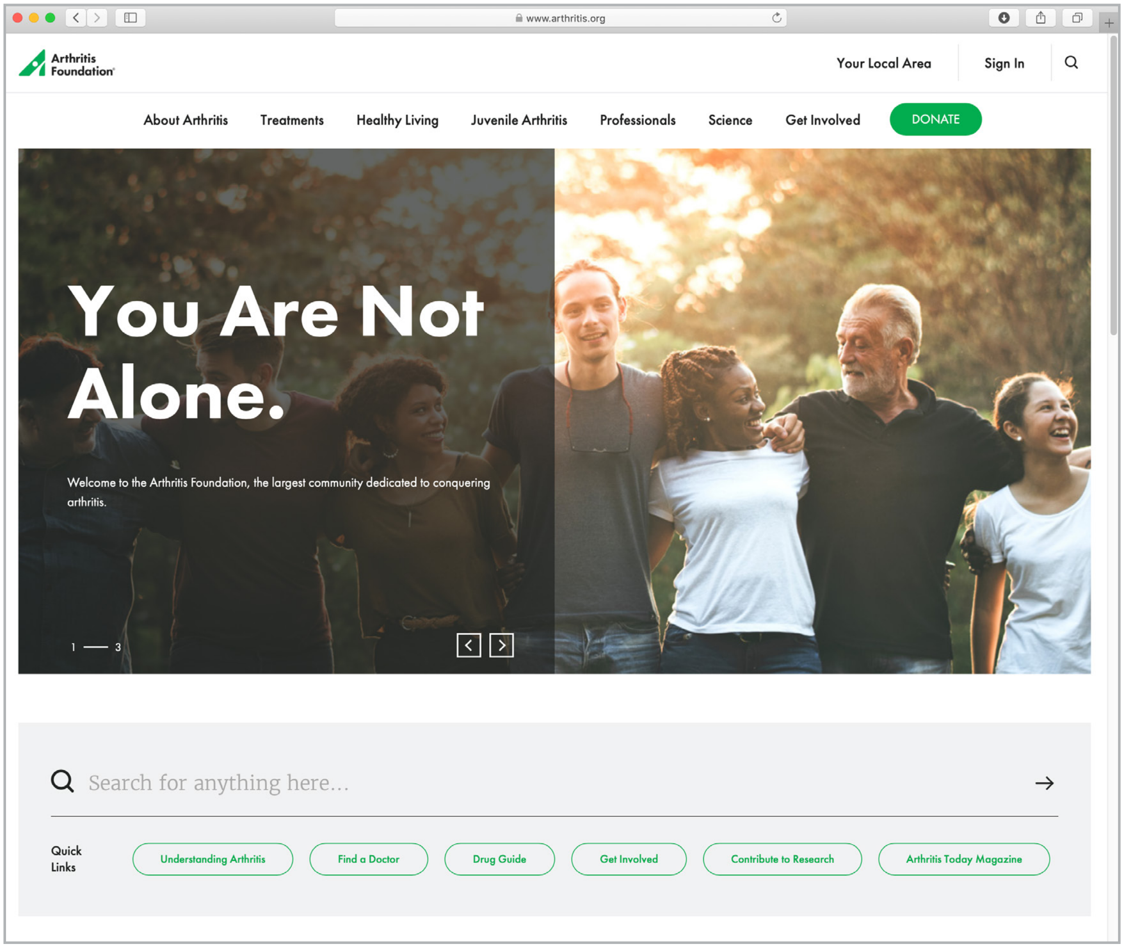
- **Pay attention to all symptoms, especially to ones that may seem nonclinical, like fatigue, stress and anxiety.**
- **When health care providers educate patients about their disease, they empower them to recognize early warning signs of symptoms that worsen their disease or weaken their ability to cope.**
- **Patients should keep talking to their doctor about fatigue symptoms and any post-exertion malaise.**

"Fostering open lines of communication between the doctor and patient is key to addressing the silent complaints in rheumatic diseases. Also, vitally important, is making sure you can advocate for yourself," continued Dr. Azar.

What's New:

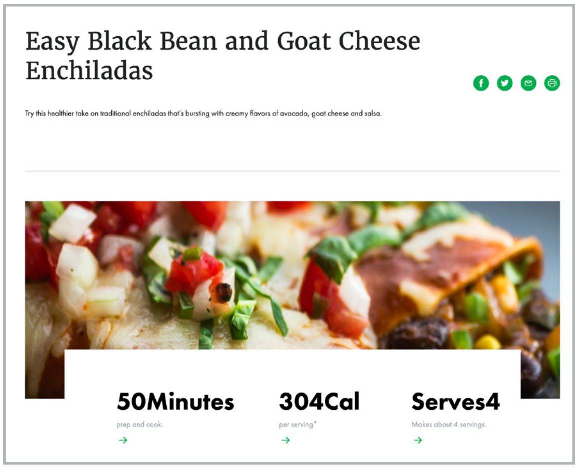
arthritis.org

The Arthritis Foundation is committed to be there when and where people with arthritis need us. With the rise of mobile technology, people are increasingly using online tools and social media to manage and inform their health care. In 2018, more than 63% of visitors to arthritis.org did so using their mobile devices. Our new website is now more mobile friendly, making it easier than ever before for people to connect with others who have similar stories, find tips for managing the disease and access information when and in the format they prefer.



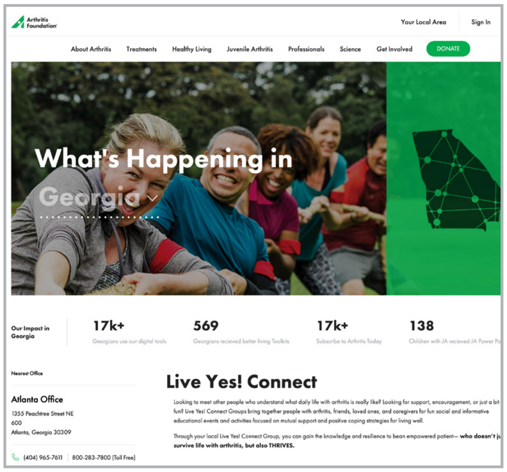
You Are Not Alone.

Welcome to the Arthritis Foundation, the largest community dedicated to conquering arthritis.



Easy Black Bean and Goat Cheese Enchiladas

Try this healthier take on traditional enchiladas that's bursting with creamy flavors of avocado, goat cheese and salsa.



Our Impact in Georgia

17k+	569	17k+	138
Georgians use our digital tools	Georgians recieved better living Toolkits	Subscribe to Arthritis Today	Children with JA recieved JA Power Pa

Nearest Office

Atlanta Office
1355 Peachtree Street NE
600
Atlanta, Georgia 30309
(404) 965-7611 | 800-283-7800 (Toll Free)

Live Yes! Connect

Looking to meet other people who understand what daily life with arthritis is really like? Looking for support, encouragement, or just a bit fun? Live Yes! Connect Groups bring together people with arthritis, friends, loved ones, and caregivers for fun social and informative educational events and activities focused on mutual support and positive coping strategies for living well.

Through your local Live Yes! Connect Group, you can gain the knowledge and resilience to bean empowered patient— **who doesn't ju survive life with arthritis, but also THRIVES.**

Live Yes! Conference of Champions Highlights

Some 500 Arthritis Warriors, top volunteers and patient partners gathered for the 2019 Live Yes! Conference of Champions from Sept. 13-15, 2019. This powerful networking opportunity is vital to helping more people with arthritis. Conference highlights included a preview video of the 2020 marketing campaign for the Live Yes! Arthritis Network and the Evening of Honors, which recognizes top volunteers.

Left to right: Michael V. Ortman; Rowland W. (Bing) Chang, MD, MPH; John L. Coalson Jr., Esq.; William J. Mulvihill; and Stanford K. Rubin, Esq.

Arthritis Foundation staffer Kevin Purcell (center), pictured with family members, received the Charles B. Harding Award for Distinguished Service.

Participants enjoyed networking, camaraderie and community connections.

Representatives of Alpha Omicron Pi Fraternity & Foundation received the Foundation's Corporate Impact Award.

Live Yes!

2019 Live Yes! Conference of Champions

Arthritis Foundation President and CEO Ann Palmer is pictured with supporters from the Independent Order of Odd Fellows & Rebekahs, who presented the Foundation with a $500,000 donation.

California Coast Classic Bike Tour

A lone cyclist rides along the scenic route from San Francisco to Los Angeles.

Named the Best Charity Bike Tour by Gran Fondo Guide, the California Coast Classic raised more than $1 million in funds for the Arthritis Foundation in its 19th year. Taking place along California's iconic Highway 1, 250 veteran and novice cyclists completed the 525-mile trek over eight days.

"Once my daughter was diagnosed with JIA, I knew I had to do something so I jumped right in. Each rider has a different connection to arthritis, and as part of this ride, we were riding with a purpose. The connection to this important cause made the journey down the coast much more meaningful," shared three-time rider, Raquel Olivo.

"As a participant, it was one of the most flawlessly executed events I have ever had the pleasure to be part of. It was a privilege and a pleasure to be with all of you, and the passion for this cause was evident in every element," shared first-year rider, Pantea Houshmand.

Team Carter celebrates at the finish line. From left to right: David Patin, Don Wood, Jerry Davis, Kyle Berg, Derek Engfelt, Bob Figari, Kevin O'Donnell. Front row center: Carter Forsyth.

Arthritis Foundation board of directors member Dennis Ehling, Peggy Ehling and Andy Miliotis take a well-deserved break.

Childhood friends Rob Kuntz and Ken Jeong enjoy a rest on day two.

The spectacular California coastline.

Conquering JA

Kids are incredibly different from adults, from their growing bodies to their developing minds. From the way that children are diagnosed, treated and the challenges they face, everything about their experience with arthritis is different.

The Arthritis Foundation understands the unique and pressing needs of families living with juvenile arthritis. Since 1984, more than 34,000 children and family members have benefited from our annual National JA Conferences.

In 2019, the Arthritis Foundation connected thousands of families through our JA programming.

1,099 JA Power Packs

2,554 campers at 38 JA camps

71 family day events

1,800 attendees at the Arthritis Foundation National JA Conference in Houston and Minneapolis

In the past 5 years, we've invested **$25 million to boost JA research through partnerships with the Childhood Arthritis & Rheumatology Research Alliance (CARRA) and other collaborators.**

Patients and caregivers reported a **43% increase in their ability to get the social support their child needs since attending the conference.**

What Are People Saying?

> "The information we took away from the experience was an absolute relief, and the people we were able to meet and share our stories together made the experience invaluable. We finally had answers for our confusion and feelings of hopelessness."
>
> - Donna Serna and Erika Moss, Seminole, Florida

2020 National Juvenile Arthritis Conference
Orlando, FL
July 23-26, 2020
Renaissance Orlando SeaWorld

Arthritis and Emotional Wellness

Managing life with arthritis can be complex and frustrating – for people living with arthritis and for those they are closest to. Research shows that feeling connected to other people can boost our emotional health and well-being.

Last year, the Arthritis Foundation connected thousands of people with arthritis in their communities and online.

LIVE YES CONNECT GROUPS:

Grew

50% from 74 to 111
Adult Live Yes! Connect Groups

Grew

317% from 12 to 50 JA Parent Live Yes! Connect Groups (Trained 141 adult group facilitators and 69 JA group facilitators)

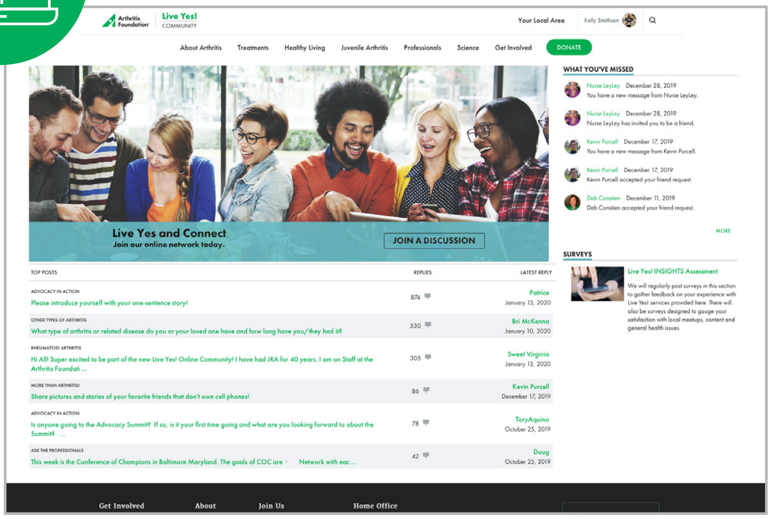
LIVE YES! ONLINE COMMUNITY:

Grew 233% from 1,500 to more than 5,000 Live Yes! Online Community registered users

Offering the largest forum group serving people with arthritis, featuring industry experts each week

What Are People Saying?

> "The Live Yes! Connect Group has been a great help to me. At a meeting my questions about depression were answered. I learned how inflammation in the body impacts the brain. It helped me understand the body-mind connection of arthritis and depression and when and how to seek help. It's also been a great way to meet and be with others who understand what it is like to have autoimmune arthritis."
>
> - Linda Halbeck
> Live Yes! Connect Group member



WHAT YOU'VE MISSED

Nurse LeyLey December 28, 2019
You have a new message from Nurse LeyLey.

Nurse LeyLey December 28, 2019
Nurse LeyLey has invited you to be a friend.

Kevin Purcell December 17, 2019
You have a new message from Kevin Purcell.

Kevin Purcell December 17, 2019
Kevin Purcell accepted your friend request.

Deb Constien December 11, 2019
Deb Constien accepted your friend request.

TOP POSTS	REPLIES	LATEST REPLY
ADVOCACY IN ACTION Please introduce yourself with your one-sentence story!	874	Patrice January 13, 2020
OTHER TYPES OF ARTHRITIS What type of arthritis or related disease do you or your loved one have and how long have you/they had it?	530	Bri McKenna January 10, 2020
RHEUMATOID ARTHRITIS Hi All! Super excited to be part of the new Live Yes! Online Community! I have had JRA for 40 years. I am on Staff at the Arthritis Foundati ...	305	Sweet Virginia January 13, 2020
MORE THAN ARTHRITIS! Share pictures and stories of your favorite friends that don't own cell phones!	86	Kevin Purcell December 17, 2019
ADVOCACY IN ACTION Is anyone going to the Advocacy Summit? If so, is it your first time going and what are you looking forward to about the Summit? ...	78	ToryAquino October 25, 2019
ASK THE PROFESSIONALS This week is the Conference of Champions in Baltimore Maryland. The goals of COC are · Network with eac ...	42	Doug October 25, 2019

SURVEYS

Live Yes! INSIGHTS Assessment

We will regularly post surveys in this section to gather feedback on your experience with Live Yes! services provided here. There will also be surveys designed to gauge your satisfaction with local meetups, content and general health issues.

ONLINE COMMUNITY CHANGES LIVES

The Live Yes! Online Community connects people who share the same everyday experiences. Doug Muench, an online community moderator, talks about his OA journey and why he got involved.

Why did you decide to become an Online Community moderator?

When I was approached about becoming a moderator, I agreed because I realized how useful the forum was, and I was interested in helping other users. I also wanted to give myself another reason to come back to the site frequently and continue learning.

What does it mean for you to connect with users in the Online Community?

I really enjoy meeting other users of the forum and helping direct them to useful information within the site and generate new comments and information from other users. Their insights and questions are unique and help me look at arthritis from new perspectives. Many new forum users are fearful and looking for answers to help them manage their pain, and I hope I can help with that process in some way.

How did it feel when you were diagnosed, and how does the Online Community help?

When I found out four years ago that I had OA in my hands, and then two years ago that my hip was showing signs of OA, I was fearful and worried. I was mainly concerned about my ability to stay active in my job and other areas of my life. I felt because of the sudden onset of symptoms that the OA would progress rapidly, and I would lose my ability to stay active.

What do you think are the benefits of the Live Yes! Online Community?

The forums provided me with connection to valuable, useful information from professionals as questions popped up from me and others. I was also able to see that my symptoms were not unique and that there are many, many people who struggle with osteoarthritis at my age or much younger.

Why have you decided to turn your arthritis into your call to action?

I've learned a lot of useful ways to manage OA and have shared some that I've developed with others. These are usually just simple tweaks that help me work better and get through the day with less pain. But they make a difference. I also enjoy reading ideas from others on how they manage things in their daily living. I look forward to continued involvement in the website and forum. I have a lot to learn and enjoy doing it. The website and forums are a very positive place to me that help a great deal. I have many people in my extended family and business contacts who are dealing with various forms of arthritis, and I've been able to direct them to the site and share valuable information and hope with them.

> "When I first found the Online Community, I had a lot of questions. So many moderators reached out to me and helped me start my journey. They showed me what tools I can use and where to find them. The one thing I love about connecting is that when I started posting, I immediately had other users help me right away. I was able to actually meet them in person at the LiveYes! Summit in D.C. These fellow Arthritis Warriors are now my friends for life, and I love supporting them as they do for me."
>
> - Brea Wiggins, Online Community moderator

Fundraising

Let’s Get a Grip on Arthritis

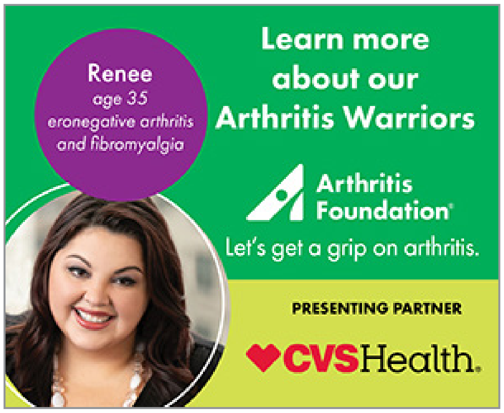
In its second year, the Let’s Get a Grip on Arthritis campaign reached more than

75 million Americans.

Press efforts included Clark Middleton from “The Blacklist,” who participated in a satellite media tour that included 24 interviews, reaching

25.7 million people.

And 4,326 photos were uploaded to our Cheerity photo-sharing activation.



Renee
age 35
eronegative arthritis
and fibromyalgia

Learn more about our Arthritis Warriors

Arthritis Foundation
Let’s get a grip on arthritis.

PRESENTING PARTNER
CVSHealth.

54 Million Americans live with chronic pain caused by arthritis

Our campaign partners are supporting our efforts to make life better by eliminating pain, instilling hope and conquering arthritis

Carson
Age 7
Juvenile Arthritis

Diagnosed with juvenile arthritis when he was just 15 months old, Carson is just one of nearly 300,000 children who have Juvenile Arthritis. While Carson initially struggled mostly in his knees, he also has limited mobility and increased pain in his wrists. While you’d think that pain would be a clear indicator of arthritis, for Carson and thousands of other children, getting a diagnosis was not that simple. The myth that arthritis is only for older people persists.

For more information visit arthritis.org/LetsGripArthritis

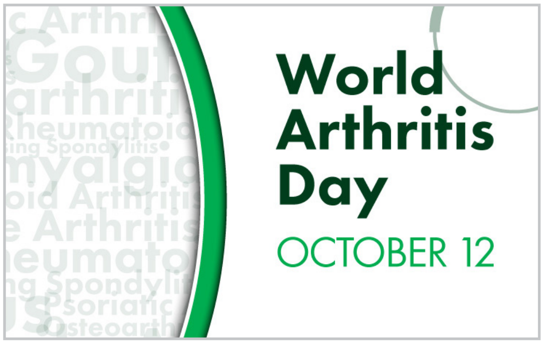
Arthritis Foundation | Let’s get a grip on arthritis.

Thank You to our partners for supporting the Let’s Get a Grip on Arthritis campaign!

PRESENTING PARTNER
CVS Health.

OFFICIAL JUICE PARTNER
cheribundi.

SUPPORTING PARTNER
ALEVE



WORLD ARTHRITIS DAY

As part of the Arthritis Foundation's World Arthritis Day takeover,

8 online influencers

were engaged to raise awareness.

DINNERS, DISHES AND DESSERTS:

Erin brought her story to life through her mother's struggle with arthritis. Sharing low-sugar options that helped her mom, **Erin's content was exposed to nearly 1M people and received nearly 1,000 engagements so far.**

RUNNING TO THE KITCHEN:

Gina is a master of delivering healthy meals in a beautifully crafted way. She shared her family's extensive battle with arthritis and served up a delicious salmon recipe, **reaching an estimated 307K people.**

HANDMADE CHARLOTTE:

Crafting experts Rachel and her team came up with a fun craft that shows followers how to modify knitting techniques if someone suffers from pain in the hands. **They reach an estimated 1M people across their platforms and have already received 400 likes on Instagram alone.**

SAWDUST GIRL:

Sandra spent the afternoon with one of our local office volunteers. The two had such a great rapport and the end result was a beautiful crafted, authentic piece. **Estimated total reach: 113K.**

TAMARA (LIKE) CAMERA:

Tamara shared her own experience with arthritis and how it has impacted her family. She nicely tied in our stats and encouraged her readers to take the INSIGHTS assessment. **Estimated total reach: 641K.**

OTTS WORLD:

Travel writer and blogger Sherry Otts recently traveled to Ireland with her mother and documented their journey the entire way – highlighting the challenges they faced due to their arthritis.
Estimated total reach: 146K.

KIDS ACTIVITIES BLOG:

Arena from Kids Activities blog shared her family's experience with arthritis and developed a simple craft that is perfect for those suffering from it, especially in their hands. **The video alone has already been viewed over 4,000 times, with estimated total reach of 5.1M.**

BEYOND FROSTING:

Julianne supported us again this year in the fight against arthritis. Only this time she offered a healthier dessert option for those with arthritis to try, along with tips and tricks to make prep even easier.
Estimated total reach: 902K.

Raising Awareness + Expanding Our Reach

The Arthritis Foundation is grateful to our celebrity ambassadors who lend their voices, time and talent to help us drive awareness around the struggles of living with arthritis.

Arthritis Foundation
@ArthritisFdn

.@Brad_B21 of the @Panthers excitingly chose the @ArthritisFdn as his nonprofit for the @NFL's "My Cleats, My Cause" campaign. "My grandmother has lived with arthritis – and all the pain and stiffness that comes along with the disease," says James. Thank you! #arthritis#WeLiveYes

1:23 PM - 12 Dec 2019

4 Retweets 9 Likes

4 9

James Bradberry – My Cleats, My Cause

Arthritis Foundation
@ArthritisFdn

The kickoffs and field goals are going to be a little more interesting in the @Colts game today at 1 p.m. as ALL-TIME great @adamvinatieri will be wearing these fantastic cleats! Thank you, Adam, for supporting the fight against #arthritis! #NFL #StrongerThanJA

7:29 AM - 8 Dec 2019

10 Retweets 37 Likes

10 37

Adam Vinatieri – My Cleats My Cause

Arthritis Foundation
@ArthritisFdn

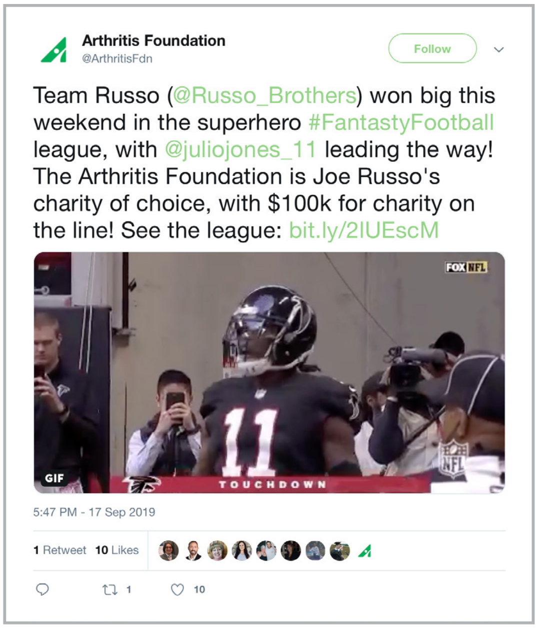
Broadway and TV star Ana Villafañe (@aanavee) is taking over our Instagram (ArthritisFoundation) today and showing us a day in her life in honor of #WorldArthritisDay tomorrow! Check it out! @NBCNewAmsterdam @NBCSunnyside 🙌 ❤️😍🌟 #WeLiveYes #StrongerThanJA

7:35 AM - 11 Oct 2019

15 Retweets 89 Likes

15 89

Ana Villafane – World Arthritis Day



Arthritis Foundation
@ArthritisFdn

Team Russo (@Russo_Brothers) won big this weekend in the superhero #FantasyFootball league, with @juliojones_11 leading the way! The Arthritis Foundation is Joe Russo's charity of choice, with $100k for charity on the line! See the league: bit.ly/2lUEscM

5:47 PM - 17 Sep 2019

1 Retweet 10 Likes

1 10

Joe Russo – Fantasy Football

Sue Decker
@C21Suesoldit

.@NatalieRacing Goooood Morning from .@NASCAR Gander Outdoors Truck Series .@HomesteadMiami Headed out for practice! Let's do this! .@DGR_Crosley @YamahaGolfCars @YamahaMotorUSA #N29technologiesllc #Yamahapowerproducts .@ArthritisFdn

6:20 AM - 15 Nov 2019

8 Retweets 143 Likes

Natalie Decker – NASCAR Driver

Taking the Lead

During the fourth quarter, the Arthritis Foundation had the opportunity to participate in several meetings with industry leaders, health care professionals and researchers.

The Arthritis Foundation's President & CEO Ann Palmer was appointed chair of the 2020 National Health Council's board of directors at the NHC's annual meeting on Dec. 10 in Washington, DC.

The National Health Council invited **Arthritis Foundation Senior Vice President Guy Eakin, PhD**, to speak to members of the Science of Patient Engagement Symposium Planning Committee about the challenges of helping patients learn to communicate with their health care providers and become partners in the decision-making process to achieve personalized care management.

Dr. Eakin spoke to the group of medical, scientific and research leaders from a variety of patient advocacy organizations, nonprofit health groups and industry on Oct. 29, 2019, at the Capital Hilton in Washington, DC.

> "Ann is a top leader in the patient advocacy community and has been an integral advisor on the NHC board, driving a revitalization of our brand in time for our 100th anniversary. Her enthusiastic leadership, in addition to the range of organizations represented by our new and returning board members, will enable NHC to thrive as we embark on our second century of putting patients first."
>
> - Marc Boutin, JD, chief executive officer of the NHC

Dr. Eakin served as a panelist to discuss the issues surrounding drug development for juvenile idiopathic arthritis (JIA) at a one-day workshop co-hosted by the FDA and the University of Maryland. The workshop, "Accelerating Drug Development for Polyarticular JIA," featured discussions and presentations about the regulatory aspects of drug development for this special population, as well as presentations on different study models that have been recently used in developing drugs for pediatric patients.

Ann Palmer spoke at the Osteoarthritis Foundation International (OAFI) Congress on Oct. 3.

Ann Palmer joined Mike Gladstone, global president of international medicine at Pfizer, for a Facebook Live event to talk about the struggles of living with chronic pain.

PEER REVIEW STUDIES PUBLISHED IN Q4

The first manuscript of the OA Patients Task Force was published. This group is an alliance of the Osteoarthritis Foundation International (OAFI) and the Arthritis Foundation in collaboration with leading international patient organizations. The paper summarizes scientific evidence on the impact of the knee on the quality of life of patients. BMC Musculoskeletal Disorders published our paper, entitled "Global management of patients with knee osteoarthritis begins with quality of life assessment; a systematic review," in October, authored by Guy Eakin, PhD, senior vice president, scientific strategy, and Deborah Scotton, MAT, research and health liaison.

Moving the Needle on Scientific Discovery

More than 50 years ago, crutches or canes were the only way to get around once rheumatoid arthritis or osteoarthritis destroyed a hip or knee joint. More recently, research has created artificial joints to replace worn-out joints with artificial ones and better pharmaceutical options to manage symptoms. There is still much discovery to be made to slow down the progression of the disease and to find cures to prevent it completely.

The Arthritis Foundation is working to speed up scientific discovery by convening the brightest minds worldwide – to bring new treatments to the market faster and ensure more people have access to health care in their community. We partner with academic and industry leaders, government agencies and other nonprofits to advance research. In 2019, we laid a solid foundation for pioneering a new era in scientific discovery.

"It is critical for the OA research field that we continue to engage and train new investigators," says Dr. Farshid Guilak, professor of orthopedic surgery and director of research for the St. Louis Shriners Hospital for Children. "They are the ones who will lead the development of new discoveries and treatments for OA."

The Arthritis Foundation and the Orthopaedic Research and Education Foundation (OREF) co-sponsored the first annual OA Fellows in Training (FIT) Bootcamp Sept. 19-21 at the Orthopaedic Learning Center in Rosemont, IL. Led by Arthritis Foundation funded-researchers, Farshid Guilak, PhD, and Richard Loeser, MD, the patient-centered program presented the work from at least a dozen innovative OA researchers, as well as OA patient perspectives on the types of research that are most important to them.

The program was an opportunity for new investigators and others to learn firsthand about patient priorities, best research practices and the most effective paths for transforming knowledge into advancements in patient care.

Dr. Loeser, director of the Thurston Arthritis Research Center at the University of North Carolina, adds, "Many advances in OA research have been made over the past 10 years. We are excited to share with the next generation of investigators, so that they have a solid grounding as they begin their research careers."

OA FIT Bootcamp

ARTHRITIS FOUNDATION-CARRA TRANSDISCIPLINARY RESEARCH GRANTS

The Arthritis Foundation funded our first two Childhood Arthritis and Rheumatology Research Alliance (CARRA) transdisciplinary research grants. These two-year grants are intended to support the development and implementation of a research project capable of advancing knowledge applicable to multiple pediatric rheumatic diseases. The grant awardees are:

Joyce Chang, MD, MSCE
Children's Hospital of Philadelphia
Measuring Post-Transfer Outcomes and Building a Framework to Implement Structured Transition Processes Across Rheumatic Diseases

Dr. Chang's project relates to care for adolescents with chronic rheumatic diseases as they transition to adult care.

Natoshia Cunningham, PhD
Michigan State University
A remotely delivered CBT intervention for youth with cSLE: A multi-site patient-engaged investigation

Dr. Cunningham's study will examine cognitive behavioral therapy as a way for kids with childhood-onset systemic lupus erythematosus to manage fatigue, pain and depression.

Cultivating a New Generation of Rheumatologists

Over the last few decades, the arthritis community has made enormous strides in helping patients. However, because many rheumatologists are retiring and not enough new students are choosing to practice rheumatology, the U.S. is currently experiencing a shortage of these specialists. Today, there are only 5,000 practicing rheumatologists in the United States, mostly concentrated in urban areas. Research shows this shortage will only worsen, even as the demand continues to grow.

"The biggest challenge is the ability to have more training programs for rheumatology specifically in regions of the country that have a greater shortage," says Sharad Lakhanpal, MD, past president of the American College of Rheumatology. The Arthritis Foundation is working to close the gap on the nation's rheumatologist shortfall through our fellowship initiative. Thanks to the generosity of our donors, we can ensure access to the right medical care for the millions of Americans with arthritis.

MEET FOUR OF OUR NEWEST FELLOWS

Sabina Ratner, MD

SUNY Downstate Medical Center, Brooklyn, NY

Arthritis Foundation Adult Fellowship Program

Dr. Ratner is a welcome addition to this program. She began her undergraduate training at Brooklyn College, then completed graduate training as a physician's assistant at SUNY Downstate in NY. She earned her medical degree from American University of Antigua College of Medicine in Antigua and Barbuda.

"It is exciting and gratifying to help improve the quality of lives of others," she says. "While the clinical experience is important to me, I'm also interested in pursuing biomedical research. Fundamentally, I am intrigued by the immune system. With the advances in disease-modifying agents and with new immunotherapies, we can improve patients' lives. That's why I hope to follow my passion and become a rheumatologist."

Already serving a diverse community, the Arthritis Foundation Adult Fellowship Program at SUNY Downstate Medical Center plans to introduce a new element in their rheumatology training. This innovative program will address the needs of young adults who are transitioning from pediatric to adult care through collaboration with rheumatologists, urban health planners, the city of Brooklyn and the Arthritis Foundation.

Matthew Clark, MD

Vanderbilt University Medical Center, Nashville, TN

Arthritis Foundation Pediatric Fellowship Program

Dr. Clark aims to build a niche in treating children with early immune symptoms that occur because of immune deficiency. During his pediatric residency, Dr. Clark served on the graduate medical education committee at Vanderbilt and was awarded the Most Outstanding Teacher Award in 2016. He then completed a chief residency in 2017. "I hope to build a career in pediatric rheumatology as a clinician educator," he says. "My goal is to develop a role in educating all levels of learners, using modern technology to increase learner engagement, retention and clinical skill in pediatric rheumatology."

The rheumatology training program at Vanderbilt serves a large area, including Appalachia, a region grossly underserved in health care in general. Dr. Clark is passionate about this program because it allows him to work with a disadvantaged population while developing innovative training programs.

Vanderbilt University Medical Center plans to develop further use of innovative technology and telemedicine to tie together its adult and pediatric programs. Thanks to the generosity of our donors, Dr. Clark will help bring us closer to a cure through this fellowship program.

William D. Soulsby III, MD

University of California, San Francisco

Charles F. and Marilyn Meier Pediatric Rheumatology Fellowship Fund Award (2019-2020)

Dr. Soulsby earned his medical degree from St. Louis University School of Medicine, then completed the internship and residency programs in pediatrics at UCSF. During his residency, Dr. Soulsby's research focused on the effects of poverty in disease activity in juvenile idiopathic arthritis (JIA), the most common form of juvenile arthritis.

"I hope to continue my career as a clinician and clinical researcher to further the field of pediatric rheumatology," Dr. Soulsby says. "Clinically, my interests are focused on JIA and systemic lupus erythematosus.

"From a research perspective, I'm interested in the complex intersection of chronic rheumatic disease, psychosocial determinants of health and how these are related to patient outcomes and predict disease activity and severity."

The Charles F. and Marilyn Meier Pediatric Rheumatology Fellowship was created because of Marilyn Meier's diagnosis of lupus at age 12. She and her husband seek to ensure prompt diagnosis and proper care for children with autoimmune diseases, as well as high-level research to better understand these diseases.

Uptej Khalsa, MD

Sanford University

Arthritis Foundation's Jessica Saal Bequest (2019-2020)

Dr. Khalsa earned her medical degree at St. George's University School of Medicine in Grenada, West Indies, and completed a pediatric residency at Children's Hospital of New Jersey in Newark. During her fellowship, Dr. Khalsa plans to improve how doctors, patients and their families communicate about treatment options.

"My fellowship research is focused on studying how families and health care providers of children with chronic rheumatologic conditions interact with a new digital health platform called OurNotes," she explains.

OurNotes engages patients and their families through mutual clinical progress notes. It aims to identify and prioritize the patient's most pressing concerns, bringing providers, patients and their caregivers closer together.

"OurNotes has the potential to improve the delivery of health care in pediatric rheumatology settings," Dr. Khalsa continues. "We want to understand how to effectively and practically engage families so it's meaningful to them."

This fellowship award is funded by the Saal family in memory of their daughter Jessica, who died in 2004 at the age of 34 from complications of juvenile rheumatoid arthritis. Jessica Saal served on the executive board of the Arthritis Foundation in the northern California region and actively supported legislation for funding arthritis research and increasing availability of prescriptions for arthritis.

Making an Impact in 2019

Arthritis Foundation®

The Arthritis Foundation takes on the biggest challenges facing people impacted by arthritis, creating a movement to galvanize the arthritis community and change the future of arthritis.

Through the **Live Yes! Arthritis Network**, we connected people online and in person.

10,000 people
participated in the Live Yes! INSIGHTS assessments, one of the largest-of-its-kind patient-reported outcomes studies.

There are now

150
local Live Yes! Connect Groups
in communities across the country.

WE CONNECTED
389 families living with juvenile arthritis at the **JA Conference**, which hosted
1,800 attendees.

WE HOSTED
2,554 campers at
38 JA camps.

TOGETHER, WE SECURED

26 state legislative wins in 20 states,
supporting legislation to curb step therapy in eight states, bringing the total number of victories to 28.

Serving as the leading organization focused on arthritis, we developed the first

CBD
Guidance for Adults With Arthritis.

WE LAUNCHED THE
Live Yes! With Arthritis Podcast.

WE'RE CLOSING THE GAP on the **rheumatologist shortage through our fellowship program, reaching underserved communities.**

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To Learn More About the Live Yes! Arthritis Network, Go to arthritis.org/LiveYes

SAVE THE DATE

National Juvenile Arthritis Conference
July 23-26, 2020
Orlando, FL

Live Yes! Conference of Champions
September 24-27, 2020
Kansas City, MO

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