

# RESILIENCE

2020 ANNUAL REPORT



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# 2020 was a year unlike any in modern times.

We all experienced the many challenges of the coronavirus pandemic. Yet, thanks to the arthritis community banding together, we powered through the hurdles and emerged stronger and more resilient.

Despite setbacks, including reduced financial support and the painful budget and staff reductions that resulted, the Arthritis Foundation and our committed contributors quickly bounced back. Our collective ingenuity and determination got us through it all. Because our mission is so important.

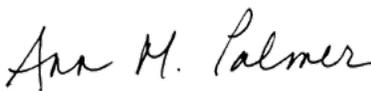
Volunteers have been our lifeblood since the Arthritis Foundation started seven decades ago. We created the Live Yes! Arthritis Network so we could reach more people and scale our delivery by being more volunteer-driven. The pandemic forced us to accelerate the plan.

We have a lot to be proud of in 2020, despite the adversity we faced.

- On the research front, we made tremendous progress in advancing solutions for osteoarthritis and inflammatory arthritis.
- On the advocacy front, we led the way in passing important policies and laws to make access to health care easier and more equitable.
- For families living with childhood arthritis, our programs remained strong and patient-centered.
- Opportunities to connect with others going through similar experiences were more possible than ever to foster courage and encouragement.

Helping patients more effectively manage their arthritis pain is a top priority of the Arthritis Foundation now and in coming years. That's what patients say they need most. And our commitment to finding a cure is still our very top goal.

In this 2020 Annual Report, you'll read about the progress we've made and continue to make. Thank you for saying Yes to conquering arthritis. This is our fight together — and our fight to win!



**Ann M. Palmer**  
Arthritis Foundation President & CEO



**Frank P. Longobardi, CPA**  
Arthritis Foundation Board Chair



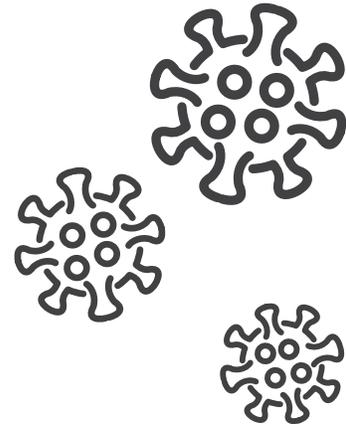
“Heightened anxiety led to increased fatigue. The constant fear, worrying and staying inside led to more depressed days than prior to the pandemic. It’s a recipe for super fatigue and takes a toll.”

—Katie in Maryland  
psoriatic arthritis & ankylosing spondylitis

# REINVENTED

## Going With the Flow

The coronavirus pandemic changed the world around us. Like most organizations and companies, the Arthritis Foundation had ambitious plans in place to move our mission forward in 2020. Instead, we suddenly had to pivot and adjust. Yet we kept our focus on what was still most needed to best support the arthritis community.



We quickly created our *Care & Connect page* on arthritis.org to make sure arthritis patients and their families were kept up to date on the latest advice, self-care tips and other important information regarding the coronavirus. We partnered with top experts around the country to ensure that timely and accurate information was being shared. There were over 200,000 webpage views; in addition to this 24/7 resource, email alerts went to those who requested to be notified as new information was released.

We're continuing to keep this page updated with the latest COVID-19 news. Other resources we provided in 2020 and beyond offered further support: Facebook Live events, webinars, podcasts, e-books, e-newsletters and more. It's all part of our promise to keep you informed and inspired.

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### Survive & Thrive

In April 2020, comedian Matt Iseman teamed up with football icon and pro championship winner Rob “the Gronk” Gronkowski and more celebrities to host *Survive & Thrive: Together in Isolation*. This engaging online fundraiser, sponsored by CBDMEDIC®, brought our

community together to raise \$240,000 for arthritis research and resources, including money donated through the special COVID-19 emergency response Giving Tuesday Now campaign the following month.

The Gronk said: “This is about helping our parents,

grandparents, next-door neighbors and people of all ages with compromised immune systems who are struggling more than ever with the dangers of COVID-19 and its crippling isolation. We can make a real difference by reaching out to them.”



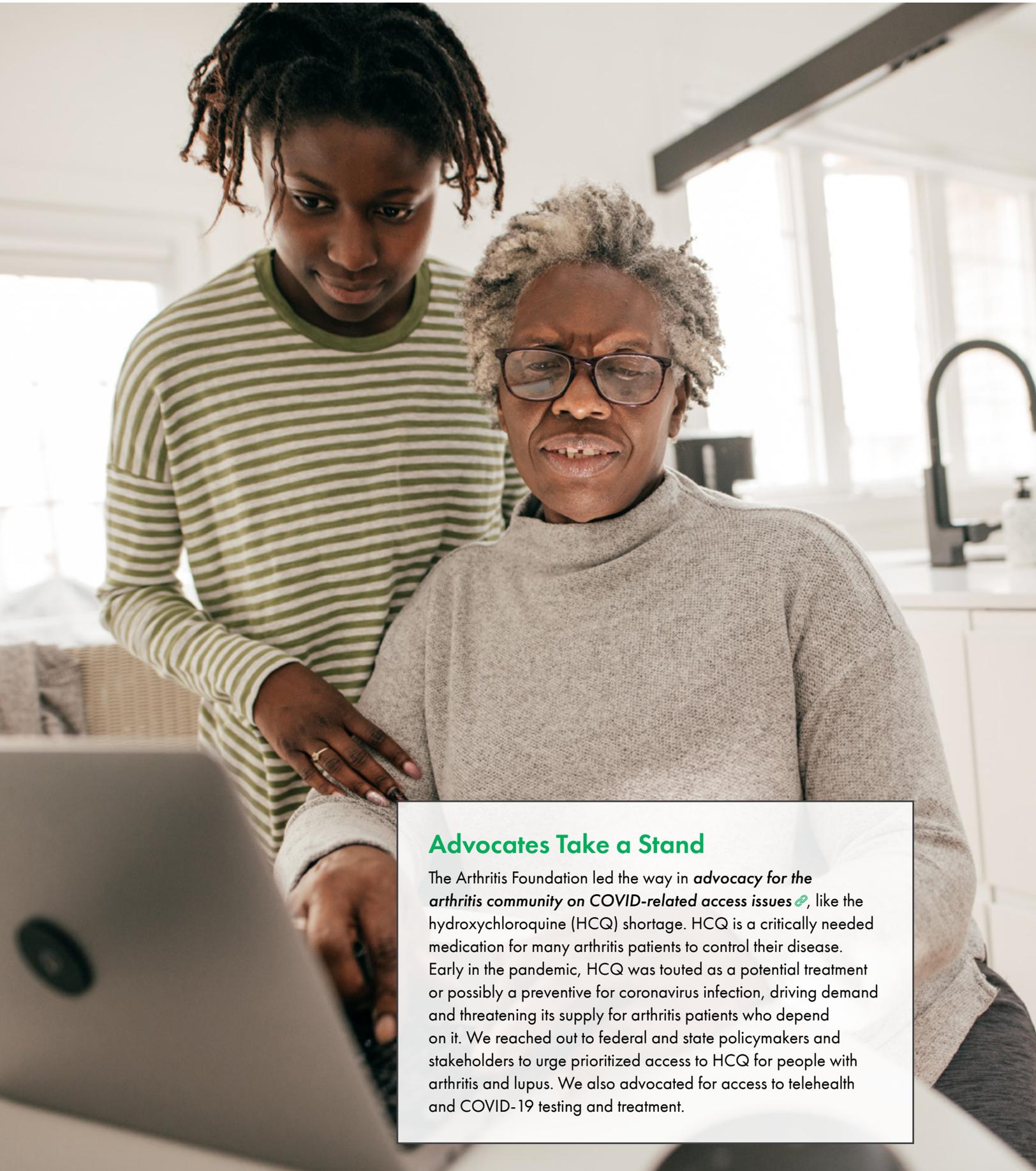
Rob “the Gronk”  
Gronkowski



Matt Iseman

“I love the community that we’ve built in the Arthritis Foundation, where you have all these people who understand the challenges we face.”

—Matt Iseman



## Advocates Take a Stand

The Arthritis Foundation led the way in *advocacy for the arthritis community on COVID-related access issues* [👉](#), like the hydroxychloroquine (HCQ) shortage. HCQ is a critically needed medication for many arthritis patients to control their disease. Early in the pandemic, HCQ was touted as a potential treatment or possibly a preventive for coronavirus infection, driving demand and threatening its supply for arthritis patients who depend on it. We reached out to federal and state policymakers and stakeholders to urge prioritized access to HCQ for people with arthritis and lupus. We also advocated for access to telehealth and COVID-19 testing and treatment.

## Volunteers in Action

### Texas Volunteers Drive Jingle Bell Win

When COVID restrictions shut down the ability to gather in crowds for Jingle Bell Run, one of our most important fundraisers, staff and volunteers nationwide were put to the test. In South and Central Texas, volunteers proved their resourcefulness and creativity. They hosted a Jingle Bell Drive in San Antonio, where participants were able to safely stay in their cars and drive through a holiday light display.

“Dr. Thomas Rennie of Rheumatology Associates of South Texas knew that it was important to bring our arthritis community together in a safe, socially-distanced way,” says Angie Billingsley, senior executive director of Central, South and West Texas. Dr. Rennie, the local medical advisory chair and corporate chair, proposed a Jingle Bell Drive.

Local volunteers reached out to Santa’s Ranch, the largest drive-through holiday light show in Texas. The folks at Santa’s Ranch were so moved by the amazing arthritis warriors they met and inspiring stories they heard that they not only donated



use of the ranch, but they even gave out free hot chocolate to every participant.

Volunteers used the opportunity to spotlight not just a few honorees; instead, they honored people with different types of arthritis to raise awareness of the many forms of arthritis there are. A local marketing company donated videos of each of the honorees and of the event at no cost, and sponsors were on site to provide information.

The event ended up being the most successful Jingle Bell fundraiser the market has ever had. It was the No. 1 Jingle Bell event in Texas and No. 3 in the country, raising more than \$141,000.

For his leadership in this event and his dedication to the Foundation and people living with arthritis, the Arthritis Foundation recognized Dr. Rennie with a Champion Award.



“People with arthritis need educational resources and emotional support. They need community, and they need to belong. That’s why I’m involved with the Arthritis Foundation.”

—Dr. Thomas Rennie



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## Arthritis Champion

### Back to the Future

Anh Nguyen has seen a lot of changes in almost 10 years of volunteering in Houston, but this past year has been one of the toughest. She has responded by renewing her commitment and redoubling her efforts to help people living with arthritis — like her father, who was diagnosed with rheumatoid arthritis (RA) in his late 50s.

“I saw how difficult it had been for my dad before he was diagnosed correctly,” Anh recalls. “Once they figured it out and found the right biologic, it was night and day.”

Anh, a marketing consultant, has been an active Arthritis Foundation volunteer since 2012. “I wanted to be involved because I didn’t want anyone else to go through what my dad did. But I knew others had gone through it, and I wanted to find that community and resources.”

For the past several years, Anh has served on the local leadership board. She stepped in when the previous chair resigned in 2020 and was elected to the position in March 2021.

The pandemic brought many challenges. All major fundraising events were canceled, and virtual events were much smaller.

“It was a huge blow to us in the Houston market,” Anh says. “We were headed into hitting that million-dollar mark, and all the work we had been doing for four or five years came to a screeching halt. And then to lose the staff members; it was challenging, heartbreaking, and many of us felt, ‘How are we going to move forward?’”

They have, thanks in part to Anh’s resolve and experience. “We’re lucky to have core volunteers who have been



Anh Nguyen

here through thick and thin.” Sponsors have stayed loyal and have committed to continuing support into 2022, and Houston is hosting virtual open houses to recruit volunteers.

“When I started, it really was volunteer-led. We only had one or two staff members, so a lot of the responsibilities fell onto volunteers. I feel like we came full-circle a decade later,” but with better resources and organization, she says.

# RESOURCEFUL

## Unleashing the Power of Volunteers

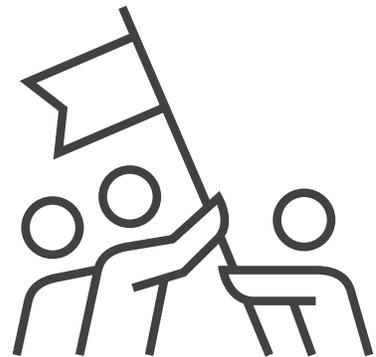
**Arthritis Foundation volunteers are — and have always been — the lifeblood of our mission.**

A few years ago, we dreamed of creating a scalable movement of connected and empowered communities of hope and action. While the pandemic influenced our steps in getting there, it didn't alter our destination. But it helped us get there faster.

We embraced our founding tradition of being an organization that doesn't just welcome volunteers; we also empower them to use their skills, passion and reach. In 2020, we put into place a system that equips volunteers with the framework, resources, training and tools so they can use their own ingenuity and creativity to best meet their local community's needs.

We've shifted our focus from delivering services to driving connections and empowering our communities. This will deepen and broaden our collective reach, steadily expand our volunteer base and open new doors to dollars needed to fuel our mission.

This was a defining moment in the history of the Arthritis Foundation. Our unprecedented challenges were tempered by the opportunity to emerge stronger than before.



### Volunteer-Driven

Empowered over 3,500 volunteer leaders to lead the fight against arthritis with customized plans for their local communities.

## Volunteers in Action

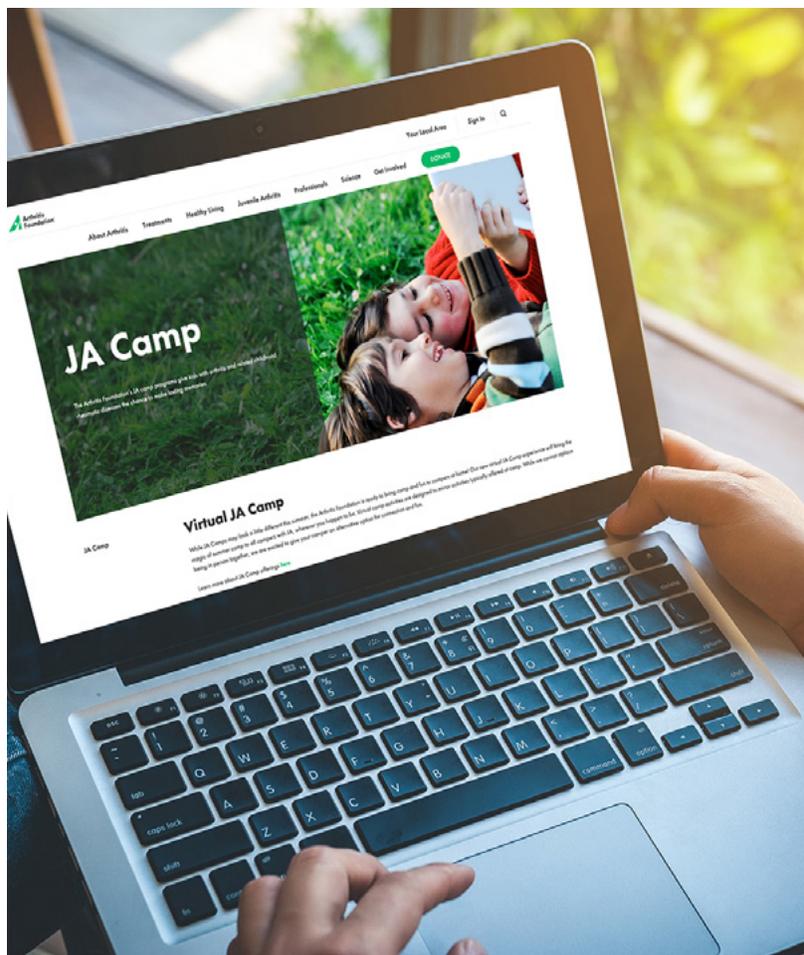
### JA Camps in Transition

Camp JRA in Pennsylvania is a great example of how Arthritis Foundation volunteers pulled together in 2020 to continue *making a difference in the lives of JA kids and their families* 🌱.

Camp JRA started in 1995, thanks to the dedication and commitment of volunteers Patricia Rettig and Annette Myarick, who wanted kids with JA to have an authentic summer camp experience.

Since the camp's early years, arthritis science and medications have advanced so much that the program is able to provide more diverse activities, including a climbing wall, ropes course and zip line. Most summers, the camp hosts up to 100 campers, plus 45 volunteers.

Last year, they had to shift to a virtual format. The dedicated volunteers — many of whom have been involved in camp since they were young campers — remained focused on providing fun activities and educational programs to help participants manage their condition while feeling empowered to advocate for themselves and others.



Thanks to a whole team of volunteers, this JA camp, like many others, is making a big impact.

As a volunteer camp leader, Caitie Dailey is celebrating her fifteenth year of being involved in Camp JRA, starting as a camper at age 13. “JA camp gave me a sense of independence that

I’m not sure I would have had otherwise,” she says.

Brian Galibinski, who attended the very first session of camp and is now a JRA camp volunteer, sums it up this way: “JA camp helped me see I could do anything I want. I want kids to benefit like I did. It made such a difference in my own life.”

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—Brian Galibinski

## Arthritis Champion

### Kwame Gets Things Done

When Kwame Mensah became chair of the Washington, DC, local leadership board in January 2020, he didn't know how challenging the year would be. But he was right for the job: resourceful, collaborative and not afraid to push the envelope to get the job done.

"I'm not the biggest fundraiser guy, but what I can do, and I think I do well, is I engage people," says Kwame, a patent attorney with a pharmaceutical and biotechnology company. "I personally believe you can ask someone for money, and they'll donate once. But if you get them to commit to the effort, then they'll donate multiple times."

He and his family have been committed since they were introduced to the Arthritis Foundation in 2017, the same year his daughter, Nyla, who has juvenile arthritis, was Jingle Bell Run honoree. Dori, his wife, became an active volunteer and co-chair of the JA committee. "Being a parent of a child with arthritis, it's personal to us," Kwame says.

In 2019, the DC market hosted its first gala, which was a big success, but COVID stopped a 2020 in-person sequel. By the end of 2020, "People were 'Zoomed out,'" Kwame says, and despite doubts that a virtual gala would succeed, they pushed ahead. "In my mind we absolutely had to do it because we have to keep these people engaged," he explains.

"We kept it really short. We said, 'Look, it's 20 minutes. Dial in, watch it, donate.' It worked really well for us. We had a lot of engagement," he says.

They're trying innovative ways to increase participation in the INSIGHTS surveys, too. "We're working on getting iPads or tablets at various rheumatologist offices — both children and adults — so folks can do the survey right while they're sitting there," he says. And they've started increasing their reach to underrepresented populations by launching a *Connect Group for the large community of veterans with arthritis*.



Nyla & Kwame Mensah

Each volunteer brings their own ideas, resources and leadership. Kwame simply acts as a conductor, he says. "I'm here to bounce ideas off of, I'm here to be creative with people, but I'm not here to set the agenda. The agenda is being set by the collective."



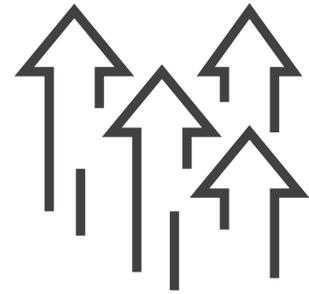
Kwame's Jingle Bell Run team stands up for his daughter, Nyla (center), and other JA families.

# RENEWED

## Advancing Mission Priorities

The Arthritis Foundation's core pillars anchor our mission. The following are some of the victories we achieved together in 2020 — to advance treatments and a cure, improve access to affordable health care and support families who are navigating childhood arthritis.

We're not just fighting to end arthritis in our lifetime. We're also finding ways as a community to get the most out of everyday moments.



### Changing Lives Through Arthritis Research

The Arthritis Foundation's scientific agenda is robust and strategic. The *research initiatives* we're investing in are grounded in what patients tell us they need the most. We aim to accelerate research and make new treatments available

sooner. More than 100 scientists we're funding nationwide are digging into possible solutions.

Osteoarthritis affects over 30 million Americans. It develops not only as people age but also at younger ages from injuries

incurred from such activities as sports, military duty and manual labor. The Arthritis Foundation is committed to *finding remedies for OA* as well as therapies for autoimmune inflammatory forms of adult and juvenile arthritis.

### ► Research Milestones

The collaborative **Osteoarthritis Clinical Trial Network** we're leading at 11 research sites around the country is setting the stage for accelerated development of new clinical trials. We're working to reduce the timeline for testing and approval of effective OA treatments.

We brought together 1,200 participants and prominent expert speakers for our OACS (Osteoarthritis Clinical Studies) forums throughout the year.



FAST OA took root as a clinical cohort study to identify knee injury characteristics that rapidly develop into OA.

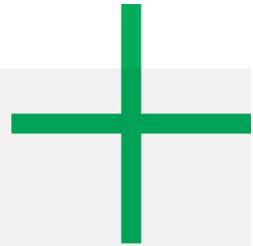
We expanded our research investment to fund the work of 15 scientific investigators for OA.

## ► Plus

We supported the Foundation for the National Institutes of Health (NIH) Biomarkers Consortium and several of its studies of arthritis biomarkers.

These include recommendations to the FDA for:

- Predictive biomarkers of cardiovascular risks in rheumatoid arthritis patients
- Qualifying biomarkers for OA drug development



We urged exploring biological pathways to better understand several forms of arthritis, as a partner in the \$53 million initiative, Accelerating Medicines Partnership, for RA and lupus, with the NIH and the Foundation for the NIH.

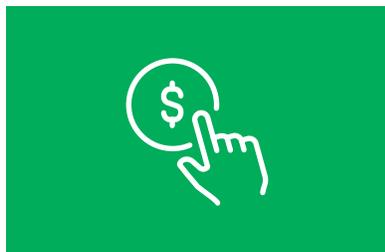
We continued to fund the CARRA Registry, which aims to understand the long-term outcomes as well as the long- and short-term safety and effectiveness of medications used to treat pediatric rheumatic diseases.

- In 2020, the registry enrolled thousands of juvenile arthritis cases. In addition, we funded investigator-led basic, translational and clinical research studies in pediatric rheumatology jointly with CARRA (Childhood Arthritis and Rheumatology Research Alliance).
- The CARRA Registry is the largest database of kids battling childhood arthritis, driving ongoing research.

We're helping train new rheumatologists through our **fellowship program**  to fill the gaps in specialists who will treat future generations, especially in underserved areas.

## ► Research Funding

In 2020, we funded \$11 million in arthritis research projects, augmenting our total investment of over \$500 million over the past seven decades.



Our strategic funding supported unmet medical needs and the scientific priorities you see in this report. We're focused on making faster progress.



We awarded five new rheumatology fellowships, bringing the total to 16.



We funded 36 research grants across 18 states

## Arthritis Advocacy on the Move

The Arthritis Foundation invites everyone to get personally involved in conquering arthritis by standing up and speaking out. Our community has made significant progress over the years —

shaping policies that benefit patients through improved health insurance coverage and passing important legislation locally and nationally to assure access to quality health care.

The power is in your hands to change the future of arthritis today. We're working together to help everyone *find their voice to advocate* for the things that matter most to the arthritis community.

### ► Advocacy Milestones



The year ended with a major victory when the No Surprises Act was passed by Congress. Arthritis Foundation Advocates firelessly lobbied to enact this law, which will help protect patients from expensive medical bills they don't expect because they were never told. In addition, the Pediatric Subspecialty Loan Repayment Program was reauthorized, which helps address shortages of pediatric rheumatologists in underserved areas.

### ► Plus

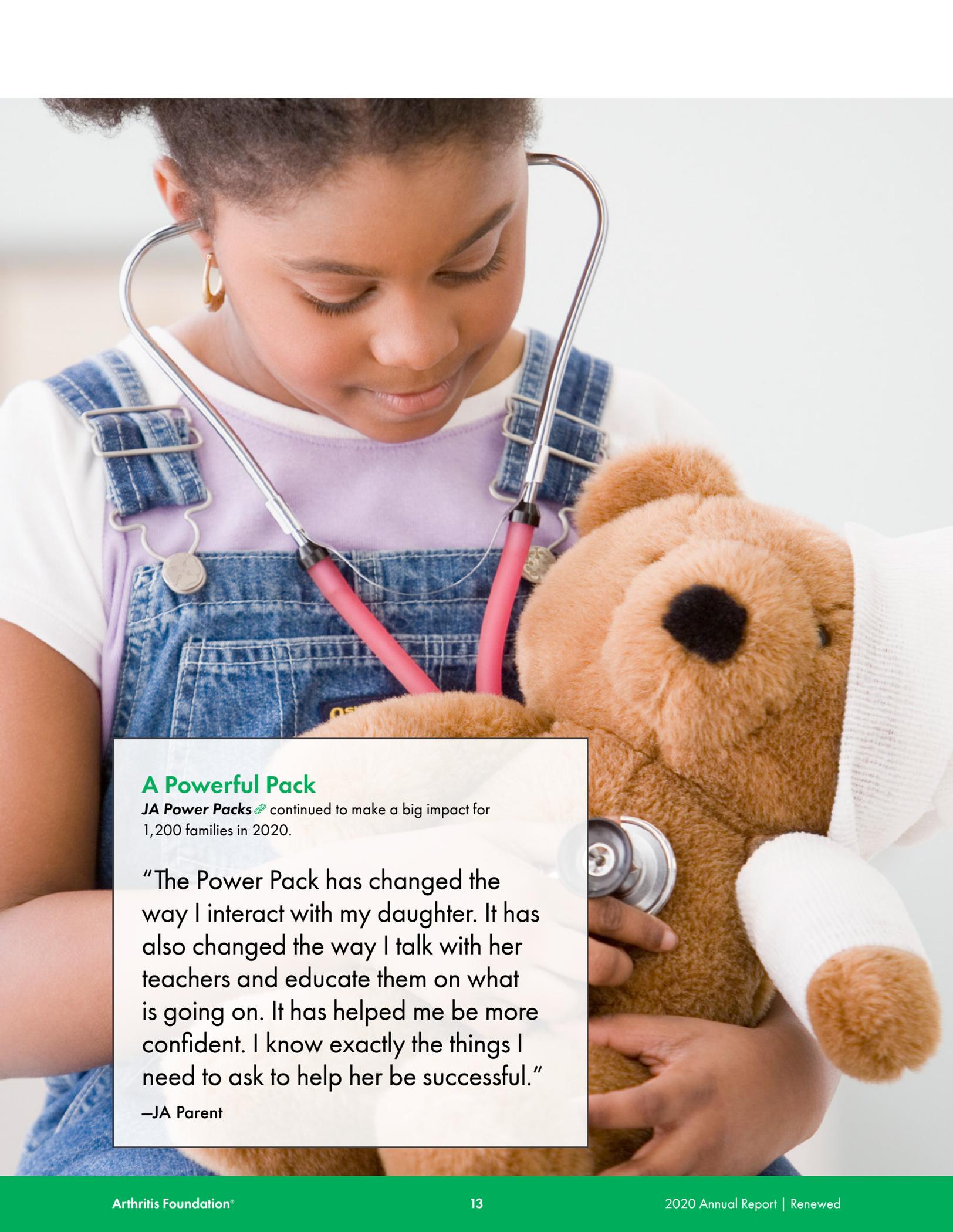
The Arthritis Foundation became an early pioneer in virtual advocacy, shaping best practices and guiding other organizations.

- We quickly turned the 2020 Advocacy Leadership Retreat planned for Capitol Hill in March, just as pandemic closures began, into a virtual event, conducting webinars and listening sessions and providing new ways to take action.



Arthritis Advocates sent nearly 4,000 messages to their legislators, reaching over 70% of congressional members.





### A Powerful Pack

JA Power Packs  continued to make a big impact for 1,200 families in 2020.

“The Power Pack has changed the way I interact with my daughter. It has also changed the way I talk with her teachers and educate them on what is going on. It has helped me be more confident. I know exactly the things I need to ask to help her be successful.”

—JA Parent

## Kids Get Arthritis, Too

Most people are surprised to learn that kids get arthritis, too. Nearly 300,000 children in the U.S. are diagnosed with juvenile arthritis or a related rheumatic condition.

Childhood arthritis isn't like adult arthritis. It often affects

organs, like the skin, eyes, lungs and heart. And it has its own complications and challenges.

Kids coping with juvenile arthritis may need special accommodations at school. They may need emotional support if they feel isolated and alone.

Since our mission began, the Arthritis Foundation has been devoted to supporting JA families. And in 2020, we stepped it up to a new level.

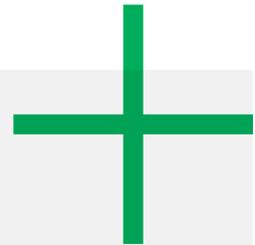
### ► Juvenile Arthritis Milestones



The virtual **National Juvenile Arthritis Conference** drew over 1,500 participants from 47 states and nine countries — 45% of whom were first-timers. The number of families joining increased by 20% over the previous year.

### ► Plus

- About 1,000 campers and volunteers in 41 states attended virtual and recorded sessions during the summer **JA Camp** season, assuring kids and their families that they're not alone in navigating JA challenges.
- New to the JA Conference and JA Camps were family activity workbooks, which we mailed to registrants so that those without internet access didn't miss out.



We funded \$75,000 in **Arthritis Champion Scholarships** for college students, and hundreds signed up for our Connect on Campus kit to help them adjust to college life with arthritis.

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## Arthritis Champion

### The Smith Family's Distinguished Service

Steve Smith is an amazing volunteer for the Arthritis Foundation. His family's journey with us began a quarter of a century ago. Three of his six (now adult) children were diagnosed with a form of arthritis, one of them at age 2. His wife, Liz, took charge while Steve pursued his career in the U.S. Navy.

Liz discovered our JA programs, especially the annual National JA Conference. The event made a big impact on their kids, so she got more involved in leading our JA efforts. Steve soon got on board, too. And together, Liz and Steve have been major movers and shakers for the JA community. In 2018, the Steve & Liz Smith Conference Legacy Award was named in

their honor, given annually to outstanding JA Conference volunteers.

Liz has been a vocal Arthritis Advocate. She started the Arthritis Foundation's Kids' Advocacy Summit, has spoken at Food and Drug Administration (FDA) hearings and served on the FDA arthritis advocacy committee. She has also served on the advisory council and a research committee for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and is an active member of a parents and patients committee for CARRA.

With his military experience, Steve is leading a virtual Live Yes! Connect Group for veterans. "I have seen what the Arthritis Foundation has



Steve Smith

accomplished for my family over the past 25+ years. If I can share just a small portion of that with my fellow vets, to make one person feel better about themselves, I will consider this group a success."

Steve received the Arthritis Foundation's *top annual award for volunteerism in 2020*: 🏆 The Charles B. Harding Award for Distinguished Service.



Steve & Liz Smith

# RE-ENERGIZED

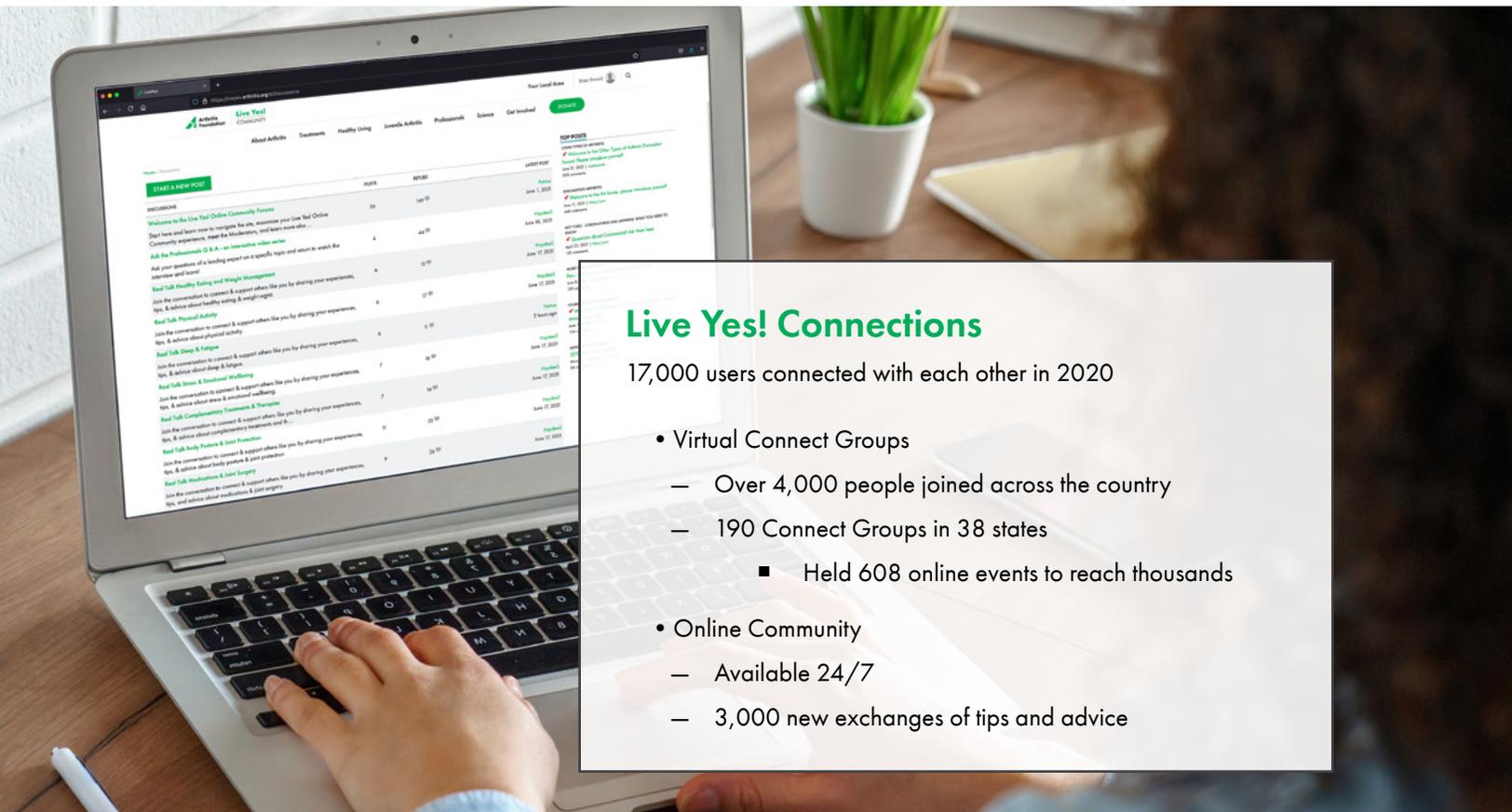
## Offering New Patient Resources

Making connections happen between arthritis patients is something the Arthritis Foundation has been doing all along. Those with arthritis want to connect with others who understand what they're going through. In our fundraising and educational initiatives, we've brought people together from all walks of life and locations to learn from and encourage each other.



Sheltering at home brought great need for the arthritis community to connect virtually in 2020, and we were ready to offer seamless support. Our *Live Yes! Online Community* and *Virtual Connect Groups* brought people together like never before.

Online forums about a variety of topics shed light on ways to deal with arthritis challenges. Participants shared advice and gained insight from experts. Geography didn't matter. Someone in Pennsylvania could easily connect with someone in Florida — or anywhere else — to bond with others who understand.



### Live Yes! Connections

17,000 users connected with each other in 2020

- Virtual Connect Groups
  - Over 4,000 people joined across the country
  - 190 Connect Groups in 38 states
    - Held 608 online events to reach thousands
- Online Community
  - Available 24/7
  - 3,000 new exchanges of tips and advice

## Podcasts & More

*Live Yes! With Arthritis Podcasts*  shared personal experiences and guidance for the whole arthritis community. To date, our podcasts have been downloaded by over 60,000 listeners who want to learn more about ways to

improve their lives. Hosted by Rebecca Gillett and Julie Eller — patients who are passionate about how their respective journeys with arthritis can help others — these podcasts inform and encourage everyone to live their best life.

Throughout the year, we also offered webinars, Facebook Live events, e-books, e-newsletters and more resources to help everyone in the arthritis community take control of their pain.



Rebecca Gillett, MS OTR/L

**Rebecca** was diagnosed with rheumatoid arthritis at age 26. Nineteen years, hundreds of injections and 15 surgeries later, she is a dedicated Arthritis Advocate and licensed occupational therapist committed to helping patients live their best lives. She started out with the Arthritis Foundation as a local volunteer. We asked her to become a staff member to advance our content strategy, using her knowledge and skills as both a health care provider and her patient perspective. Rebecca earned her BS in telecommunication from the University of Florida and her MS in occupational therapy from Colorado State University.

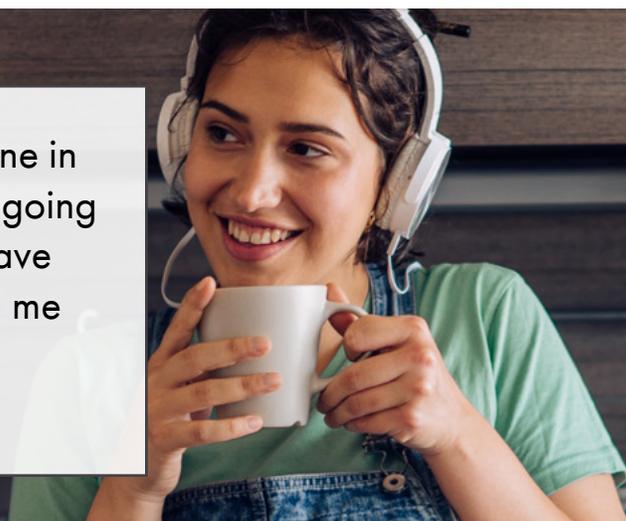


Julie Eller

**Julie** has been living with arthritis since she was diagnosed at age 7. Her worst days were when she needed a wheelchair to get around school. But in 2019, she biked 525 miles down the California coast. Julie's mission is to elevate patient voices for decision-makers in research, policy and product development to ensure that they are at the heart of health care decisions. She earned her BS in public health from Stockton University in her home state of New Jersey, and she is now pursuing her master's in public health at Harvard.

"Living with severe chronic pain, no one in my circle really understands what I'm going through. I found your podcasts and have listened to every episode. It has given me hope back that I'd lost months ago."

—Sarah, Live Yes! podcast listener



## ► Arthritis Helpline ☎ 800-283-7800

- Every month in 2020, more people reached out to us than in the month before
- December 2020 saw a 436% increase in calls and emails compared to the prior year
- We responded to 5,500 patient inquiries during the year



## ► Partnerships: ☎ Casting A Wide Net

Working together, we can change more lives. In 2020, we engaged with partners who expand our reach. To name a few, we ...

- Formalized our partnership with the American Physical Therapy Association
- Recruited the Rheumatology Nurses Society for our National Advocacy Committee
- Coordinated with the Centers for Disease Control and Prevention (CDC), National Association of Chronic Disease Directors, National Recreation and Park Association and Osteoarthritis Action Alliance to expand our Walk With Ease resource through virtual programming
- Extended Arthritis Foundation Aquatic Program and Arthritis Foundation Exercise Program training and certification agreement with Aquatic Exercise Association
- Created a Live Yes! INSIGHTS campaign with PatientPoint, putting our scientifically-validated assessment in 7,000 doctor's offices around the country



"Our goal at the Arthritis Foundation is and will always be to empower you to live your best life. I urge you to use and share the tools and resources we offer, and to engage with our community and share your experiences to help others."

—Ann Palmer, Arthritis Foundation President & CEO

## Volunteers in Action

### A Hole in One Fundraiser

For years, the Arthritis Foundation's Halloween-themed Bone Bash fundraising gala was a big deal in Topeka, Kansas, raising crucial funds for arthritis research and resources. With the pandemic posing a risk to large indoor gatherings, the event's volunteer leaders considered alternatives for an in-person event in the safer outdoors.

Led by volunteer co-chairs Butch and Kathy Eaton along with Tammy Dishman, they came up with the idea to host a golfing fundraiser instead, securing a venue at no cost and \$45,000 in sponsorships. In just weeks, this team of volunteers came together, masked and motivated, to plan it all out.

"This impromptu event exceeded our expectations," says Tammy, president of the Capitol Federal Foundation, who helped propel the new fundraiser. "Thankfully, we had a strong, hard-working team to make it happen."

"We put together a fantastic golf tournament," says Anya Leonard, also of Capitol Federal Foundation. "It was fun to see everyone come together and have a little bit of normalcy while supporting a great cause."



Golf tourney volunteers (L-R) Kathy Eaton, Tammy Dishman and Anya Leonard



Butch Eaton



The Arthritis Foundation Golf Classic in Kansas was a fabulous success, says Steve Rock, senior executive director

there. "We raised over \$56,000 with 102 registered golfers and 16 sponsors, and we're going to do it again in 2021."

## Arthritis Champion

### Striving for a World Record

Faced with the challenge of drumming up participation in a virtual event last year, Paulo Pinho, MD, New Jersey leadership board chair for the Arthritis Foundation, came up with a way to re-energize the *Jingle Bell Run* fundraiser: He drove efforts to turn the event into a record-breaker for Guinness World Records.

“It was challenging to get people motivated to do anything but watch cable news,” he says with a laugh. “2020 forced us to think about how we attracted people to participate.”

The Guinness challenge not only created buzz and raised awareness of the event and of arthritis, but it helped tap new participants. While people in the arthritis community join Jingle Bell Run because they’re already invested in the cause, there’s a

whole other group who might participate because they’re runners or just looking for a fun activity; for them, the fact that it’s for a good cause is a bonus.

Paulo, a runner, had taken part in a similar run, and he saw the appeal. “I’m very clear on the fact that I’m not going to break any world records in running,” he says. “Just to be able to say that two of my passions aligned in such a way that I was able to be part of a record-breaking attempt resonated very well with me.”

Although the event did not reach Guinness World Record status, it did accomplish its goals. “There was a lot of energy around it, a lot of positivity in general,” he says. It helped draw more than 14,000 runners and raise \$3 million.

It’s a great example of how volunteers drive the



Paulo Pinho, MD

Foundation by bringing their own experience and strengths to the table.

“I’ve been part of a lot of organizations where I sit on committees, and that’s all I do is sit on the committee,” Paulo says. With the Arthritis Foundation, “I think there is an imminent need for people to really showcase their talents and think out of the box because of all the challenges posed by 2020. And I think the Foundation is accommodating in that regard. They want those skill sets.”



Paulo Pinho, MD & Family

# REVOLUTIONARY

## Making Patient Insights Matter

In 2018, the Arthritis Foundation launched our revolutionary **Live Yes! INSIGHTS study**. By the end of 2020, nearly 40,000 survey assessments had been submitted and analyzed. The overall message was clear: 100% of people with arthritis said they experienced pain over the previous seven days. Four out of five patients experienced more difficulties in their ability to function physically than the general population.



We're not just talking the talk, but also walking the walk. Our 2020 **Mandate for Action** report summarized initial results — and urged lawmakers, policymakers and other constituents, like drug companies, insurers and others, to help us come up with solutions. Latest survey results led to our **How It Hurts** follow-up report in May 2021 — which takes a deeper dive into pain and underscores why further action is needed. And why we are taking extra steps to put into patients' hands a powerful new tool they can use every day.

The Arthritis Foundation has embarked on a three-year pain initiative to make measurable achievements to minimize the pain patients experience. Based on latest research, we launched our Vim pain management app in May 2021 to help people with arthritis set goals, track their accomplishments and access tips to help them along the way. Arthritis patients guided us in the app's development from the beginning.

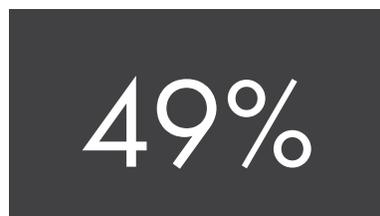
We're also working to close gaps in survey outreach to include greater diversity in our database. Underserved and underrepresented populations are vital to helping inform an inclusive plan of action.

INSIGHTS is a dynamic listening tool, amplifying the most pressing needs of the arthritis community. This study is the impetus for our ongoing work to radically transform every patient's experience with pain.

### ► INSIGHTS Highlights



75% of respondents said pain interfered a lot in daily activities.



49% said they couldn't walk easily.



Over two-thirds experience more fatigue than the general population.

## Arthritis Champion

In 2020, we extended our INSIGHTS study to hear from parents of kids with arthritis. Results are just starting to come in. Esmee's story shows why it's so important to consider the unique needs of JA families.

### Esmee's Special Gift

At 12 years old, *Esmee Guerrero* embodies the spirit of helping others, and she has embraced the Arthritis Foundation as a recipient of her generosity. Esmee, who lives in Orange County, California, has been raising money for her birthday and Christmas gifts and contributing it to the Foundation.

Esmee was diagnosed at age 6 with juvenile idiopathic arthritis. "It's hard to describe if

you haven't felt really hard pain that's long-lasting," she says. "It's just really bad. You can't move anything. You're confined in what you can do. I was playing softball and dancing, and I couldn't do that anymore."

Fortunately, unlike many children with JA, she was diagnosed and received treatment quickly. Medications now help control her arthritis.

Her mother discovered the Arthritis Foundation in her search for more information about the disease. Esmee, with support from her parents, Yolanda and Gus, decided she wanted to help.

"I've always encouraged both of my daughters to do whatever they can do to be part of the



Esmee Guerrero

community," says Yolanda of Esmee and sister, Uma. When she suggested Esmee donate a gift to help others on her birthday, "She said, 'I just want to raise money to help the Arthritis Foundation's work.' We saved all of her money and gave it on Giving Tuesday in 2019." The Guerrero family kept their new tradition going in 2020, including donations from others in Esmee's honor.



Esmee (center) with her sister and father

## 2020 Donors

We appreciate the generosity and commitment of our 2020 donors. You are the heart and soul of the arthritis community's many victories and our collective vision going forward.

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*The Arthritis Foundation would like to salute those companies that provided emergency funding during the coronavirus pandemic — not only helping us meet the rising concerns of our patient community, but also helping us offset the incremental expenses and reduction in donations we experienced.*

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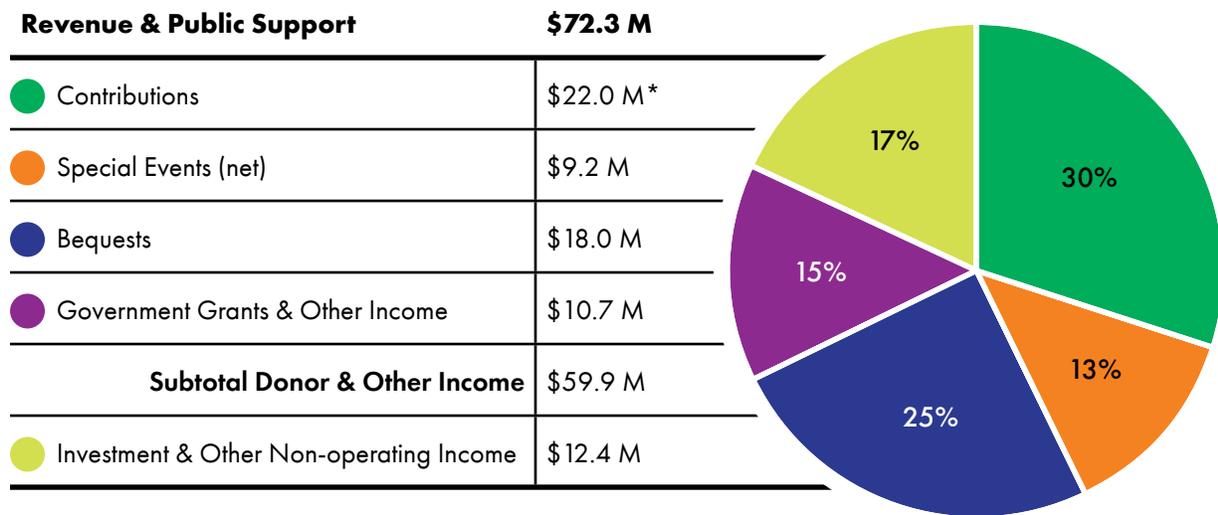
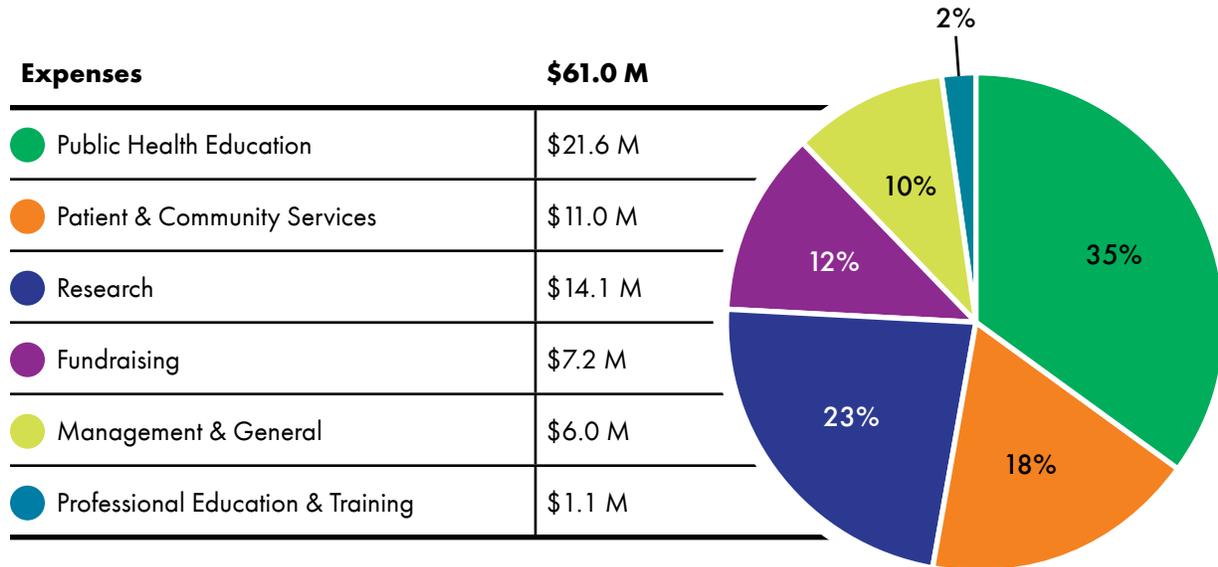
**Anna Ryan**  
Regional Vice President, West Region

The Arthritis Foundation exceeds standards of excellence. We've achieved the National Health Council's highest standards of accountability, stewardship and organizational effectiveness.



## 2020 Financial Highlights

In 2020, the Arthritis Foundation invested over \$35.7 million in research and public health education.



### Net Assets End-of-Year: \$166.4 M

Complete audited financial statements are available online at [arthritis.org/financials](https://www.arthritis.org/financials).

\*Includes \$10.5 M in pharmaceutical, biotechnology and medical device corporate support, representing 15% of total organization revenue.

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## 2020 Annual Report Links Index (in order of appearance)

### Care & Connect COVID Updates:

[arthritis.org/care-connect](https://arthritis.org/care-connect)

### Survive & Thrive Blog:

[blog.arthritis.org/news/survive-thrive-together-in-isolation/](https://blog.arthritis.org/news/survive-thrive-together-in-isolation/)

### Coronavirus, Advocacy & Arthritis:

[arthritis.org/care-connect/coronavirus-survey](https://arthritis.org/care-connect/coronavirus-survey)

### Ways to Volunteer:

[arthritis.org/volunteer](https://arthritis.org/volunteer)

### Living With Juvenile Arthritis:

[arthritis.org/juvenile-arthritis](https://arthritis.org/juvenile-arthritis)

### Veterans Connect Group Blog:

[blog.arthritis.org/living-with-arthritis/virtual-veterans-live-yes-connect-group/](https://blog.arthritis.org/living-with-arthritis/virtual-veterans-live-yes-connect-group/)

### Scientific Research:

[arthritis.org/science](https://arthritis.org/science)

### Osteoarthritis Research:

[arthritis.org/science/initiatives/advancing-osteoarthritis-treatments](https://arthritis.org/science/initiatives/advancing-osteoarthritis-treatments)

### Osteoarthritis Clinical Trial Network:

[arthritis.org/science/oa-clinical-trial-network](https://arthritis.org/science/oa-clinical-trial-network)

### Cultivating New Rheumatologists:

[arthritis.org/science/initiatives/cultivating-a-new-generation-of-rheumatologists](https://arthritis.org/science/initiatives/cultivating-a-new-generation-of-rheumatologists)

### Advocacy Opportunities:

[arthritis.org/advocate](https://arthritis.org/advocate)

### JA Power Pack:

[arthritis.org/juvenile-arthritis/get-your-ja-power-pack](https://arthritis.org/juvenile-arthritis/get-your-ja-power-pack)

### National Juvenile Arthritis Conference:

[arthritis.org/events/ja-conference](https://arthritis.org/events/ja-conference)

### Juvenile Conference Camps:

[arthritis.org/events/ja-camps](https://arthritis.org/events/ja-camps)

### Arthritis Champion Scholarships:

[arthritis.org/juvenile-arthritis/arthritis-champion-scholarship](https://arthritis.org/juvenile-arthritis/arthritis-champion-scholarship)

### Volunteer Spotlight: Steve Smith

[blog.arthritis.org/living-with-arthritis/2020-evening-honors-highlights/](https://blog.arthritis.org/living-with-arthritis/2020-evening-honors-highlights/)

### Community Connections:

[arthritis.org/liveyes](https://arthritis.org/liveyes)

### Live Yes! With Arthritis Podcasts:

[arthritis.org/liveyes/podcast](https://arthritis.org/liveyes/podcast)

### Arthritis Helpline:

[arthritis.org/i-need-help](https://arthritis.org/i-need-help)

### Partnerships:

[arthritis.org/partnership](https://arthritis.org/partnership)

### Jingle Bell Run:

[arthritis.org/events/jbr](https://arthritis.org/events/jbr)

### Live Yes! INSIGHTS Study & Survey:

[arthritis.org/liveyes/insights](https://arthritis.org/liveyes/insights)

### Mandate for Action Report:

[arthritis.org/about-us/news-and-updates/largest-arthritis-assessment-2020](https://arthritis.org/about-us/news-and-updates/largest-arthritis-assessment-2020)

### How It Hurts Report:

[arthritis.org/liveyes/insights/how-it-hurts](https://arthritis.org/liveyes/insights/how-it-hurts)

### Esmee Guerrero's Story:

[blog.arthritis.org/living-with-arthritis/esmee-guerrero/](https://blog.arthritis.org/living-with-arthritis/esmee-guerrero/)

### Arthritis Foundation Financials:

[arthritis.org/about-us/financials](https://arthritis.org/about-us/financials)

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## Quick Links

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