# Victories & Vision

2019 ANNUAL REPORT





At least 1 of every 4 Americans struggles with a form of arthritis.



#### 2019 was a great year. Working together, the arthritis community made giant leaps forward.

Last year, the Arthritis Foundation spearheaded the unique Live Yes! INSIGHTS study, which validates what we've been hearing from people with arthritis for over seven decades. As time goes by, we're learning even more about how arthritis affects so many of you every day, in every way. The unprecedented findings in our Mandate for Action report will help change the future of arthritis.

In 2019, our community also made a big impact to remove barriers. Together, we changed policies and laws that stand in the way of accessing the quality care we deserve. Over the past few years, we've influenced over 100 bills to make arthritis and other chronic disease care easier to navigate, especially in step therapy requirements.

#### We are changing with the times, adjusting to a different world.

The Live Yes! Arthritis Network grew enormously this year. Online, and in person when possible, we offered many ways to get engaged and involved in your own way. The Arthritis Foundation continues to provide vast resources to help people live better every day — and an assortment of opportunities to connect with others on a similar journey.

You are also propelling research forward, to find better treatments — and a cure. Our Online Community features conversations with others who understand, including health experts who are ready to answer your questions. And local Connect Groups have grown to more than 150 nationwide for the local support you need.

In this annual report, we're looking back to 2019. We've come so far. But as we look back, we know it's a new world now. The 2020 coronavirus pandemic has changed everything. So, we are changing with the times, adjusting to a different world. A new way of helping everyone fighting arthritis live their best life. Please count on us to help you along the way as things keep changing.

What you need to know most: Our mission of conquering arthritis hasn't changed. Today, we're working harder than ever to turn today's challenges into new solutions, and forge new paths ahead. There are new opportunities. And together, we'll keep making a difference.

Thank you for your ongoing alliance and allegiance. We can't do it without you.

Ann M. Palmer

Arthritis Foundation President & CEO

Ann M. Palmer

**Laurie Stewart** 

Chair, Arthritis Foundation Board of Directors



#### **Walking to Ease Pain**

Rose Zhude, 70, of North Carolina, tried Walk With Ease last year and got hooked. "Walk With Ease lets you do what you can, and it's amazing." Her enthusiasm led her to become a certified teacher, and 20 people signed up for her first class.

Walking regularly improves circulation and can help with weight loss and build stronger bones, muscles and joints. The Walk With Ease program allows patients to ease into a new walking routine – on your own or with others – no matter your fitness level.

Her advice for others is to take it slow and know their limits. The FITT tool (frequency, intensity, time, type) helps you know when you're doing too much. Rose recommends doing 10 minutes at a time to start out. "Do what you can, even if it is only for a minute."

arthritis.org/WWE

"Parents of a child with juvenile arthritis just want to talk to others who really understand them. Nobody really understands like another group member in similar situations."

Heidi Larson (above right)
Live Yes! Connect Group leader

"I'm glad I found this place. It seems like a good spot to sit and get acquainted with others who understand how this whole thing can really change your life."

#### **Gayle Asher**

Online Community member

### BETTER BECAUSE OF THE ARTHRITIS FOUNDATION

Patients who get involved with the Arthritis Foundation take better care of themselves than those not involved.

94% are positive about being successful in life.

71% start eating a healthier diet.

50% begin taking fitness classes.

50% start a weight loss program.

46% start a home workout routine.

Source: Arthritis Foundation Consumer Needs Survey conducted by Nielsen

We know at least **54 million people** in the United States have doctor-diagnosed arthritis. That number nearly doubles when you add those who self-report arthritis symptoms. It is America's number one cause of disability, costing over **\$300 billion annually** in medical costs and earning losses. But do we know the true magnitude of this disease and what it means for people living with arthritis day after day?

#### **MEASURING & MONITORING**

With this important opportunity in front of us, the Arthritis Foundation spearheaded a first-of-its-kind You can always find proven, trusted tools and resources through the Arthritis Foundation. From helping you get moving to nutrition tips and much more — we've got you covered at every age and stage.

arthritis.org/LiveYes

yearlong initiative — working closely with arthritis patients, health care providers, measurement experts and leading scientists — to develop a scientifically-grounded, patient-validated assessment tool that examines what living with arthritis is really like.

The data we're collecting through our **Live Yes! INSIGHTS** study underscores that the human toll is astronomical in terms of the pain, hardship, isolation and marginalization arthritis causes. People with arthritis deserve more; they deserve to be heard, understood and acknowledged by legislators and other policymakers, product designers, care providers and everyone else in their lives.

## VISION





### Here are the gaps we're working hard to fill . . .

43% of people with arthritis cannot walk easily. They either can't walk at all or have major difficulty walking.

51% of those with osteoarthritis are impacted, more than any other type of arthritis.

**58%** of people in West Virginia are impacted, more than any other state.

**54%** of African Americans are impacted, more than any other race.

Source: Arthritis Foundation 2019 Mandate for Action

#### **Changing the Future**

We are using the data from our **Live Yes! INSIGHTS** to build the Arthritis Foundation's national agenda going forward. We're opening the eyes of decision-makers at all levels, showing that arthritis is a life-altering disease that demands more research, interventions and attention.

Together, with your support and participation, we are taking unprecedented steps to close the gaps and change the future of arthritis today and for generations to come.



"Being an Arthritis Warrior
means taking the best care
of myself, fighting for my
best life and then helping
fight for others who may not be
able to speak up. I fight for the Arthritis
Foundation because they care about
people who are living with arthritis, and
I'm doing everything in my power to
make an impact for a cure."

Raquel Masco
Arthritis Warrior in Texas

#### A Mother's Fight for Her Son

From a young age, Kristine DiDesiderio lived with autoimmune disorders and daily pain. However, she wasn't diagnosed until adulthood. She now has to manage the effects of fibromyalgia, Sjogren's syndrome, ankylosing spondylitis and RA, which are all arthritis-related diseases. While Kristine was able to deal with her illnesses, she was unprepared when her son, Lorenzo, experienced similar pain at the age of 7.

After seeing multiple medical professionals over a three-year period, Lorenzo was finally diagnosed with JA. While her heart sank for her son, Kristine became committed to advocating for the 300,000 children nationwide living with forms of JA. She passionately took a stand to change step therapy barriers, which both mother and son have dealt with. Last year, Kristine had liver failure because protocols required her to try a specific medication first, and she nearly died.

The DiDesiderio family inspires strength and resilience for their commitment to advocacy and sharing their story.

### BETTER BECAUSE OF THE ARTHRITIS FOUNDATION

We held a Virtual Summit in conjunction with the Advocacy Summit, asking people from around the country to tell us why they #AdvocateforArthritis.

I #advocateforarthritis because sharing my story gives me hope and purpose in my daily battle with this disease

#### @just.call.me.jai

I #AdvocateforArthritis with the @arthritisfoundation because patients are the ultimate stakeholders in health care.

#### @debondek ©

I've learned what it means to have a voice, to share my story, to make a difference. I've learned how to step up and show courage. I share my story so others can find hope in theirs.

@jess\_poof ©

The Arthritis Foundation is committed to improving people's lives in three key areas:

- ▶ Physical Health Helping people with arthritis function better with less pain so they can perform daily activities and enjoy the things they love to do.
- ► Emotional & Social Health Helping people with arthritis better manage stress and depression by connecting them with others who understand.
- ▶ Better Experience of Care Helping people with arthritis get the support they need to take control of their health care and make the most of it.

We represent the 54 million Americans living with arthritis. In 2019, alongside donors, volunteers and other partners, we made big strides in advocacy, research and the development of resources that positively impact people's lives in many ways.

To help facilitate those improvements, the Arthritis Foundation created a model for bringing communities together called the Live Yes! Arthritis Network.



- We make vital connections possible, both in person and online, empowering people with arthritis to live their best life.
- ➤ We help them live life with less pain, find strength in each other, manage stress and communicate better with their health care team.

## VISION





## Here are the gaps we're working hard to fill . . .

100% of people with arthritis report moderately strong pain that can't be ignored.

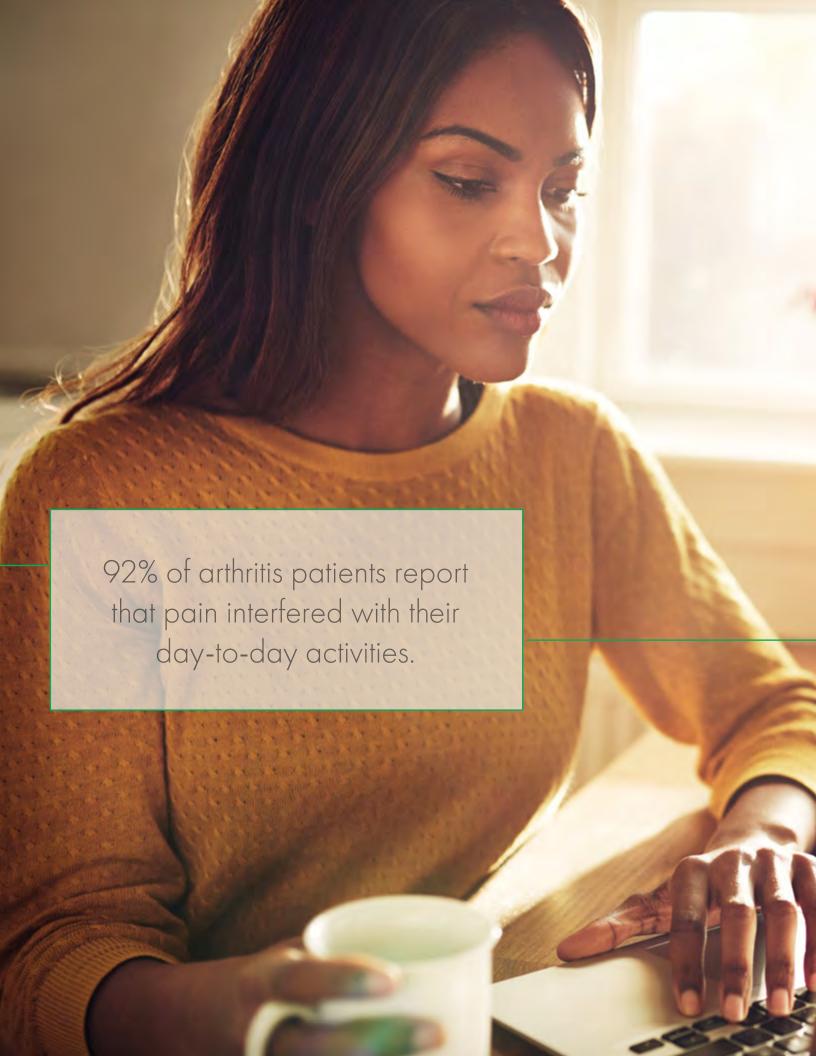
**92%** report that pain interfered with their day-to-day activities.

73% report feeling fatigued, and less than 1 in 3 slept well.

Source: Arthritis Foundation 2019 Mandate for Action

## A Nationwide Network of Committed Advocates

- ▶ 150,000+ Arthritis Foundation Advocates amplify our voices and urge lawmakers to support policies that benefit those living with chronic diseases like arthritis.
- Several states passed legislation to curb step therapy in 2019.
  - This brings the total number of state-level step therapy victories to 28.
- The Safe Step Act has been introduced in both the U.S. House and Senate and will reform step therapy protocols nationwide.





"I've been able to contain my gout flares. Conquering OA, which is a sinister and progressive disease that slowly degenerates joints, has been challenging. We all desire the best quality of life, whatever stage. We want to function and remain active members of society. Research is constantly learning more, so keep the faith."

Craig Buhr
Battles Gout and OA

#### **Help Wanted**

There is a severe rheumatologist shortage in the U.S.

This is particularly worrisome in pediatric rheumatology, where JA patients often have to travel out of state for treatments and adequate care. The Arthritis

Foundation's fellowship program is closing this gap.

Stephen Chee-Yung Wong, MD, a pediatrician, will complete his pediatric rheumatology fellowship funded by the Arthritis Foundation in 2020. He is looking forward to the opportunity to do more research in pediatric rheumatology as a physician scientist.

His current research examines cognitive dysfunction in children who have lupus. "I hope to shed light on cognitive functioning of young lupus patients and give hope to families for treatment of this terrible disease," he says.

### BETTER BECAUSE OF THE ARTHRITIS FOUNDATION

We moved the needle in advancing arthritis research in 2019, making major progress to discover new interventions and therapies.

9 new rheumatology fellowships, funded by our generous donors.

5 Osteoarthritis Centers of Excellence established, to tackle solutions for OA.

200% increase in JA patients in the CARRA registry to lead to new treatments.

The Arthritis Foundation is transforming how people with arthritis can live life with less pain and be more active in their care.



- Our Live Yes! Online Community offers forums on many topics, 24/7. Members connect and share tips and encouragement with each other, plus get their questions answered by health care experts.
- On our website and in e-newsletters, online forums and other interactions, our tools, tips and resources make a life-changing difference.

In 2019, we built a solid foundation for changing the future of arthritis. We're providing solutions for today and offering hope for tomorrow. For example, we elevated our work to alleviate osteoarthritis, which affects over 30 million Americans, aiming to discover treatments that don't yet exist.

- ▶ Local **Live Yes! Connect Groups** bring together people battling arthritis with others who understand what they're going through.
  - 150+ local support groups have formed, with more getting started all the time. If there isn't a group in your area, it's easy to start one.
- Licensed, clinical social workers are ready to answer questions, make referrals and provide guidance and other assistance at our Helpline: 800-283-7800.

Engage with the arthritis community at arthritis.org/LiveYes

## VISION





### Here are the gaps we're working hard to fill . . .

72% of arthritis patients report having trouble doing work for their job and/or at home.

67% report having trouble doing the family activities they want to do.

2 in 3 report feeling depressed, anxious and/or fearful.

Source: Arthritis Foundation 2019 Mandate for Action

## New INSIGHTS Into Everyday Life

In 2019, the unprecedented and ongoing **Live Yes! INSIGHTS** study revealed a first-of-its-kind look into what arthritis patients deal with every day.

▶ 93% of patients said it's extremely important to talk to a professional who can answer their questions and provide the help they need.

#### **YET...**

- Only 69% surveyed were satisfied with their health care experience.
- Only 57% said they got the help they needed.



Racing for a Cure

Natalie Decker was diagnosed with JA at age 2 and received therapy with chemo-type medications for a decade. But she didn't let this stop her from attaining her dream. From a young age, she knew she wanted to race in NASCAR. Last year, she was the highest finishing female in Automobile Racing Club of America competition, taking fifth place.

After keeping quiet most of her life, she revealed her illness to the world and announced a fundraiser to support the Arthritis Foundation. All proceeds helped raise awareness and funds for the Arthritis Foundation's mission, fueling research for a cure as well as resources and support for life-changing juvenile arthritis camps nationwide.

Her advice to others? "Whoever you are and whatever you want to do, do it because you want to and love it. Whatever you put your mind to, you can absolutely do it."

"It's hard to say having arthritis sucks because I've had it almost my entire life. It's just a part of me. Like my name. There are days I'm grateful for it because I have no doubt it's helped shape my life and career. There are also days I hate it because of the limitations it brings. It's a love-hate relationship, I guess. Much like my thighs."

Kennita Hickman

Walk to Cure Arthritis,
Milwaukee Warrior Chair

### BETTER BECAUSE OF THE ARTHRITIS FOUNDATION

In 2019, the Arthritis Foundation led the way in providing guidelines for the usage of CBD — cannabidiol, a plant-based compound — to relieve arthritis pain. Ours was the first-ever CBD guidance from a major health organization, garnering widespread media attention.

We listened to our constituents and consulted with leading experts to make recommendations to adults interested in trying CBD.

"The Arthritis Foundation values the patient voice," says Stacy Courtnay, rheumatoid arthritis patient and member of the Arthritis Foundation Patient Leadership Council. "Some doctors aren't open to discussing CBD with patients, and it's fantastic and encouraging that the Arthritis Foundation is helping people with arthritis gain access to whatever treatments might help them."

To learn more, visit arthritis.org/CBD

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

By reaching millions living with arthritis and listening to what is on people's minds, the Arthritis Foundation is learning more about what matters most to individuals and families. We're collaborating with them to develop the resources they need, influence research and change systems to improve quality of life. We appreciate the commitment of generous volunteers, donors, partners and other supporters who are the heart and soul of our mission.

Driving our priorities is real-life data from our ongoing **Live Yes! INSIGHTS** study, which gauges arthritis pain, its profound impact and the enormous obstacles patients face. We received 18,000 assessments, making the INSIGHTS program one of the largest in the world and leading to our Mandate for Action report.

#### MANDATE FOR ACTION

It is our mandate to make sure people with arthritis are heard. We're putting relevant and meaningful data from the INSIGHTS assessment into the hands of national and community leaders.

Our Mandate for Action report reveals the eyeopening realities of arthritis, and we will continue updating it as more results come in. By sharing these findings with those across a wide spectrum of decisionmakers and influencers, we are shaping health care today and intensifying our quest for a cure.

Read the report at <u>arthritis.org/insights</u>.

## VISION





People with arthritis can't wait any more. Neither can we. Let's conquer arthritis together.

## Throughout the year, the Arthritis Foundation continued to change the course of arthritis. Our INSIGHTS study shows,

for the first time, that no community or group is immune from the disease's devastating toll.

Across all states and all segments of society, there's a wide gap between what patients need to live well and what's available to help them do so.

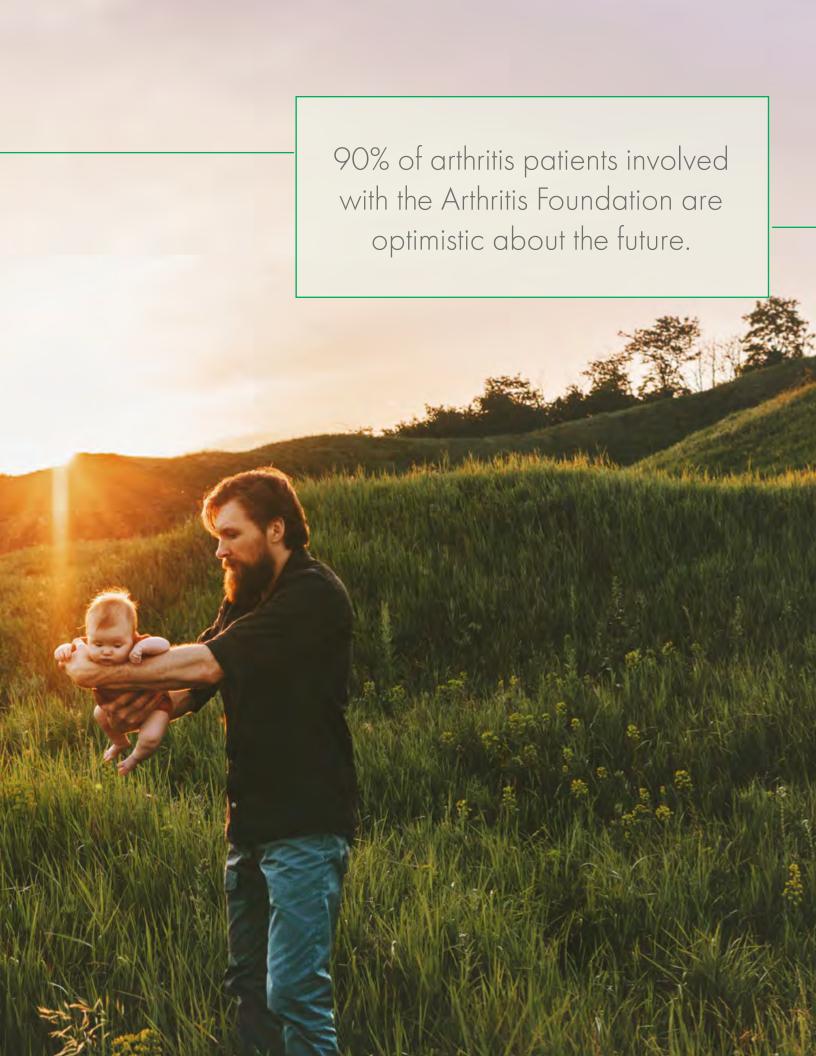
Patient perspectives demand the focused attention of many: researchers, care providers, product

developers, regulators, lawmakers and the patients themselves.

#### **United We Stand**

Together, our community is uniting hearts, minds and resources to mobilize action and enhance lives.

Together, we are fighting for everyone who battles arthritis. Advocating for advancements. Getting connected. Closing gaps. This is not the fight for one — it's the fight for all.



We appreciate the generosity and commitment of our 2019 donors. You are the heart and soul of the arthritis community's many victories and our collective vision going forward.

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## Be the ONE

"The Arthritis Foundation's greatest achievements and impact are accomplished thanks to you, our donors. We will continue seeking better treatments and, ultimately, a cure for arthritis."

#### **Laurie Stewart**

Chair, Arthritis Foundation Board of Directors

Special thanks to the Ludlow-Griffith Foundation for funding the Montana pediatric fellowship, bringing access to care for children living with arthritis in Montana and surrounding states.

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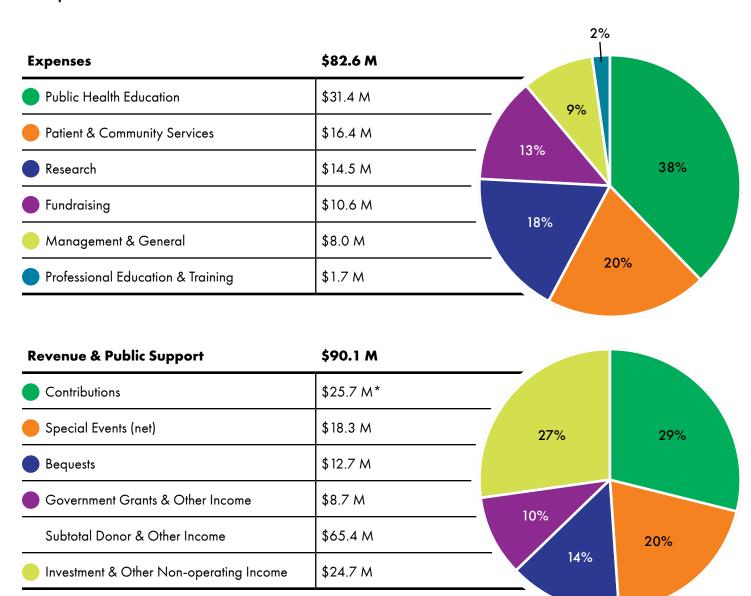
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### In 2019, the Arthritis Foundation invested over \$45.9 million dollars in research and public health education.



Net Assets End-of-Year: \$155.2 M

#### Complete audited financial statements are available online at arthritis.org/financials.

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