A Mandate for Action

Live Yes!
INSIGHTS LIVE

A Live Yes! INSIGHTS Event

New York City • March 3, 2020
Raj Karia
Network Leader,
New York City
Leadership Board of Directors

Welcome
Evening Agenda

5:15 pm - Welcome and Program
   Raj Karia, Network Leader Arthritis Foundation’s Board of Directors
   Ann Palmer, Arthritis Foundation CEO
   Cindy McDaniel, Arthritis Foundation Senior VP Consumer Health & Impact
   Shannan O’Hara Levi, Patient Leadership Council Member
   Dustin Levi, Shannan’s husband
   Chris Altizer, Facilitator

6:00 pm - A Mandate for Action Discussion

7:00 pm - Dinner Served

7:45 pm - Interactive Showcase and Dessert Reception

8:30 pm - Event Concludes
Ann M. Palmer
President & CEO

A Mandate for Action
Mission Statement

The Arthritis Foundation is boldly pursuing a cure for America’s #1 cause of disability, while championing the fight against arthritis with life-changing information, advocacy, science and community connections.
Establish the Arthritis Foundation as Champion of Yes!
Helping people overcome “No” and say “Yes” to the things they love to do
YOU ARE NOT ALONE

Helping people create personalized plans for YES
Welcome to this year's JA Conference. Thank you for being part of our community.

Our Focus: The 4 Pillars

Scientific Discovery
Accelerate progress in new and better diagnostics and treatments, achieve results faster with an inclusive approach.

Help & Support
Make a major difference in the lives of people with arthritis through personalized attention and expert guidance – whenever, wherever.

Advocacy & Access
Be the most respected, authoritative voice for people with arthritis to regulators, insurers, employers and policy makers.

Juvenile Arthritis
Meet the unique needs of JA families with practical services and support to improve their lives every step of the way.
Advocacy & Access

We’ve helped secure more than 135 state legislative victories in all 50 states since 2014.

Our Network includes 150,000 Advocates and 1,400 Ambassadors.
Juvenile Arthritis

More than 34,000 children and caregivers have benefited from our annual National JA Conference since 1984

In the past five years, we’ve invested $25 million to boost JA research with CARRA
Scientific Discovery

Over the past seven decades, we’ve invested $500+ million into arthritis research, leading to life-changing discoveries.

Focused On:
- Advancing OA Treatment
- Childhood Arthritis
- Cultivating a new generation of rheumatologists
- Improving quality of care
Of those who have interacted with the Arthritis Foundation

3 in 4 say our organization has had a positive impact on their lives

and nearly all say the information is helpful.

Source: Arthritis Foundation Consumer Needs Study, conducted by Nielsen/Harris, July 2016
Goals of the Network

- Personalized experience from Day 1
- Unleash the power of our community
- Improve care
- Influence research agenda
Network Impact: Building on Three Focus Areas

Improved Physical Health

Improved Emotional & Social Health

Better Experience of Care
We offer people with arthritis the right tools and resources they need to help understand their disease, take action to improve their quality of life and be a part of finding a cure.
People Diagnosed With Arthritis and Future Projections*

Source: National Health Interview Survey, 2023-2025; www.cdc.gov/vitalsigns/arthritis

*Doctor diagnosed
What we know

about people with arthritis...

- **29%** report fair/poor health status
  (33% = good; 39% = very good or excellent)

- **38%** are obese
  (33% = overweight; 25% = underweight/normal weight)

- **25%** have heart disease

- **19%** have diabetes

Source: https://www.cdc.gov/mmwr/volumes/66/wr/mm6609e1.htm?s_cid=mm6609e1_w
Listening to Patients

Live Yes! INSIGHTS™

Received 24,000 Live Yes! INSIGHTS assessments

First 18,000 included in A Mandate for Action report
Integrity in Research

Establishing an organizational structure to support our work:

- Internal review board
- Voluntary participation and informed consent
- Data security and monitoring
Domain Selection Process:

• Three broad domains were selected based on previous research and interviews

• Domains: physical health, emotional and social health, and experience of care

• Developed new PRO measuring profiling tool (named PROMPT) to narrow measures from 40 down to nine (three per domain)

• Twenty-two patients worked as a committee to review and vote on the measures that best reflected the life of a person living with arthritis

Measures Selected:

• PROMIS-29 profile v 2.0

• PROMIS Emotional Support Short Form v 2.0

• Health Care Empowerment Questionnaire
Assessments empowering people, no matter where they live, to lend their voice
Results represent a wide variety of arthritis types

- Osteoarthritis: 61%
- Rheumatoid Arthritis: 42%
- Fibromyalgia: 20%
- Osteoporosis: 14%
- Psoriatic Arthritis: 8%
- Ankylosing Spondylitis: 6%
- Sjogren’s Syndrome: 6%
- JA Persistent to Adulthood: 4%
- Gout: 4%
- Lupus: 4%
White: 76%
Black/African American: 11%
Hispanic/Latino: 8%
Multiple: 1%
American Indian/Alaska: 1%
Asian: 3%
national race/ethnicity
Live Yes! INSIGHTS

**National Age**
- 46% 65+
- 12% 18-44
- 42% 45-64

**National Gender**
- 41% Male
- 59% Female

- Other/Prefer Not to Answer: 14%
43% 18+ years
24% 5 years or less
33% 6-17 years
Key Findings

Impaired physical function. Chronic sleeplessness. Constant fatigue.
92% report that pain interferes with their day-to-day activities.

Reduced work abilities. Decreased family connectivity. Increased depression.
72% report having trouble doing all usual work.

Only 57% report receiving the help they need.

Disparities between our communities.
Wide-ranging differences between markets.
PAIN CAN’T BE IGNORED. IT IS AN INTENSE AND CONSTANT PRESENCE.

100% of patient responders REPORTED PAIN over the last seven days — with an average pain score of 5 on a 10-point scale.

92% of patients reported that pain interfered with their day-to-day activities.

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. *

PAIN CORRUPTS PATIENTS’ SLEEP AND UNLEASHES FATIGUE.

LESS THAN

1/3 slept well in the past seven days.

73% reported feeling fatigued over the past seven days.

Lupus patients are more impacted at 88%.

People in Oklahoma and Maine are impacted even more at 83%.

Hispanics are impacted more than any other race at 78%.
NOT LIVING THE LIFE THEY WANT IS TAKING AN EMOTIONAL TOLL.

2/3 said they felt depressed during the past seven days.

2/3 said they felt anxiety or fear during the past seven days.
Patients have trouble working. 72% 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 Indian or Alaska Native are impacted more than any other race at 81%.
PAIN LIMITS ABILITY TO WALK.

Almost half of our community cannot walk easily.

43% reported that they could not walk at all or had major difficulty walking for at least 15 minutes during the past seven days.

- Osteoarthritis patients are more impacted at 51%.
- People in West Virginia are impacted even more at 58%.
- African Americans are impacted more than any other race at 54%.
PATIENTS MISS OUT ON FAMILY ACTIVITIES.

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

- Ankylosing Spondylitis patients are more impacted at 81%.
- People in Alabama are impacted even more at 80%.
- African Americans are impacted more than any other race at 73%.
UNMET NEEDS. DISPARITIES IN HEALTH CARE.

93% of patients reported that it is extremely important to have the ability to talk to a professional to answer their questions.

YET ONLY
69% surveyed were satisfied with their experience.

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.
Not only are results monitored at a national level, but the 70 local Arthritis Foundation markets across the country are making positive changes in their communities through tailored programs based on localized data.
As the leading health charity focused on conquering arthritis, our mandate is to change lives while boldly pursuing a cure.
What does this mean for patients?
Rapid Table Discussion:
• What are your reactions to the data?
• What does it mean for us here in NYC? gaps we can close? opportunities we can expand?

Facilitated Discussion:
• What can we DO with it?
Change is Needed Now
Closing and Action Steps
As you learned in tonight’s program, *A Mandate for Action* highlights real-life arthritis patient experiences. The pain, hardship, isolation and marginalization of people with arthritis can no longer be ignored.

Review the commitment cards at your place and choose the answer that best describes how you feel about fighting for change with us!

Awareness  Commitment  Action  Outcome