

2022 JA INSIGHTS REPORT

# INSIGHTS & Action

Annual Findings on the Impact  
of Juvenile Arthritis Pain

# Pain Is a Priority for Kids With JA

Nearly 300,000 children in the United State battle juvenile arthritis. Yet most people still think of arthritis as a disease affecting only adults, usually older adults. The Arthritis Foundation is working to change that perception and to improve the lives of children and their families living with JA.

We know that JA can turn people's lives upside down. And although great strides in treatments for juvenile arthritis (JA) have been made over the past few decades, many young people still feel debilitating pain.



That is why the Arthritis Foundation wanted to get a clearer picture of the challenges of JA. Through our partnership with researchers at Dartmouth College, the co-creators of our Live Yes! INSIGHTS study that assesses adults with arthritis, we were able to develop JA INSIGHTS.

This report is the first on the study's findings. It's based on more than a year's worth of data collected from assessments completed by parents of children under 18 with JA.

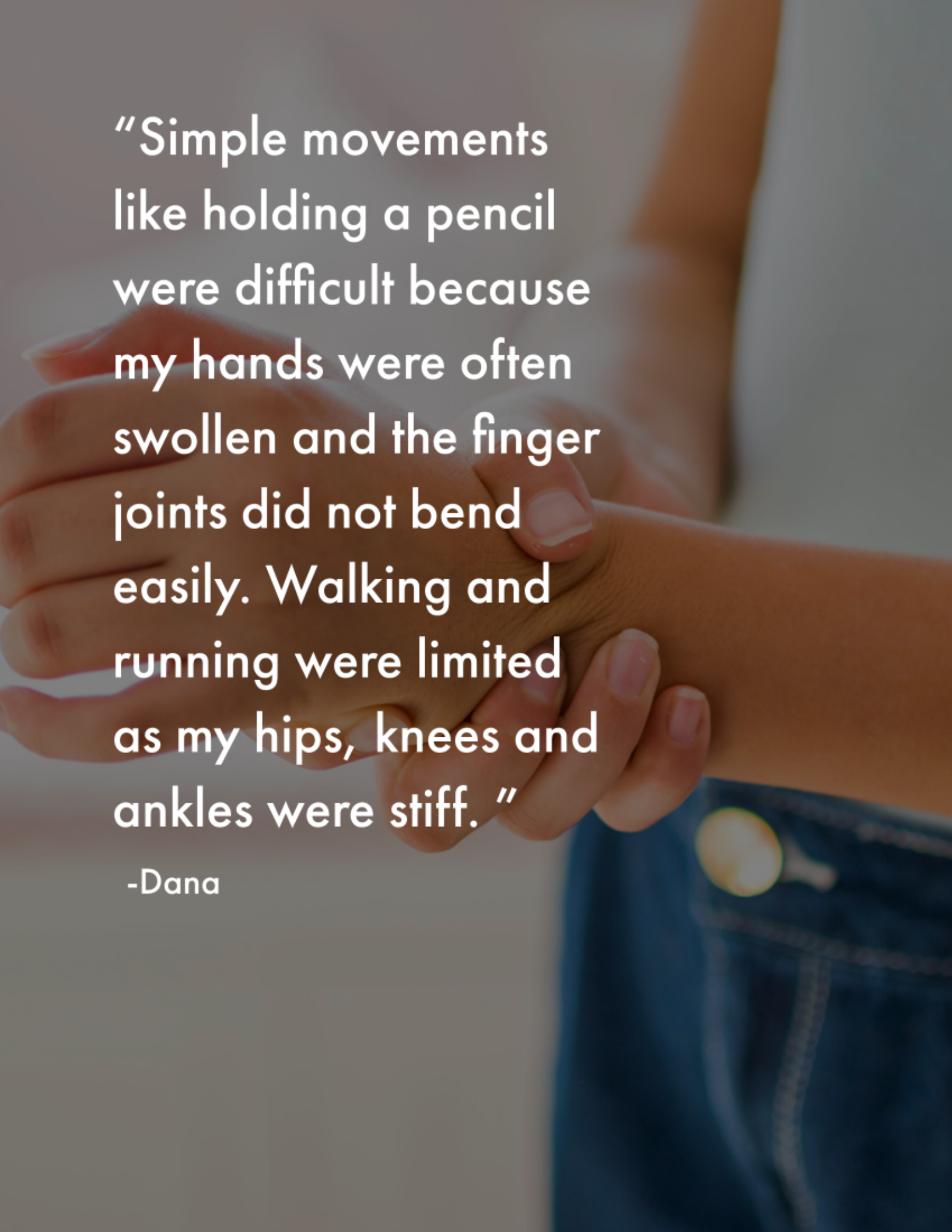
It didn't surprise us that pain is a top priority. More alarming is the impact on physical function and on social and emotional health: Nearly 80% reported pain that interfered daily at a moderate or severe level; and more than two-thirds reported moderate to severe anxiety and depression.

The data collected from JA INSIGHTS will help guide our priorities, arming us with evidence to support our patient education, science and advocacy initiatives. We have already started to create robust resources and programming to address mental and emotional health, while also continuing to add to our resources on physical health. And as a cornerstone of the Arthritis Foundation, we will continue to offer ways for children and their families to connect with others and share their stories.

The Arthritis Foundation is committed to the JA community, and we thank all of you who have taken part in our JA INSIGHTS. If you haven't taken part, please participate in the JA INSIGHTS study to share your child's experience.

A handwritten signature in black ink that reads "Steven Taylor".

**Steven Taylor**  
President & CEO  
Arthritis Foundation

A close-up photograph of a person's hands clasped together. The hands appear slightly swollen, particularly around the knuckles and fingers. The person is wearing blue denim jeans. The background is a soft, out-of-focus light blue.

“Simple movements like holding a pencil were difficult because my hands were often swollen and the finger joints did not bend easily. Walking and running were limited as my hips, knees and ankles were stiff. ”

-Dana



## What is JA INSIGHTS?

Demographic research tells us that nearly 300,000 children in the U.S. live with [juvenile arthritis](#) — a term used to describe pediatric rheumatic diseases. What it doesn't do is depict exactly how the illness affects children and their families in their daily lives. How does pain interfere with their physical and emotional health, their relationships and self-esteem? Are families able to find adequate care? Do parents feel empowered to participate in their child's medical care?

To get answers, we partnered with researchers at Dartmouth College, who developed a scientifically validated tool to measure the impact of JA on children and their families. The study compared participants with two populations: children with [juvenile idiopathic arthritis](#) (JIA, the most common form of JA) and children in the general population — those without arthritis.

Parents or guardians of children ages 5 to 17 with juvenile arthritis are invited to take the [JA INSIGHTS](#) assessment. It was the product of a series of focus groups, review of existing scientific research and input from a range of stakeholders, including health care providers, patients, parents and guardians and scientists.

[Live Yes! INSIGHTS](#), geared toward adults living with arthritis, is now in its third year. Seeing the need for a similar study of JA families, we launched JA INSIGHTS in 2021. This ongoing study will continue to inform the Foundation's priorities and programs in an effort to meet the needs of the JA community.



Learn more about the studies and  
help spread the word at [arthritis.org/insights](https://arthritis.org/insights).





## About This Report

This is the first report on findings from the ongoing JA INSIGHTS study, based on eligible assessments completed from Oct. 12, 2020, to Dec. 31, 2021. Some of the key questions the analysis seeks to answer:

- What does pain look like in this population of children with JA?
- How does the level of pain affect how much pain interferes with their life and activities?
- To what extent does pain interfere with their physical health?
- To what extent does it interfere with their social and emotional health?
- To what extent does it interfere with their quality of life?

Total included: 512 children represented by assessments submitted by 502 parents

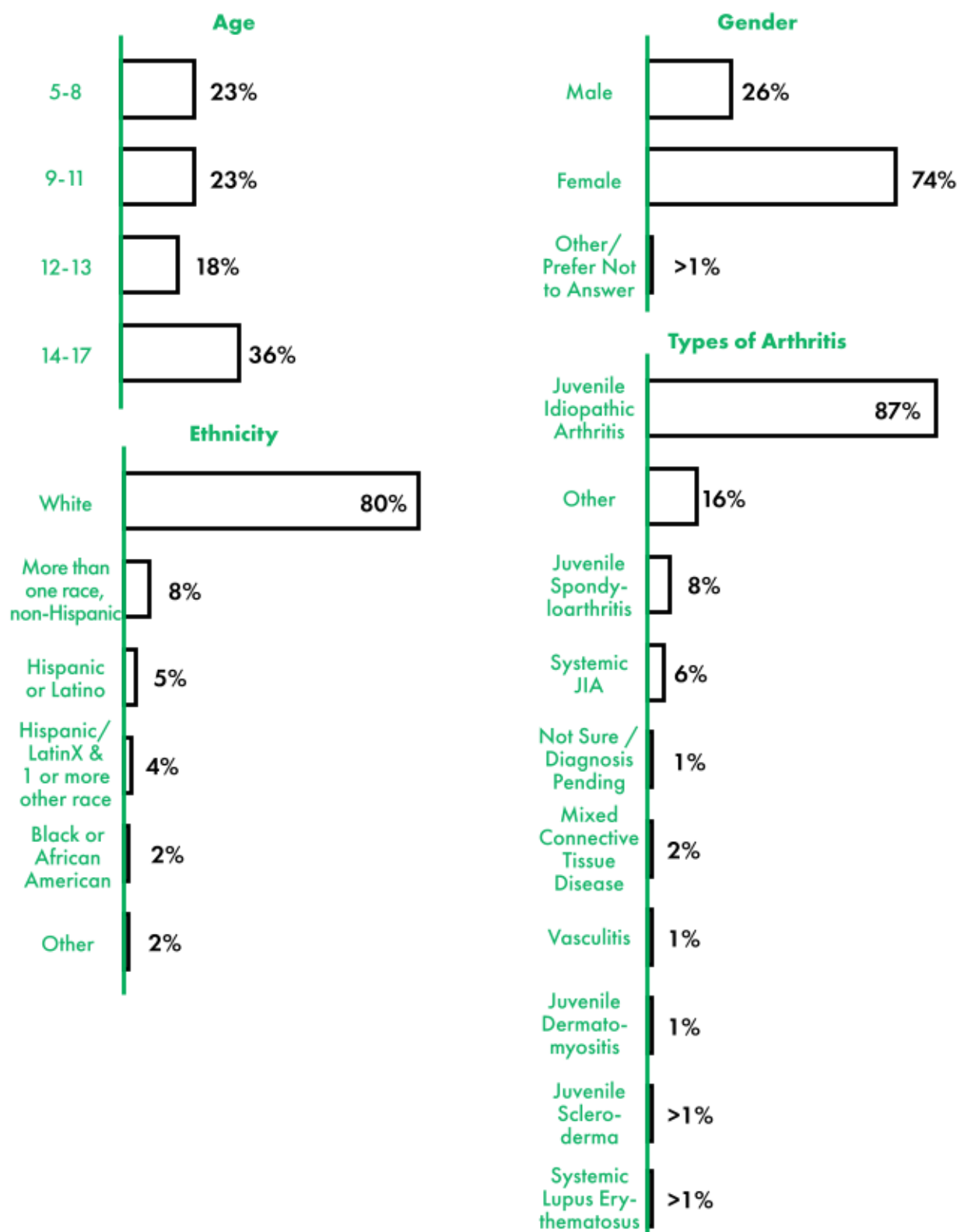


"It disrupted my sleep,  
my education and  
my family's financial  
situation. I missed weeks  
of school for surgeries  
and treatment. I gained  
a lot of empathy for all  
people with diseases  
and disabilities."

-Joshua

## Demographics of JA INSIGHTS Participants

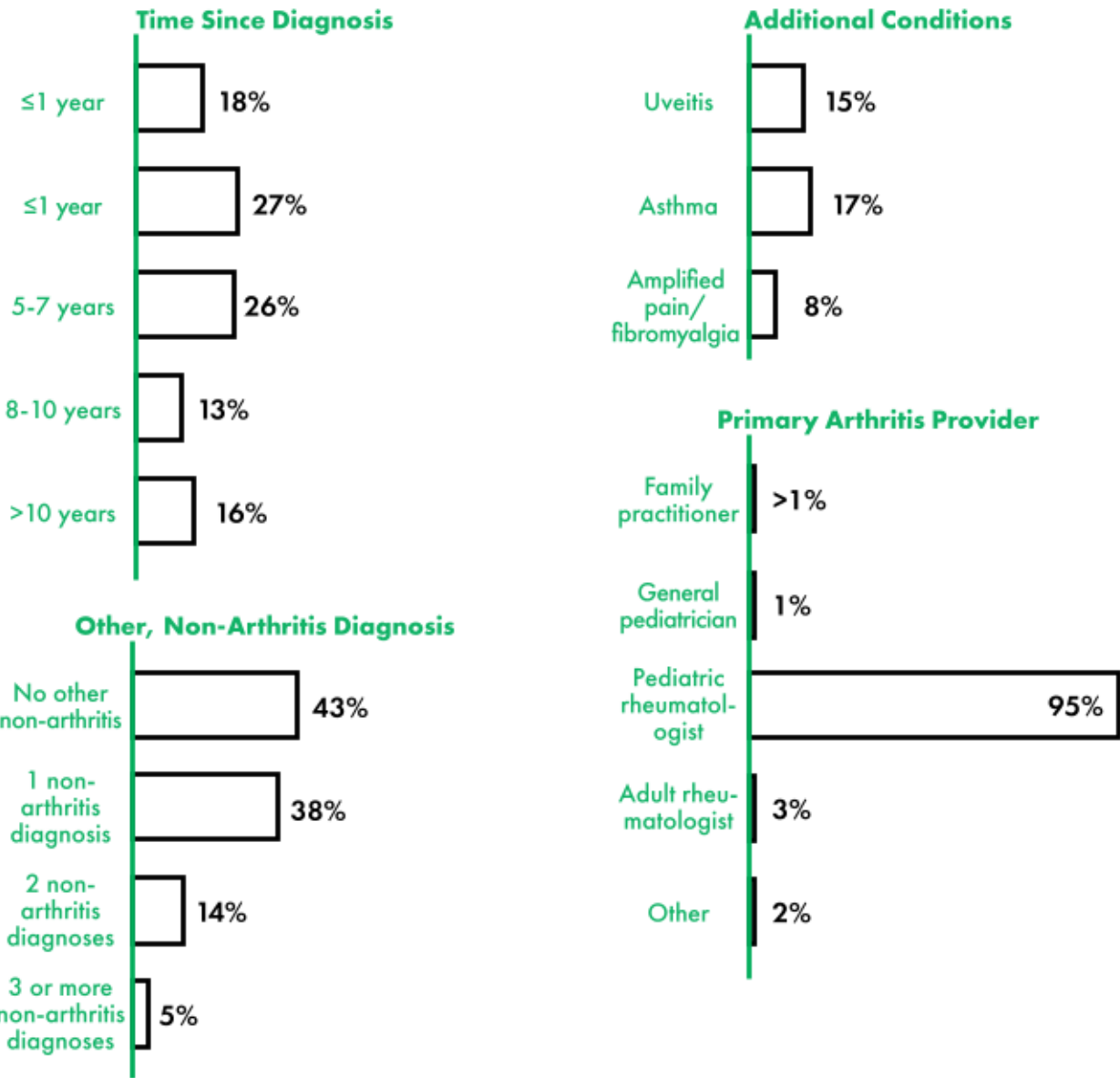
Most of the children in this analysis see a pediatric rheumatologist, which is not typical of kids with JA, and a majority are white girls with JIA. More than half also have at least one non-arthritis condition.





# Demographics of JA INSIGHTS Participants

The adults completing the JA INSIGHTS assessments were primarily white (86%) mothers (95%) and 68% had at least a college degree.





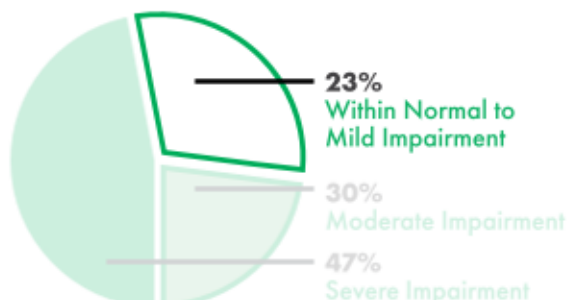
## How We Conducted the Study

The JA INSIGHTS assessment is deployed using an online survey platform through Qualtrics®. Participants across the country are invited to share their data using a combination of direct marketing, social media, website promotions and person-to-person outreach.

This program incorporates measures included in the PROMIS™ Pediatric Profile-25 (Parent Proxy), Patient Self-Advocacy Scale (Parent Proxy). Parents complete the assessments on behalf of their children ages 4 to 17. The value of including these measures is that it provides a benchmark for comparison to assess the impact of arthritis on those living with pain every day.

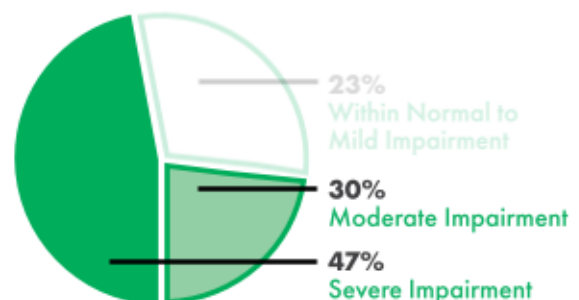
## Interpreting the Charts

The use of validated measures provides a comparison to benchmarks of the general population. When the score for a given measure is within the benchmarked range of the general population, the score is considered “within normal limits.” In this example, the white pie slice represents the proportion of juvenile arthritis patients represented in the survey who either experience an interruption in their daily lives due to arthritis pain similarly to those without



arthritis — or “within normal limits” — or who have some mild impairment.

The two green slices represent the proportion of juvenile arthritis patients represented in the survey who experience a more significant interruption in their daily lives due to arthritis pain. What you will see on the following pages is how the majority of juvenile arthritis patients whose parents participated in this study are being impacted negatively by their arthritis throughout all aspects of their lives.



## Measuring Impacts

To help us understand the impact arthritis has on every facet of an arthritis patient's life, we focused on the following areas.

### Physical Function & Fatigue (PROMIS™)



- Pain intensity
- Pain interference with sleep
- Ability to run or participate in sports/exercise
- Ability to walk one block
- Ability to get off the floor
- Ability to climb stairs without support
- Ability to pay attention or keep up with schoolwork

### Mental and Emotional Wellness (PROMIS™)



- Level of anxiety
- Feelings of sadness or depression
- Feelings of loneliness
- Feelings of hopelessness
- Ability to have fun

### Social Health (PROMIS™)

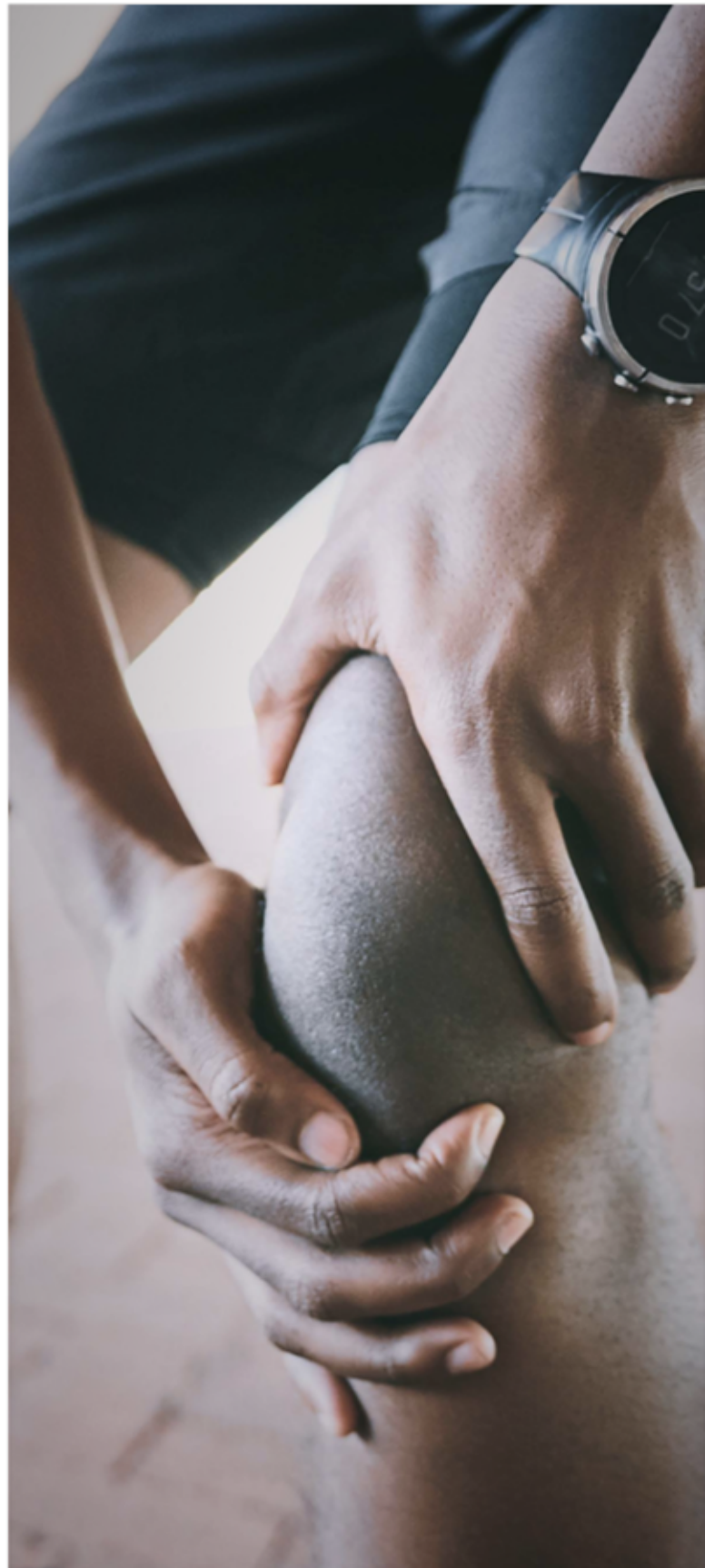


- Acceptance by peers
- Supporting friendships

### Experience of Care (PSAS)



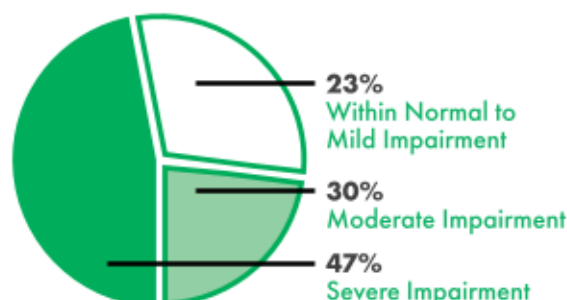
- Parent's health knowledge
- Parent's assertiveness
- Parent's probability of taking an active role in child's care
- Parent's probability of challenging or not following medical advice





## Pain Is a Daily Obstacle

Pain is prevalent with arthritis, and it has real impacts on day-to-day life for children with JA.



**75%**

of parents reported that pain moderately or severely interfered with their child's ability to sleep, pay attention, run, or walk one block over the past week.



**58%**

of the time, the child's pain intensity was in line with how much it interfered with their activities and life, meaning pain didn't interfere very much in those with less pain and it had greater impacts on those with more pain.



**36%**

of children had high pain levels that affected them and their activities a lot.

**41%**

were affected a lot even though they didn't have as much pain, suggesting that even a little pain can undermine quality of life.

## Pain and Physical Abilities

Pain is linked to worse physical function and mobility. Parents reported that in the previous seven days, their child was significantly limited by pain.



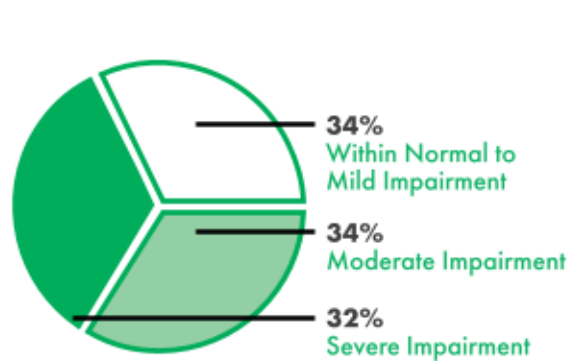
**22%**

reported their child couldn't or had trouble climbing stairs.

- 20% said their child had some or a lot of trouble getting up off the floor.
- 18% reported that their child couldn't do exercise or sports like other children or could only do it with great difficulty.

## Pain and Fatigue

More pain is also correlated to [worse fatigue](#), making it more difficult for a child with JA to keep up with schoolwork, participate in [sports](#) or exercise or do other things they enjoy.



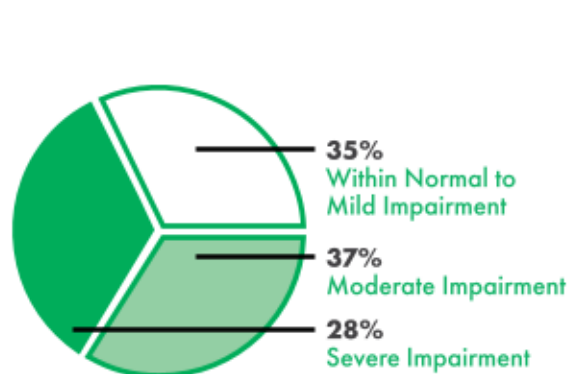
**32%**

of parents reported that their child often or almost always tired easily

- 23% reported that fatigue made it difficult for their child to keep up with schoolwork.

## Pain and Mental Health

The degree to which pain interferes with a child's quality of life — more so than the level of pain — was linked to [depression](#) in this assessment.

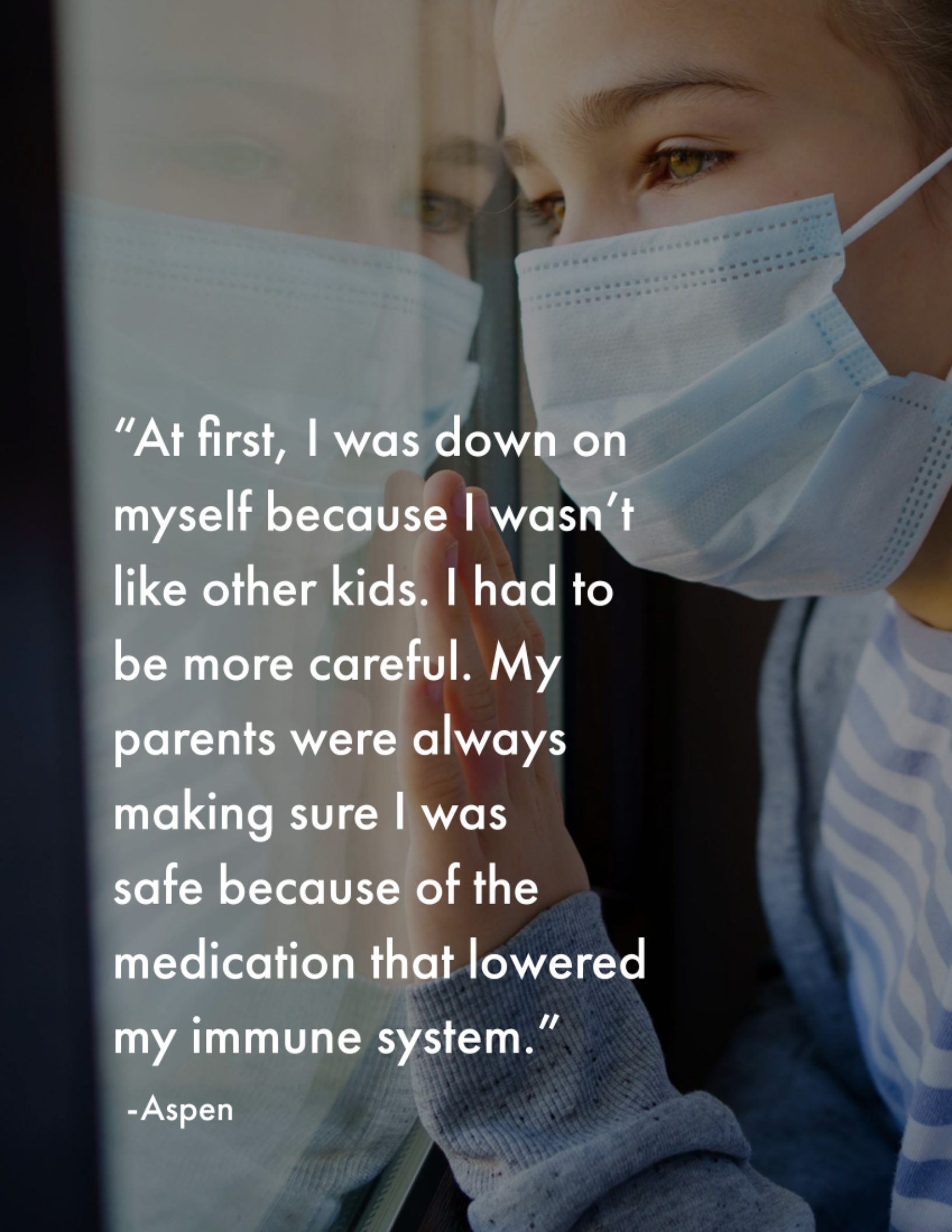


**65%**

of kids had moderate to severe depressive symptoms.

- Only 7% reported having poor friendships
- One-third reported having moderate to severe anxiety



A close-up photograph of two children, likely of Asian descent, looking out of a window. They are both wearing light blue surgical face masks. The child in the foreground is wearing a blue and white striped shirt and a grey sweater. The child in the background is wearing a white shirt. Their hands are pressed against the glass of the window. The lighting is soft and natural, coming from the window.

“At first, I was down on myself because I wasn’t like other kids. I had to be more careful. My parents were always making sure I was safe because of the medication that lowered my immune system.”

-Aspen



## Pain and Non-arthritis Conditions

Children with three or more conditions in addition to arthritis (comorbidities) had the worst pain, it affected their lives the most, and they had the most fatigue and least physical function.

The three most common non-arthritis conditions reported were

- [Uveitis](#) (eye disease)
- Asthma
- [Fibromyalgia](#) or other amplified pain condition

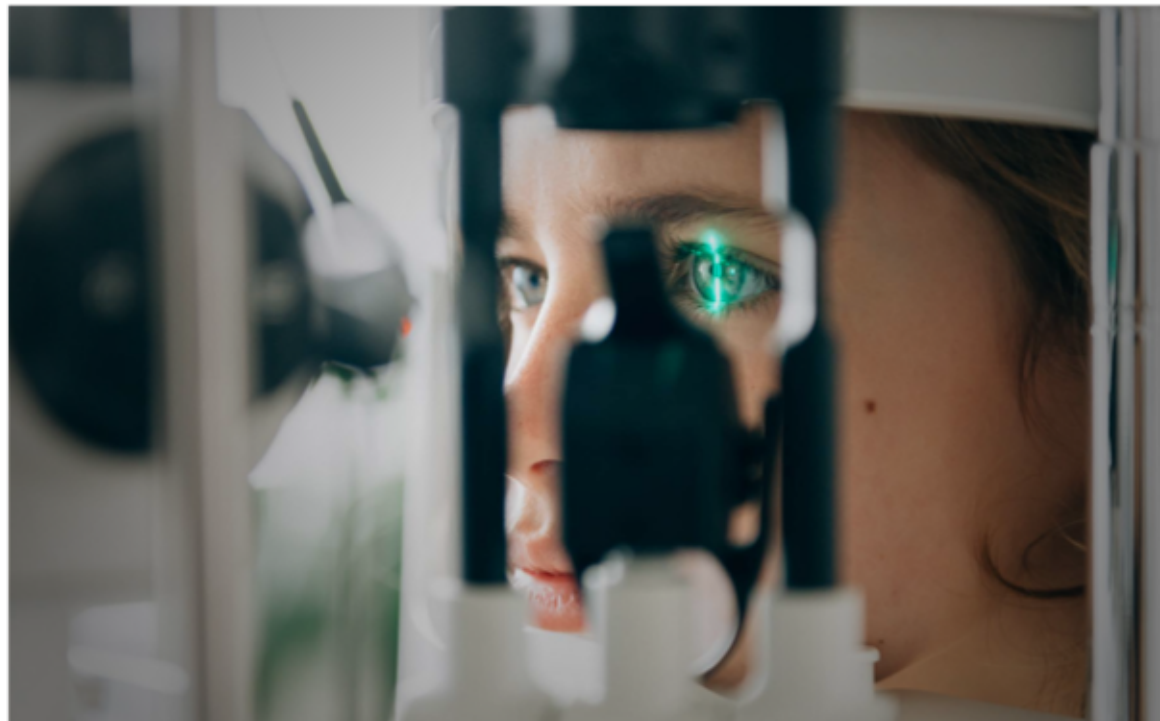
22% reported that their pain was not very intense and it didn't interfere in their life very much, especially those who

- Have parents with higher education (30% with a graduate degree)
- Were ages 5 to 8 (33%)

Those with two or more comorbidities had, on average, severe fatigue compared with the general population, and moderate to severe fatigue compared with others who have JIA.

Older children (ages 14 to 17) had worse pain and it impacted their life more than younger patients.

The lack of demographic diversity in this analysis limited the ability to measure differences by demographic group. This demonstrates the need to reach more and diverse groups of people to participate in JA INSIGHTS for future analyses.



## How We Are Responding

We launched Live Yes! INSIGHTS and then JA INSIGHTS to further scientific understanding of how arthritis and juvenile arthritis affect people's daily lives and quality of life. Just as important, though, is their role in guiding our priorities. We are refining our programming and resources to address and amplify physical health, social and emotional wellness and experience of care in our JA programs as well as in our advocacy and science initiatives.

### JA Conference

[The annual JA Conference](#) draws JA families from across the country to connect, share and learn more about JA, its treatments and ways to live better with JA. The most valuable benefit, however, may simply be the opportunity for kids with JA and their families to meet others facing the same experiences and struggling with the same challenges.

This year, the conference highlights sessions for parents, young adults, teens and kids with JA (as well as their siblings) focused on physical, social and emotional health, as addressed in JA INSIGHTS. They include:

- **For parents:** topics addressing life and medical transitions as children grow up, such as staying physically active, helping kids cope and fostering independence; social and emotional health; plus, complementary therapies, pain management and sleep health with JA
- **For kids:** Panda Clinic highlighting social and emotional health; coping skills; development of social and emotional skills; understanding their disease; and physical activities such as yoga
- **For teens:** sessions on physical health and mindful movement, including yoga; social and emotional coping skills; understanding their disease, fostering independence; talks with young adults about living with JA, and making connections and building relationships and support systems
- **For well-being of parents:** addressing caregiver stress; and making connections and building support systems





## JA Camps

Physical, mental and social health are cornerstones of [JA camps](#).

As camps resume in person as well as virtually, they include activities to promote physical activity, including yoga and movement activities. Programming activities that support social and emotional health include mindfulness and guided meditation, expression through art, connecting with nature, leadership development, fostering independence, making connections and building relationships, talks with doctors, and talks with young adults living with JA.

## JA Days

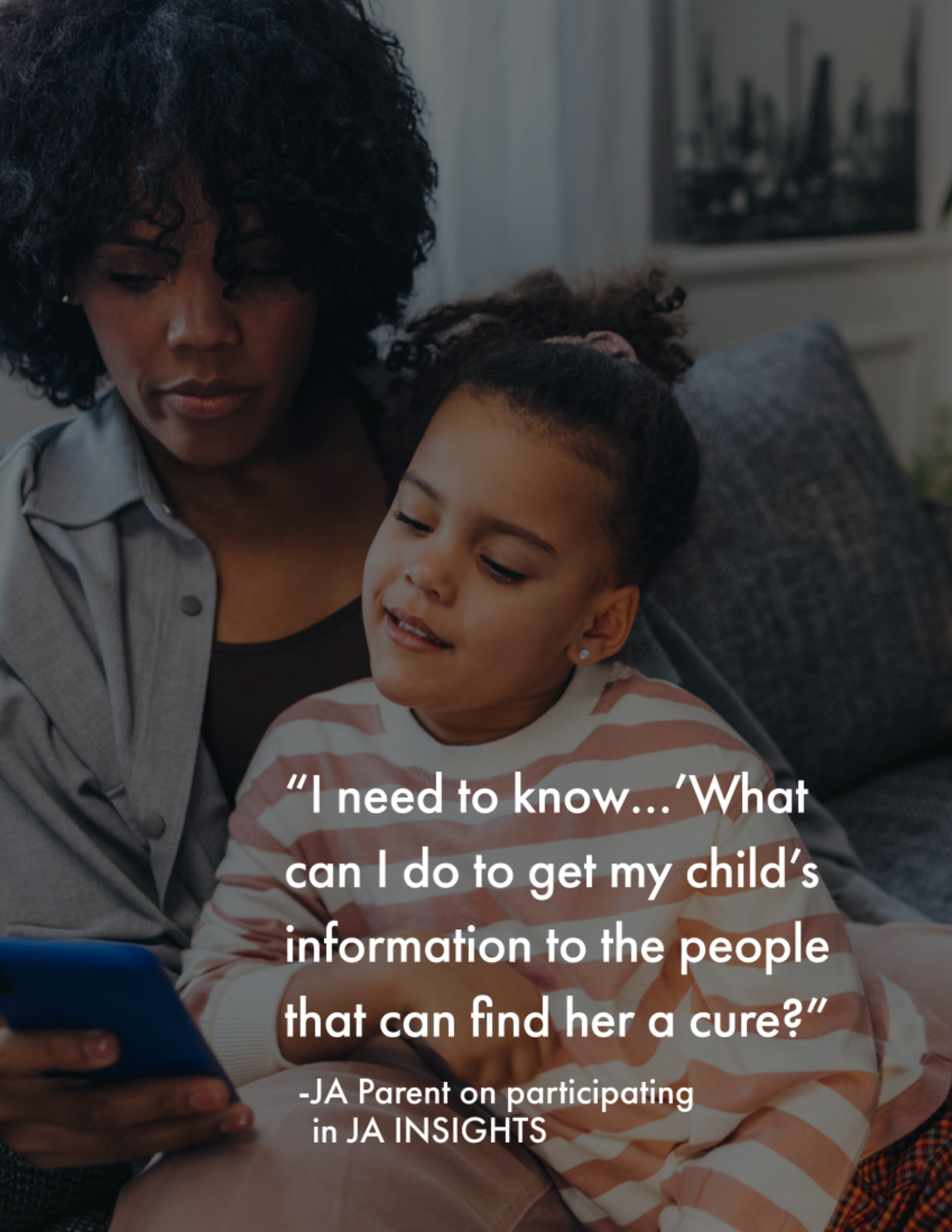
Hosted in local communities throughout the country, JA Days provide opportunities to connect and build relationships as well as to gain and share knowledge about various disease-management topics.

## Other Resources

The Arthritis Foundation has a variety of other new and expanded resources to help JA families.

- [Educational webinars](#), including “[JA and Emotional Health](#)” geared to different age groups and “Back to School – Educational Rights.”
- [JA Parent Connect Groups](#), with programming topics focusing on the three domains that facilitators can choose from. New this year are national virtual groups by age group.
- Newly redesigned website with in-depth [information about JA](#) and dedicated [resources for JA families](#), articles on juvenile arthritis and depression, on helping your child cope with everyday anxieties, on exercises for kids with JA and more. You’ll also find information and stories about other kids and families living with JA, including a [podcast](#) with NASCAR driver and JA patient Natalie Decker.
- Newsletters for JA families highlight articles, resources and activities addressing physical, social and emotional wellness, among other topics.



A woman with dark curly hair and a young girl with curly hair tied back are sitting together, looking at a blue tablet. The woman is wearing a grey button-down shirt over a dark top. The girl is wearing a white and orange striped sweater. They are in a dimly lit room with a grey cushion and a framed picture of a city skyline in the background.

“I need to know... ‘What  
can I do to get my child’s  
information to the people  
that can find her a cure?’”

-JA Parent on participating  
in JA INSIGHTS

## INSIGHTS Informs Improved Care & Treatments

**The Arthritis Foundation developed Live Yes! INSIGHTS and JA INSIGHTS as tools to capture the experiences and challenges of everyday life with arthritis in adults and children, respectively.** What makes JA INSIGHTS especially impactful is that it echoes the voices of patients through direct input from their parent or guardian. The findings from these personal accounts reflected in JA INSIGHTS are key to shaping the Foundation's priorities for our work to improve care and treatments for JA.

**Improving life and treatments for those living with juvenile arthritis has long been a pillar of our mission**, and our [science initiatives](#) reflect that. We employ science to improve quality of life for JA families by funding [CARRA \(Childhood Arthritis and Rheumatology Research Alliance\)](#) programs that focus on:

- Developing better JA consensus treatment plans and addressing the gap in care during transition from pediatric to adult rheumatological care.
- Correlating pain and patient-reported outcomes to disease progression and improving outcomes for all people living with arthritis.
- Funding curriculum development that aims to increase the number and diversity of adult rheumatologists, pediatric rheumatologists, and allied health care professionals.

**Since 2018, we have awarded \$2.75 million in clinical fellowships to 14 academic institutions**, including \$400,000 toward diversity, equity and inclusion research and curriculum development to address health disparities. Most of the fellows currently supported through the program are pediatric rheumatologists.

**Since 2015, we have invested \$33.5 million into CARRA**, including \$4 million in 2021 to support growth of its registry, investigator-initiated research and more. This has helped advance our knowledge and understanding of pediatric rheumatologic conditions. Based on AF funding, data from an interesting study was published that found poverty is associated with disability but not disease activity in polyarticular JIA, but that race/ethnicity is associated with both functional disability and disease activity. These findings emphasize the need to gain broader demographic participation for the CARRA registry and JA INSIGHTS.





## JA INSIGHTS Influences Health Care Policies

**JA INSIGHTS findings guide and support our advocacy efforts.** In combination with patient stories, these findings amplify the voices and experiences of those living with JA to make legislators, policy makers and other decision-makers aware of the challenges so they can drive change for better health care and quality of life.

Here are some of the steps we're taking through advocacy:

**We're addressing workforce shortages to improve experience of care.** We have been a leader in pushing for loan repayment for pediatric subspecialists like rheumatologists who practice in rural and underserved areas. We helped secure funding for the Pediatric Subspecialty Loan Repayment Program in 2022 and will continue to advocate for more funding to address the shortage of pediatric rheumatologists our JA families rely on.

**We're addressing access issues to improve experience of care.** The health coverage barriers that impact adults and parents also impact kids with arthritis. We've worked diligently over the years to secure protections for people with arthritis to better afford and access their medications, including:

- **Step therapy:** We have secured step therapy protections through legislation in more than 27 states.
- **Out-of-pocket costs:** We have secured patient cost protections through legislative efforts like co-pay caps and the ability to count co-pay assistance toward your cost-sharing in more than 14 states.

These efforts continue, and we invite our JA families to have a voice in helping to secure more victories in our current efforts, including:

- **[HR 2163/S 464, Safe Step Act.](#)** This legislation would provide guardrails around the use of step therapy. Our goal is to pass this legislation by January 2023. JA families can ask their members of Congress to co-sponsor this legislation through this action alert.
- **[HR 5401, HELP Co-pays Act.](#)** This legislation would ensure that co-pay assistance would be counted toward a patient's cost-sharing. JA families can ask their members of Congress to co-sponsor this legislation through this action alert.

**The voices of patients and their parents or guardians are vital to elevate our advocacy efforts.** The power of their stories cannot be understated. We bring the first-hand experiences of patients to our advocacy every day — and it makes all the difference. We encourage JA families to share their stories about their health care experiences through our [online story-bank](#). They make our work and impact even more powerful.

**Kids have a voice, too.** We encourage children with JA aged 13 to 17 to join our [Junior Ambassador program](#) to stay connected and engaged in advocating for themselves.





# Impact the Future of JA With **JA INSIGHTS** An Arthritis Foundation Study

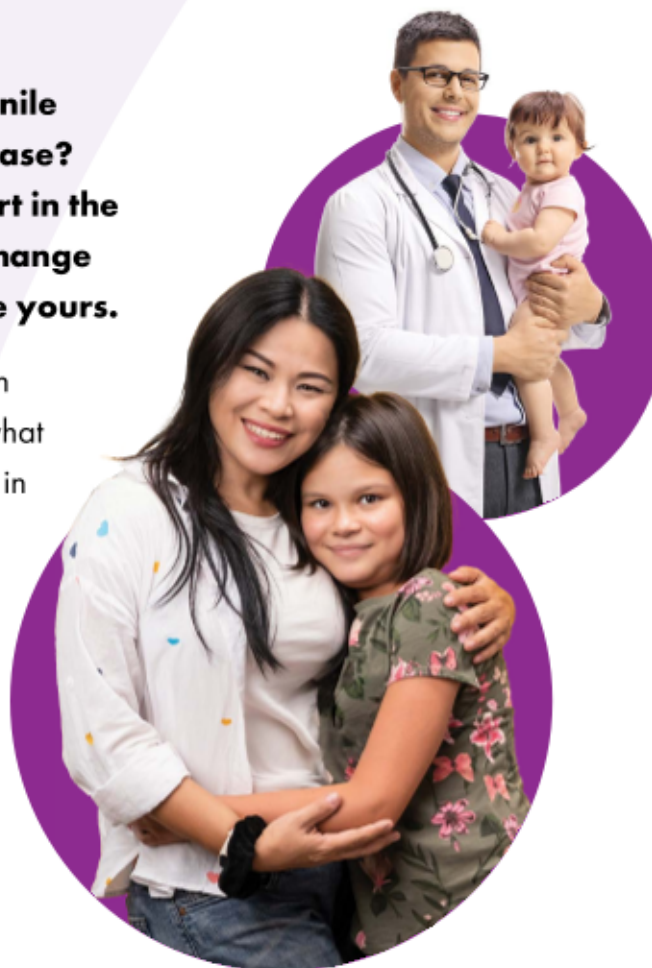
**Are you a parent of a child age 5-17 with juvenile arthritis or a related childhood rheumatic disease? The Arthritis Foundation needs you to take part in the **JA INSIGHTS** research study. You could help change the lives for 300,000 children and families like yours.**

There are so many questions for a child growing up with arthritis. As a parent and caregiver, you worry about what their quality of life will look as they grow. Your answers in the **JA INSIGHTS** study could lead to more effective care for children living with arthritis, more programs that meet your community's needs and help shape a powerful agenda that fights for them.

**Imagine a world without juvenile arthritis. You can help us get there at [arthritis.org/JAINSIGHTS](https://arthritis.org/JAINSIGHTS)**



SCAN ME





### **Acknowledgments**

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Arthritis Foundation Patient Leadership Council

110 patients, health care professionals and measurement experts who helped select the measures

JA Families who took the assessment

**The Arthritis Foundation is grateful to Alpha Omicron Pi for their support  
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**ALPHA OMICRON PI**