2025 ANNUAL REPORT

A Year of Impact.

CARRA

Childhood Arthritis and Rheumatology Research Alliance

The connections I made with the support of CARRA directly sparked a new collaborative project with the SJIA/MAS working party. Six months later, that collaboration is actively moving forward, reflecting the impact of the connections and ideas generated during the meeting."

– **ESRAA ELOSEILY,** MD, MSc.
UT Southwestern Medical Center

Won the CARRA-PReS Travel Award to attend the PReS conference in Europe in 2025

This past year has been full of meaningful progress, exciting collaboration, and continued momentum for CARRA as we work together to improve the lives of children living with rheumatic diseases.

STACY ARDOIN, M.D.
CARRA President

As I reflect upon 2025, one theme stands out: partnership. The progress reflected in this report would not be possible without the dedication of our physician-investigators, the engagement of patients and families, and the generosity of our partners and donors who believe in our mission.

TOGETHER, IN 2025 WE:

- **Conducted a Strategic Planning process**, working with a diverse community to refine our mission, vision, values and goals.
- **Launched a critical initiative to strategically modernize the CARRA Registry**, strengthening the most comprehensive, representative, and scientifically rigorous pediatric rheumatology research platform in North America.
- **Awarded nearly $2 million in grants** through the CARRA-Arthritis Foundation Grant Program to support pediatric rheumatology research.
- **Celebrated impactful publications** that illustrated the breadth and depth of CARRA's research community – from STOP-JIA outcomes to global collaborations of pediatric specialists focused on CAR T cell therapy for children.
- **Put patients and families first**, as CARRA continues to elevate their voices in research.

As we look ahead, CARRA remains focused on advancing research excellence, fostering innovation, and strengthening the partnerships that make discovery possible. While there is still much work to do, we are encouraged by the momentum we are building together and the opportunities ahead to accelerate progress.

Thank you for your continued support, partnership, and commitment to improving the future for children living with rheumatic diseases.

Kind regards,

Stacy Ardoin, M.D.
CARRA President

WELCOMING OUR NEW CEO

CARRA proudly welcomed **Rachel Myslinski, MBA**, an experienced nonprofit and health care leader with more than 20 years of experience in strategic planning, financial management, philanthropy, and healthcare policy. In her most recent role, she was the Executive Director of the Rheumatology Research Foundation, where she oversaw the organization's strategy and operations.

A STRATEGIC VISION

A diverse group of stakeholders helped to shape CARRA's next Strategic Plan. We refined our mission, vision, and values, and identified three areas of focus with strategic goals.

OUR MISSION

To unite the pediatric rheumatology community to drive research and transform the lives of children with rheumatic diseases.

OUR VISION

A world where every child with rheumatic disease thrives.

OUR VALUES

Impact
Inclusiveness
Trust
Innovation,
Stewardship
Collaboration

AREAS OF FOCUS

Achieving Research Excellence • Leveraging Community Engagement • Ensuring Organizational Excellence

> CARRA advocates for patient and caregiver involvement – not just in day-to-day treatment, but in research, workgroups and the Strategic Planning process. The community knows what they need if you ask them. I applaud CARRA for doing just this."
>
> **– SHILOH KANTZ**
>
> *Parent to a child with systemic sclerosis and a member of the Strategic Planning Taskforce.*

A Record-Setting **ANNUAL SCIENTIFIC MEETING**

CARRA's Annual Scientific Meeting (ASM), which was held in Denver in 2025, is a direct investment in the pediatric rheumatology workforce, bringing together the entire spectrum of physicians, investigators, nurses, research professionals, and caregivers.

We are grateful to the following ASM sponsors for their commitment to advancing pediatric rheumatology and supporting our workforce: the Arthritis Foundation, Boehringer Ingelheim, Cure JM, The Lupus and Allied Diseases Association, Inc. (LADA), Novartis, Sobi, and Wilson Sonsini Goodrich & Rosati.

400+ ATTENDEES

118 FIRST-TIME ATTENDEES

52 CAREGIVERS & PATIENTS

92 TRAINEES

6 COUNTRIES + **37** STATES

50+ WORKGROUPS

Supporting **PEDIATRIC RHEUMATOLOGY RESEARCH**

CARRA's peer-reviewed grant program supports investigators at all career levels and advances research to fuel discovery.

From the CARRA-Arthritis Foundation Grant Program and the CARRA-PReS Collaborative Research Award to travel awards designed to empower early investigators, CARRA offers a range of dynamic funding opportunities to fuel innovation and collaboration.

In response to changes in the federal funding environment, the Arthritis Foundation and CARRA increased funding for the grant program by $200,000 in 2025.

2025 CARRA-ARTHRITIS FOUNDATION GRANT PROGRAM

NEARLY **$2 MILLION** AWARDED

FIVE OF THE **13** AWARDEES WERE **FIRST-TIME RECIPIENTS**

50% INCREASE IN APPLICATIONS

FUELING RESEARCH WITH THE ARTHRITIS FOUNDATION: A GLOBAL IMPACT

A 2019 CARRA-Arthritis Foundation Small Grant helped launch an international collaboration with the Pediatric Rheumatology European Society (PReS) as part of a global effort to improve outcomes for children with juvenile systemic sclerosis, a rare, complex disease requiring global collaboration to find effective therapies.

> "This global partnership is helping to develop outcome measures that work across diverse clinical environments, so no child is left behind. CARRA's support has been vital in moving this work forward, bringing us closer to targeted, life-changing treatments for kids everywhere."

– **NATALIA VASQUEZ-CANIZARES, M.D.**, *A pediatric rheumatologist at The Children's Hospital at Montefiore*

Researchers surveyed rheumatology providers in North America, Europe, South and Central America, Asia and Africa, laying the groundwork for future international clinical trials.

Vasquez-Canizares received a CARRA publication support grant in 2025 to share what they have learned so far in Pediatric Rheumatology.

TOTAL FUNDING GIVEN BY CARRA IN 2025

26 GRANTS

MORE THAN **$2M**

24 INVESTIGATORS

IMPACT OF CARRA'S GRANTS SINCE 2016

241 AWARDS

$10.4 MILLION INVESTED

148 PRINCIPAL INVESTIGATORS

82 INSTITUTIONS

$14.9 MILLION IN ADDITIONAL FUNDING

121 PUBLICATIONS

"At the heart of CARRA's work is a deep commitment to children and families affected by rheumatic disease. This award accelerates our work to identify biomarkers that predict disease trajectory and treatment response in Juvenile Spondyloarthritis, bringing us closer to more personalized and effective treatments for kids."

– **BRITTNEY NEWBY, M.D., PH.D.**, The Children's Hospital of Philadelphia
Won a Mentored Career Development Award in 2025.

2025 was a banner year for CARRA researchers, with publications that advanced science, elevated patient voices and strengthened collaborations across institutions, funders and disease areas. These studies – just a few of many – demonstrate how CARRA's community-driven research model drives the future of pediatric rheumatology.

PHASE IV STUDY: LONG-TERM SAFETY OF CANAKINUMAB IN SJIA

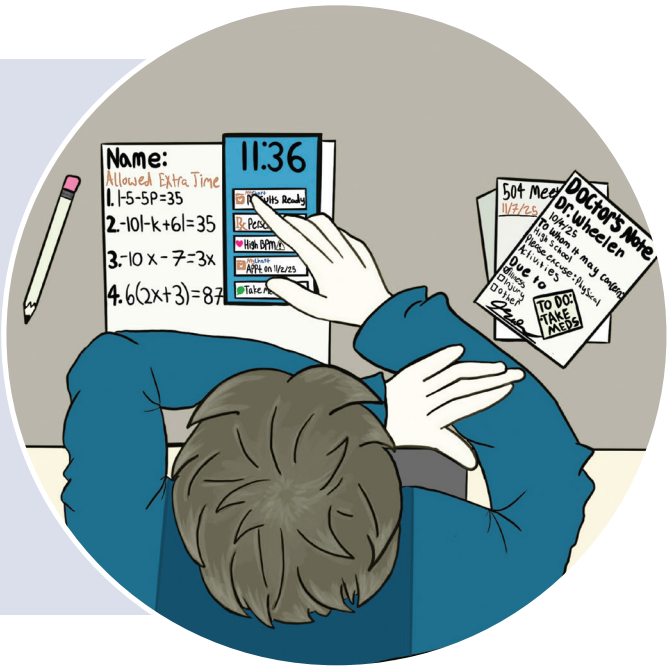
We are proud to highlight a publication in *Pediatric Rheumatology* about a prospective study that used the CARRA Registry to evaluate the long-term safety of canakinumab in patients with systemic juvenile idiopathic arthritis (sJIA).

CARRA partnered with a leading pharma company to conduct this Phase IV study of canakinumab, and it marks **the first Phase IV study using the CARRA Registry that has been completed and published in a peer-reviewed medical journal.**

This study followed patients with systemic JIA – whose ages ranged from 2 through 17 when they started treatment – for a minimum of five years to collect data on serious adverse events and events of special interest. The final analysis, which included 177 patients, suggests that **canakinumab is effective in managing systemic JIA** and has a favorable safety profile with long-term use in real-world settings.

MENTAL HEALTH LEADERSHIP

Did you know that mental health problems, especially anxiety and depression, are more common in children with rheumatic diseases? CARRA's Mental Health Workgroup, including patients and families, led the way to develop the first evidence-based consensus guidance statements for mental health concerns in kids age 12 and up with rheumatic disease. These were endorsed by American College of Rheumatology and published in *Arthritis Care & Research* in 2025.



Study Shows Earlier Effective Treatment Results in Better Outcomes for **CHILDREN WITH POLY JIA**

New three-year results from a landmark **STOP-JIA** study powered by the **CARRA Registry and CARRA's Consensus Treatment Plans (CTPs)** showedthat very early use of biologics can improve long-term outcomes for children with Polyarticular Juvenile Idiopathic Arthritis (poly JIA).

This longer-term analysis of the STOP-JIA study looked at the effect of the CARRA CTPs, which differ in the timing of when biologics are started for this disease.

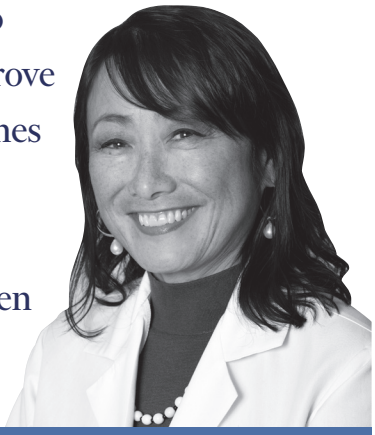
After following nearly 300 children with poly JIA in the CARRA Registry for three years, the study showed the following:

- Children who began the Early Combination CTP (starting biologics and methotrexate together) spent significantly more time in inactive disease than those who received the Step-Up CTP (starts with methotrexate alone and adds a biologic after 3 or more months if needed).
- In a separate analysis, children who started biologics within two months had a much higher likelihood of being in the best long-term trajectory.

Published in 2025 in *Arthritis & Rheumatology* and funded by the Patient-Centered Outcomes Research Institute (PCORI), STOP-JIA (Start Time Optimization of biologics in Polyarticular Juvenile Idiopathic Arthritis consensus treatment plans study) is an example of how CARRA's collaborative model drives research that directly informs clinical care.

Consensus Treatment Plans make it possible to conduct comparative effectiveness research through the CARRA Registry, which makes enrolling large numbers of patients feasible. By narrowing treatment approaches and then studying how patients respond to each, physicians can better identify which treatment may be most effective.

"The latest results show that by starting biologics earlier, we may be able to significantly improve long-term outcomes and reduce the overall disease burden for children with poly JIA,"



– **YUKIKO KIMURA, M.D.** {Principal Investigator}
Division chief of pediatric rheumatology at Hackensack University Medical Center

"This STOP-JIA study has allowed us to continue learning about how best to start biologics in children with recently diagnosed poly JIA and helps doctors and families to make more informed decisions.

– **LAURA SCHANBERG, M.D.**
Professor of pediatrics at Duke University and co-PI of the study.

The study underscores CARRA's leadership in pediatric rheumatology research and highlights the impact collaborative research has on clinical care."

How **SOCIOECONOMIC FACTORS** Affect Kids with Lupus

A study published in *Lupus Science & Medicine* used CARRA Registry data to examine disease activity over time in children with lupus.

RESEARCHERS FOUND:

- Socioeconomic factors were strongly linked to worse outcomes.
- Children with more pain at baseline had a harder time getting their disease under control.
- Findings highlight the need for equitable access to resources and targeted support for high-risk pediatric populations.

This research is part of an ongoing project, which is funded by the **Centers for Disease Control and Prevention**. The project, led by CARRA members Aimee Hersh, M.D., of University of Utah School of Medicine and Primary Children's Hospital; Andrea Knight, M.D., M.S.C.E, of The Hospital for Sick Children; and Mary Beth Son, M.D. of Boston Children's Hospital, reinforces the importance of patient-centered outcomes.

A Partnership that **POWERS PROGRESS**

The Lupus and Allied Diseases Association, Inc. (LADA) and CARRA partnered in 2025 to advance two major childhood lupus research efforts:

- **Molecular profiling study** to better classify and treat cSLE, led by **Dr. Linda Hiraki** with **Dr. Laura Lewandowski** advising
- **Mental health study** examining trauma and emotional well being in youth with cSLE, led by **Dr. Natoshia Cunningham**, **Dr. Andrea Knight**, and **Dr. Tamar Rubinstein**

These projects aim to improve both medical outcomes and mental health support for young people living with lupus.

THE FUTURE OF CAR T for Children with Autoimmune Diseases

The **international** Integrated Multidisciplinary Paediatric Autoimmunity and Cell Therapy (IMPACT) group brought together experts in pediatric rheumatology, oncology, and cellular therapy, immunology, and nephrology who published a *Nature* article outlining the promise of **B-cell-targeted CAR T cell therapy** for children with systemic rheumatic diseases.

FOR CHILDREN WITH AGGRESSIVE RHEUMATIC DISEASES, THE STATUS QUO IS SIMPLY NOT GOOD ENOUGH.

These patients face:

1. Lifelong therapy beginning in childhood
2. Substantial toxicity burdens from chronic immunosuppression
3. High cumulative costs of care
4. Persistent morbidity and mortality risks

This is cracking a door that was closed for decades: the possibility of durable remission without lifelong immunosuppression.

REVIEWING TWO DECADES OF PROGRESS IN JIA

CARRA leaders Christy Sandborg, M.D.; Grant Schulert, M.D., Ph.D.; and Yukiko Kimura, M.D. wrote a review article about JIA for *The New England Journal of Medicine*, one of the most prestigious and well-read journals in the world. The article highlights:

- Dramatic improvements and outcomes for children with JIA since 2000.
- The pivotal role of CARRA Registry studies – like Limit-JIA and STOP-JIA – in transforming care.
- How collaborative research continues to shape the future of JIA management.

This publication serves as a critical resource for healthcare professionals, researchers, and families worldwide seeking to better understand JIA.

CARRA BIOSAMPLES LEAD TO JUVENILE DERMATOMYOSITIS DISCOVERY

Thanks in part to support from the Cure JM Foundation, the CARRA Registry has been able to establish the largest North American multi-center juvenile dermatomyositis (JDM) inception cohort with more than 530 participants, as well as biosamples collected from about 30% of participants.

Using samples from the **CARRA Biobank**, researchers analyzed thousands of proteins in children with JDM at diagnosis and follow-up These novel findings, published in the *Annals of Rheumatic Diseases*, identified patterns linked to disease activity and JDM subtypes.

These discoveries lay the groundwork for future biomarker development and more personalized treatment approaches.

THE CARRA REGISTRY: Now and What's Next

The CARRA Registry & Biorepository is the largest ongoing, observational registry in North America focused on pediatric-onset rheumatic diseases. It captures clinical data, patient reported outcomes (PROs), and biospecimens that power safety studies, comparative effectiveness research, natural history insights, and translational discovery. For more than a decade, the Registry & Biorepository has been the backbone of multicenter pediatric rheumatology research. **In 2025, we laid the groundwork for its most significant evolution yet.**

WHAT'S NEXT?

In 2025, CARRA began the modernization process of the CARRA Registry & Biorepository to become a modern, unified platform that will connect clinical data, patient-reported outcomes, biospecimens, and EHR integrated data in one ecosystem. This transformation will reduce site burden, improve data quality, and expand access to research for children and families.

The Registry & Biorepository Modernization Process will:

- Provide real-time biospecimen visibility and faster access to high-quality data
- Give us the capability to expand enrollment to additional rare diseases, community sites, and enroll remote participants in the future.
- Support advanced analytics, predictive modeling, and rapid trial feasibility
- Accelerate translational discovery

This initiative will help CARRA produce better real world evidence, use more advanced analytic tools, and speed up the research and access to data needed to improve care and outcomes for children.

100,000+ NUMBER OF VISITS

16,000+
NUMBER OF PARTICIPANTS ENROLLED *as of Dec. 30, 2025*

70+ ACTIVE SITES

80+ INVESTIGATOR-INITIATED RESEARCH STUDIES

BY DISEASE:

13,400+
Juvenile Idiopathic Arthritis (JIA)

510+
Juvenile Dermatomyositis & Juvenile Polymyositis (JDM/JPM)

1,900+
Systemic Lupus Erythematosus (SLE) & Related Conditions

105 Scleroderma

NUMBER OF BIOSAMPLES (BLOOD) COLLECTED: **2,200+** ACROSS **22 COHORTS**

"CARRA's Advancing Biosample Collection Award is helping us expand biospecimen collection and longitudinal follow-up for children with lupus across multiple centers in the CARRA Registry. This data will help us understand how epigenetic changes relate to disease severity over time and ultimately develop more precise, targeted therapies for this high-risk population."

– **MEGHAN NELSON, DO**, of the National Institutes of Health

Our **CARRA COMMUNITY** in 2025

EXPANDING OUR NETWORK

The CARRA community brings together a diverse range of researchers, clinicians, patients, caregivers, industry partners, and advocates united by a shared commitment to improving outcomes for children with rheumatic diseases.

In 2025, CARRA welcomed **190 new members – a 28% growth rate** – and maintained an **86% renewal rate** among physicians, investigators, and trainees. This strong engagement reflects a vibrant, committed community and a pipeline of future leaders.

SUPPORTING THE NEXT GENERATION

Following the lead of our European colleagues at the Pediatric Rheumatology European Society (PReS), CARRA launched the **Pediatric Rheumatology Early Investigator Meeting**. This annual event offers keynote speakers, oral abstracts, roundtables and mentorship opportunities designed to support emerging investigators.

CARRA PATIENT AND FAMILY PARTNERSHIP

CARRA has been a national leader in patient and caregiver engagement. Families collaborate with researchers throughout the lifecycle of research, from ideation to dissemination. Families also have a voice in prioritizing research by reviewing every research proposal submitted to CARRA for funding. They also participate at meetings, and as work-group and committee members.

ALMOST **30%** of our Physicians & Pediatric Rheumatology Investigator Members **ARE EARLY CAREER.**

By working closely with families, CARRA ensures our research focuses on what matters most to patients and is designed to make participation meaningful and feasible for families.

30+
GRANT APPLICATIONS
reviewed by patients and caregivers in 2025.

EVERY
CARRA-ARTHRITIS FOUNDATION GRANT
gets reviewed by patients or caregivers.

50+ PATIENTS & CAREGIVERS
attended CARRA's Annual Scientific Meeting, in Denver as **research partners**.

"Through CARRA, I collaborate with doctors and help prioritize research. Being involved in CARRA has allowed me to play a part in helping others with rheumatic diseases, and I'm grateful to share my voice."

– **AVERY WENT,** *who served as a grant reviewer and is a member of CARRA's Long Term Follow-Up Subject Matter Expert Group.*

Our **CORPORATE PARTNERS**

Our corporate partnerships fuel modernization, collaboration, and essential fieldwide infrastructure to support the resources needed for critical, lifesaving and changing research.

In 2025, CARRA's Corporate Advisory Council brought together pharmaceutical leaders to pinpoint the key challenges slowing pediatric drug development and to explore how collective action with CARRA can transform the field. We thank AstraZeneca, Boehringer Ingelheim, Cabaletta Bio, Johnson & Johnson, Novartis, and Sobi for their partnership in advancing solutions that help children access treatments faster.

These corporate partners are passionate about changing the landscape for pediatric patients with rheumatic diseases. With their help, together we are:

1 Accelerating Treatment Options

De-risking clinical trials through innovative approaches to Registry extrapolation, innovative trial design, and partnership with the FDA.

2 Innovating through New Science

Ongoing research in immune-mediated diseases and treatment pathways to change the course of disease in children.

3 Improving Standards of Care

Enabling earlier, more effective interventions, helping children achieve remission or low-diseaseactivity sooner, and improving quality of life.

4 Supporting a Critical Ecosystem

Investing in the next generation of pediatric rheumatologists, collaborating and engaging with patient families, and accelerating the drug development process.

A Legacy That **CONTINUES TO INSPIRE**

Honoring Jessica Saal Through Purpose, Service and Hope

When Harry and Carol Saal lost their daughter, Jessica, to complications of juvenile rheumatoid arthritis, their world changed forever. In the years since, Harry has devoted himself to carrying forward the values Jessica lived every day: resilience, generosity and a deep commitment to helping others. Jessica's spirit lives on in Sips of Life, a collection of reflections inspired by the way she faced extraordinary challenges with optimism and purpose.

> "I made it my mission to focus my energy on things that she had been passionate about" – **HARRY SAAL**

Despite living with significant pain and undergoing multiple joint surgeries as a teenager, Jessica pushed forward. She excelled in school, graduated from Tufts University, and gave back to her community. She served on the board of the Northern California Arthritis Foundation and championed children with juvenile arthritis long before most people understood the disease. Her advocacy, especially for kids from underserved rural areas, remains a powerful part of her legacy.

LIVING LIFE TO THE FULLEST & GIVING BACK

A moment in Spain with Harry as Jessica embraced life in all its splendor.

Harry and Carol encouraged Jessica to pursue her dreams despite her polyarticular JIA. "We always fought hard for that," Harry said. And today, they continue that fight on behalf of thousands of children and families.

For more than a decade, Harry has shared his insight, lived experience and business expertise as a member of the CARRA Board. "I'm proud of how far we have come and how much CARRA is still growing," he said. "It has always been a pleasure to serve with this great team of very committed people."

"When Jessica was diagnosed in the early 1970s, treatment options were extremely limited," Harry said. "So much has changed, and CARRA has been a key part of advancing new therapies and ensuring they are safe and effective for kids."

JESSICA'S LEGACY

Yet Harry remains clear eyed about the work ahead. "We still don't have a cure, and children still face complex medical problems, limited access to care, and social challenges," he said. "Our work is not done."

CARRA extends heartfelt gratitude to Harry Saal for his leadership, generosity and unwavering dedication to our mission. And, for ensuring that Jessica's legacy continues to inspire hope, purpose and progress for children everywhere.

Having patients and caregivers on our project team ensures our study reflects what matters most to families. And with team members not only from different walks of life but also from around the world, it's another reminder of the special connections that CARRA makes and the amazing doors that grants like this can open."

– **DANIEL HORTON, M.D., M.S.C.E.**
Rutgers, The State University of New Jersey

Won the Clinical Management of JIA Grant for his project entitled JIA Flares, Recapture of Inactive Disease, and the Patient's Voice.

Meet the **MAHJONG MAMA**

Lindsey Fraser, mom of a young daughter with juvenile idiopathic arthritis, turned her online community into a force for good in 2025. Using her @mahjongmamanwa platform, she rallied players across the country to pre-order National Mah Jongg League cards, raising awareness and support for CARRA.

Based in Rogers, Arkansas, Lindsey and her husband and two daughters know the challenges families face, from managing medications and insurance to living with unanswered questions about her daughter's condition. There is no pediatric rheumatologist nearby, so she travels three hours each way to Arkansas Children's Hospital in Little Rock to see her daughter's specialist. Her daughter is doing well, and Lindsey is glad to be able to give back to the pediatric rheumatology community.

> "We're sending $3,306 toward pediatric rheumatology research and better outcomes for kids, like my daughter, living with arthritis. I'm very grateful to everyone who helped me support a cause close to my heart."

– **LINDSEY FRASER,** *Mahjong Mama*

> "The CARRA-Arthritis Foundation Bridge Grant was pivotal – it enabled me to develop a translational disease model that can drive future therapies."

– **LAUREN COVERT, M.D.**
Duke University School of Medicine

Who won a Bridge Grant for her research on "Using Bioengineered Human Muscle to Understand Mechanisms of Juvenile Dermatomyositis."

The Power of **COMMUNITY SUPPORT** in 2025

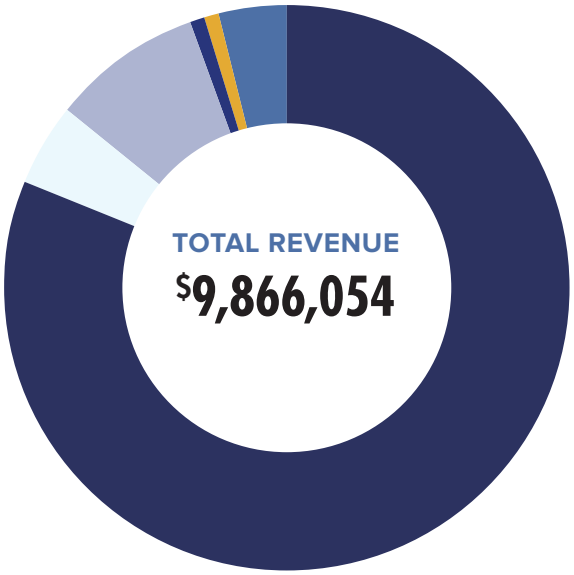
In 2025, the generosity of our donors helped advance critical pediatric rheumatology research and supported collaboration across the CARRA community – bringing hope to children and families affected by rheumatic diseases.

$49K
INCREASE IN TOTAL FUNDS RAISED in 2025 compared to 2024

20%
YEAR-OVER-YEAR fundraising increase

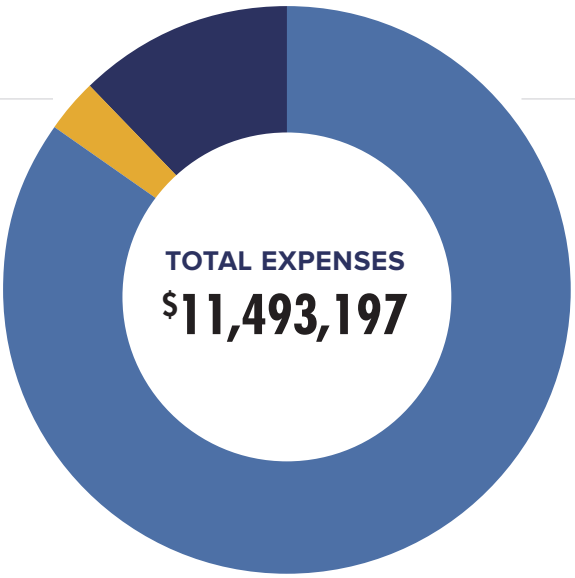
29%
of ONLINE DONORS during our year-end campaign were new supporters of CARRA

85% OF EXPENSES are for PROGRAMS AND SERVICES



REVENUE

Contract Revenue	81.38%
In-kind	4.48%
Investment Income	8.83%
Sponsorships	0.71%
Memberships	0.84%
Donations	3.76%



EXPENSES

Program	85.40%
Fundraising	3.09%
Management & General	11.51%

Net Assets without Donor Restrictions:	$10,071,378

"Families like mine face uncertainty when making these difficult decisions about medications, tapering, and the possibility of future flares. I'm grateful to support research that incorporates the patient voice into these decisions."

– **ANNA SUTTON, MPH**
Caregiver serving on Dr. Horton's project team.

CARRA
Childhood Arthritis and Rheumatology Research Alliance

Arthritis Foundation

CARRA is grateful for the ongoing financial support of the Arthritis Foundation.

CARRA

Childhood Arthritis and Rheumatology Research Alliance

MISSION: To unite the pediatric rheumatology community to drive research and transform the lives of children with rheumatic diseases.

SIGN UP for our e-newsletter

carragroup.org

Charity Navigator FOUR-STAR 2026

Platinum Transparency 2026 Candid.