A YEAR OF
IMPACT

Accelerating Research, Improving Lives

CARRA

Childhood Arthritis and Rheumatology Research Alliance

2024 ANNUAL REPORT

Dear Colleagues and Partners,

As I look back on 2024, I'm filled with deep pride and gratitude for the extraordinary strides we've made together as a community. It has been a year marked by growth, collaboration, and a renewed sense of purpose in our shared mission: to prevent, treat, and ultimately cure pediatric rheumatic diseases through collaborative research.

Together, we've reached powerful milestones that speak to the heart of what CARRA stands for:

- **The CARRA Registry enrolled its 15,000th participant in October** — an incredible achievement as we also mark its 10th anniversary. The Registry and Biobank continue to serve as foundational pillars of our research efforts, with growing utilization by investigators and increasing demand for biobank samples to power innovative studies.

- **CARRA awarded $1.8 million in grants in 2024**, with nearly half of those awards going to first-time recipients. This reflects our steadfast commitment to nurturing emerging investigators and ensuring that the next generation of pediatric rheumatology researchers is well-supported.

- **Membership in CARRA grew by more than 20% over the past year** — a powerful reminder that our vision is resonating, and our community is expanding with new voices, perspectives, and energy.

These are not just numbers; they are the result of tireless efforts by researchers, clinicians, families, and advocates. They represent breakthroughs on the horizon, hope delivered to families, and a future shaped by knowledge, collaboration, and compassion.

And yet — we're only just beginning.

This year's annual report outlines the focus areas of our 2023–2025 Strategic Plan and demonstrates the real progress we're making toward our goals. It also reinforces a truth we see every day: None of this work happens alone. We are fortunate to partner with so many dedicated individuals — across academia, industry, government, advocacy organizations, and most importantly, within the patient and family community.

On a personal note, CARRA has been a part of my journey from the very start — from my earliest days as a trainee to now serving in this role as President. It's an honor I carry with humility and purpose. Supporting the next generation of pediatric rheumatologists and researchers is not just a responsibility — it's a passion, and a privilege.

Thank you for standing with us. For believing in the power of collaboration. And for being part of a movement that is transforming the future for children living with rheumatic diseases.

With sincere appreciation,

Stacy Ardoin, M.D.
President, CARRA

CARRA'S STRATEGIC PLAN & RESEARCH AGENDA

2023-2025 STRATEGIC PLAN

- **Achieving Research Excellence**
- **Leveraging Community Engagement**
- **Ensuring Organizational Excellence**
- **Embracing and Advancing Diversity, Equity, Inclusion, and Accessibility**

RESEARCH AGENDA PRIORITIES

- **Methodologies and Approaches**
- **Public Health and Systemic Biases**
- **Therapeutics**
- **Understanding Disease**

WHY CARRA?

Children with rheumatic diseases often struggle with pain, joint damage, and disability, as well as challenging side effects from their medicines. We urgently need research to give every child a chance at a healthier, happier childhood and a future free from the long-term burdens of these diseases.

CARRA'S VALUES

INCLUSIVENESS

We operate transparently and maximize stakeholder participation.

TRUST

Individually and collectively, we are reliable partners in managing, conducting, and sharing research.

IMPACT

We focus on activities of greatest significance to our stakeholders.

INNOVATION

We continuously look for ways to improve our research and operations.

ACHIEVING RESEARCH EXCELLENCE

> I am still in awe of the progress that has been made since the time I was diagnosed at age four with juvenile arthritis and uveitis. To think biologics weren't widely available back then is now hard for me to believe. This is truly a testament of how much scientific research can change lives."
>
> – Tara Cotumaccio, Patient member of CARRA's Uveitis Workgroup

As part of our Strategic Plan, CARRA developed a broad scientific agenda, independent of specific diseases, to guide and focus our work. The scientific agenda addresses critical unmet research needs, supports partnership opportunities, and enables prioritization of resource utilization and future growth.

CARRA's goal is to conduct and support innovative and collaborative clinical and translational research that generates new knowledge and improves the lives of children and families affected by pediatric rheumatic disease.

TOTAL FUNDING GIVEN BY CARRA

in 2024

$1.8 MILLION

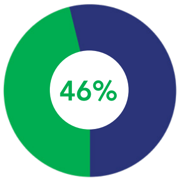
26 GRANTS

First-time Awardees

Supporting early investigators and fostering growth of the pediatric rheumatology field. In 2024:

12 OF THE 26

awardees were first-time recipients of a grant from CARRA.



CARRA provides essential seed funding to clinician-scientists who are early in their careers, which often leads to additional grants and awards from sources such as National Institutes of Health, U.S. Food and Drug Administration, and others.

For example, the ongoing research focused on treat-to-target states across the CARRA Lupus Registry and United Kingdom Juvenile Onset Systemic Lupus Erythematosus Cohort Study began with funding from a 2021 CARRA-Pediatric Rheumatology European Society Collaborative Research Award, and it is currently funded by a Foundation for Research in Rheumatology/Rheumatology Research Foundation Partnership Award.

“I would not have become a pediatric rheumatologist without exposure to CARRA, nor would I be able to continue my research without CARRA’s support. I am especially proud of CARRA’s commitment to understanding and improving health disparities to improve care for all children with rheumatic disease.”

– Danny Soulsby, MD, of UCSF, 2024 CARRA-AF Mentored Career Development
Award Recipient

CARRA’s Impact: Pediatric Rheumatology Research

195 GRANTS AND AWARDS

$8.3+ MILLION TOTAL

100+ UNIQUE PRIMARY INVESTIGATORS

70+ ACADEMIC INSTITUTIONS

LED TO MORE THAN $9.5+ MILLION IN ADD-ON FUNDING (SINCE 2016)

2024 Grants by Disease

7	Juvenile Idiopathic Arthritis (JIA)
2	Uveitis
5	Lupus
2	Scleroderma
2	Chronic Nonbacterial Osteomyelitis (CNO)
1	Juvenile Dermatomyositis (JDM)
3	Multiple diseases (including JDM, JIA, Ankylosing Spondylitis, Lupus, Scleroderma, Sjogren’s Syndrome, others)

“CARRA’s support has enabled me to gain important experiences in translational research so that I can be successful in pursuing a career as a physician scientist. The Advancing Biosample Collection Award allows us to collect biosamples for a new cohort for CARRA’s bioresspository and will help us to better understand the mechanisms in different types of juvenile arthritis. Our collaborative environment enables us forge meaningful contributions and discoveries to advance care.

By working together, we are in the best position to advance research to better understand these complex diseases and develop and identify the best treatments for children with rheumatic diseases.”

– Susan Canny, MD, PhD, of Seattle Children’s Hospital
2024 CARRA-Arthritis Foundation Advancing Biosample Collection Award

LEVERAGING COMMUNITY ENGAGEMENT

CARRA, which began with a handful of physicians working to ensure the future of pediatric rheumatology and make it possible to have widespread research participation, has grown exponentially. Today CARRA has a membership of more than 829 physicians, trainees, research and healthcare professionals, and patients/caregivers.

> Membership grew more than 20 percent in 2024 from the prior year.

Trainees, which include graduate students, medical students, residents, and fellows, are an especially important part of CARRA's community. Supporting trainees is essential to the future of pediatric rheumatology, as this sub-specialty still has shortages in providers.

> There are nine states that don't have a single pediatric rheumatologist, and there are four states that have only one.*

CARRA supports the next generation of pediatric rheumatologists by fostering career development, facilitating participation in research, and providing mentorship for trainees. Last year, more than 30 fellows joined one of CARRA's Workgroups to gain valuable experience and collaborate with experienced clinician-researchers. The Early Investigators Committee offers programs for CARRA members who have completed their terminal research degree or postgraduate clinical training in the past seven years.

> "I am thankful to the Early Investigators Writing Accountability (Working) Group for keeping me motivated and helping me get manuscripts across the finish line. I am excited about all the work being done across CARRA that I can use to better care for my patients."
>
> – Erin Treemarki, DO,
> University of Utah; Chair, Early Investigator Committee

Patient and Family Voices are Integral to Research

Patients and families are an essential part of our community. From its inception, CARRA established a distinctive and effective model for partnering with patients and caregivers at every stage of the research process. Their involvement is deeply woven into the fabric of the organization and is central to CARRA's mission. Parents and patients serve on research workgroups, in committees, on research grant applications and as reviewers as part of our peer review grant program. For instance, every grant submitted since the CARRA-Arthritis Foundation Grant Program began in 2016 has been reviewed by a patient or caregiver. Patients and caregivers have also served on study teams, shaped research study design, and many have been co-authors on peer-reviewed journal publications sharing CARRA research.

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* Data reflects rheumatologists certified through the American Board of Pediatrics as of August 2024 and does not account for pediatric rheumatologists with other board certifications or general rheumatologists that also treat juvenile arthritis patients.

> “Being given the opportunity to join CARRA and work specifically with the CRMO/CNO Workgroup has allowed me to step fully into the research process in a truly unique way. I’ve become part of a team where every member’s expertise and perspective – whether patient, physician, parent, or statistician – is recognized and valued. As a patient and parent, it’s all too easy to feel invisible within the medical system. But at CARRA, we’re given an equal seat at the table, and our experiences are treated as essential components of the research process.”
>
> – Elizabeth Murray, (pictured fourth from left above) a CNO parent who has been working with CARRA’s CRMO/CNO Workgroup since 2016. Elizabeth is a dedicated advocate who has been organizing the CRMO/CNO community internationally, raising awareness, speaking publicly, and fundraising for research for many years.

ENSURING ORGANIZATIONAL EXCELLENCE

CARRA is actively planning for the future by improving our organizational efficiency, strengthening strategic partnerships, and working to diversify resources to strengthen CARRA’s capacity to realize its mission.

To better meet the needs of our community, CARRA recently moved to a CEO-led model of operations, which has led to greater organizational efficiency and effectiveness. CARRA was reorganized with a new governance framework, staff model, and research committee structure. We also launched new internal and external communication initiatives to inform and engage our audiences.

By streamlining research operations and enhancing several other research processes, CARRA is now able to better support its members and deliver a more efficient experience. For instance, in 2024, we launched a single sign-on portal for members to access all CARRA resources in one convenient place, including the new Research Portal. We have also worked to ensure that all research efforts are aligned with the strategic plan.

Increasing revenue will be critical to meet financial challenges and support our mission. As we look ahead, CARRA is focused on strengthening existing partnerships, as well as diversifying funding sources by developing new collaborations and exploring innovative opportunities for growth, including those that support research capacity building of the pediatric rheumatology community and advance the drug development life cycle.

Fundraising

Our team is working to ensure the resources are in place to expand our impact — strengthening our pediatric rheumatology community and advancing research that improves the lives of children and families affected by rheumatic diseases.

Year-End Campaign and Giving Day

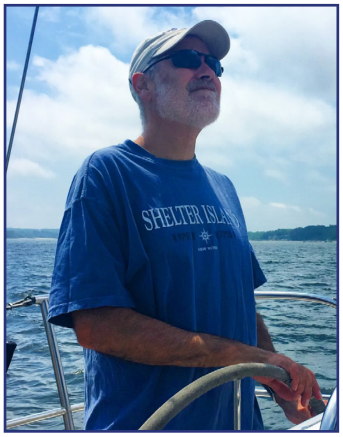
CARRA's 2024 year-end campaign was our most successful to date, marked by increases in both dollars raised and participation among our membership. The campaign was powered by two generous matching opportunities: the Board and Founders Match, which doubled all new and increased gifts, and the McGrath Family Match, which matched every donation. Giving Day in December brought our community together to raise awareness and highlight the need for research funding.

McGrath Family Match

The McGrath Family made an extraordinary $100,000 donation to support CARRA's mission and help strengthen our growing fundraising program. Their gift served as a powerful match during our year-end campaign, doubling the impact of every donor's contribution.

This remarkable show of generosity not only helped raise critical funds but also drew in new supporters and spotlighted pediatric rheumatology research.

Memorial Giving: Honoring Dr. Norm Ilowite and Dr. Betsy Mellins



This past year, the CARRA community honored the legacies of two of its most influential founders — Dr. Norman Ilowite and Dr. Betsy Mellins. In tribute to Dr. Mellins, the keynote address at this year's Annual Scientific Meeting was named in her honor, a reflection of her lasting impact on the field of pediatric rheumatology and on CARRA. Donations made in Dr. Ilowite's memory funded travel for fellows to attend our Annual Scientific Meeting in honor of his incredible legacy of mentoring the next generation of pediatric rheumatologists.

THE CARRA REGISTRY

The CARRA Registry was launched in 2015 as a long-term study to follow patients with pediatric rheumatic diseases over time and track their health outcomes, including treatment-related adverse events. Over the course of nearly ten years, the Registry has enrolled participants with juvenile idiopathic arthritis, lupus, and dermatomyositis, as well as started a biorepository to collect patient samples. The CARRA Registry has over 70 active sites in the United States and Canada. The Registry enrolled its 15,000th participant in October 2024.

Aligned with CARRA's Strategic Plan, CARRA is making advances to modernize and expand the Registry's reach to patients and caregivers at home. Last year, the CARRA Registry launched a new platform called REDCap Cloud so that participants can complete important patient-reported outcome surveys online, outside of the clinic. We also plan to leverage the increased participant engagement to continue following participants once they transition from pediatric to adult rheumatology care to learn about long-term health outcomes.

The CARRA Registry is an unparalleled resource for pediatric rheumatologists and researchers to learn about these rare diseases, including which patients are most likely to develop certain diseases and related complications and understanding the right treatments to give to the right patients.

The CARRA Registry

More than 15,200 participants; enrollment has increased each year

JIA: 12,800+

Lupus and Related Conditions: 1,700+

JDM: 470+

Scleroderma: 105

As of January 2025

CARRA Registry-Supported Research

2,000+ biosamples collected across 18 cohorts with studies focusing on:

- providing insight into disease etiology and pathogenesis
- identifying biological predictors for treatment response

80+ investigator-initiated research studies

40+ published manuscripts

The CARRA Registry is a cornerstone of pediatric rheumatology research and has led to collaborative projects with pharmaceutical companies, patient advocacy organizations, the National Institutes of Health, the Centers for Disease Control and Prevention, and Patient-Centered Outcomes Research Institute (PCORI).

EMBRACING AND ADVANCING DIVERSITY, EQUITY, INCLUSION, AND ACCESSIBILITY (DEIA)

Public health and systemic biases were identified as priorities in CARRA's Research Agenda.
This includes research focused on:

- Epidemiology
- Explicit and implicit bias
- Racism
- Social determinants of health
- Diversity/inclusion within CARRA research

In addition, CARRA's DEIA Committee established these DEIA Prioritized Agenda Goals:

- Achieve organizational DEIA in research, processes, and people
- Establish robust and diverse pipeline of researchers and leaders
- Ensure sustainability, accessibility and representativeness of registry and biorepository
- Members, patients, caregivers, staff, and partners meaningfully engaged and experience value from CARRA participation

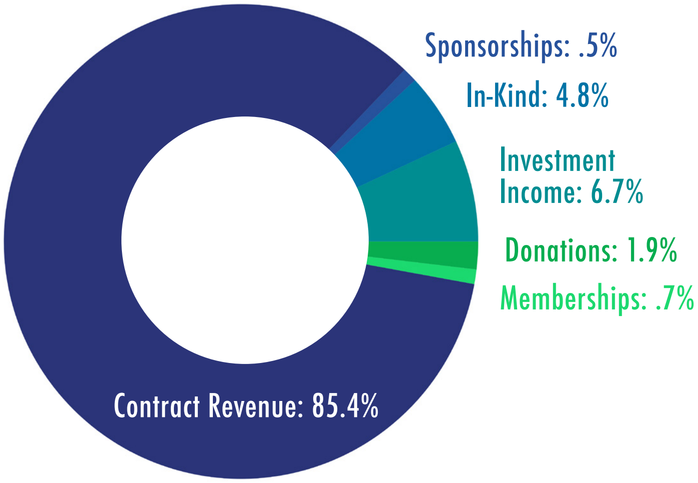
CARRA also aims to ensure the sustainability, accessibility and representativeness of CARRA's Registry and Biorepository. During the 2024 grant cycle, we offered for the first time the "CARRA-Arthritis Foundation Investigation of Representativeness in the CARRA Registry – Planning Grant."

In 2024, 20% of the intramural awards selected DEIA as a strategic area of focus.

> "I was diagnosed with juvenile arthritis at age nine, yet I did not learn about pediatric rheumatologists – or the work of CARRA – until decades later. These gaps in awareness and access have shaped my passion for health equity. In my research in human medical genetics and genomics, I have seen how social and structural factors drive disparities in complex rheumatic diseases. Through both my lived experience and my involvement with the Health Equity Workgroup, I am committed to making precision medicine and genomic research more inclusive and accessible to underserved communities."
>
> – Tada Vargas, Patient Member of CARRA's Health Equity Workgroup

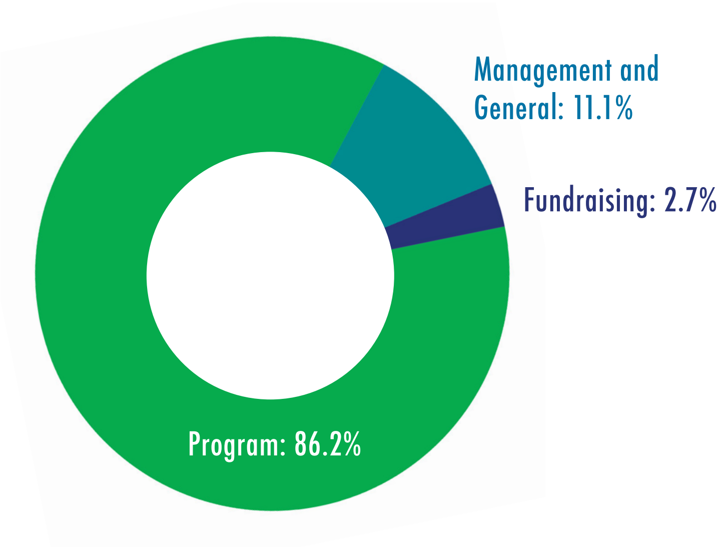
FINANCIALS

REVENUE



Total Revenue: $10,078,121

EXPENSES



Total Expenses: $11,077,964

Net Assets Without Donor Restrictions: $11,698,490

> “Throughout the [PReS] conference, I engaged in meaningful discussions with colleagues from Italy, UK, Slovenia, and the Netherlands. These conversations revolved around potential cooperation in research projects, shared resources, and joint initiatives aimed at improving patient care and outcomes.
>
> These interactions were not only inspiring but also instrumental in deepening existing collaborations and forging new partnerships that promise to benefit both CARRA and PReS in the future.”
>
> – Greta Mastrangelo, MD, of The Hospital for Sick Children in Toronto
> 2024 CARRA-PReS Travel Awardee who attended the PReS Conference in Sweden

CARRA

Childhood Arthritis and Rheumatology Research Alliance