

# IMPACT REPORT

2024



USHERING IN  
A NEW ERA OF  
PROGRESS

CureJM<sup>®</sup>  
FOUNDATION

# 2024 IMPACT REPORT:

## A NEW ERA OF PROGRESS

This year's Impact Report, "Ushering in A New Era of Progress," highlights the groundbreaking advancements made possible by your support.

Throughout this report you will hear about our progress to:

- **Enhance clinician education and collaboration**, so every doctor has the latest information to treat juvenile myositis
- **Expand of our Cure JM Clinical Care Network**, to help kids get the best care
- **Educate and support patients and parents**, so every family has the information needed to care for this complicated disease
- **Fund cutting-edge research** to find better treatments and progress towards cures.

Thank you for your steadfast support.

**Together we are rewriting the future for juvenile myositis.**



*"JM is tough, but  
I'm tougher.*

*With research, we can  
make sure no other kid  
has to go through what  
I've been through."*

**Isabel**

Diagnosed at age 6

# Our Mission

To find a cure and better treatments for juvenile myositis and improve the lives of families affected by JM.



# Dear Friends,

As my term as Chair of Cure JM's Board of Directors ends and I transition to the Chair Emeritus of the Board, I am filled with pride and gratitude for our progress over the past decade. When I began, we faced major challenges in understanding and treating this rare disease. Thanks to our researchers, clinicians, and supporters, we are now on the verge of breakthroughs that once seemed distant.

**Advancements in Research:** Our understanding of JM has deepened significantly. Collaborative efforts have identified new genetic markers and immune pathways, leading to more accurate diagnoses and targeted therapies.

**Innovative Treatments:** New therapies like biologics and JAK inhibitors show great promise. These treatments are reducing disease activity and improving the quality of life for many children. Although trials and studies continue, our progress is encouraging.

**Improved Patient Outcomes:** The most notable progress is in patient outcomes. Where once children faced severe complications, earlier diagnoses and effective treatments now help more children lead fulfilling lives. Our Clinical Care Network and education programs strive to provide the best care for every child.

**Advancing Toward Cures:** Our goal remains to discover cures. Research advancements and new treatments are crucial steps toward this aim. Community support is vital as we pursue this ambitious goal.

**Community and Collaboration:** This progress is due to our community's collective efforts. Support from families, friends, researchers, healthcare providers, and corporate partners has driven research and provided essential resources.

**Looking Ahead:** While we've achieved much, our journey is far from over. The next decade holds great promise, and I'm confident that with continued dedication and collaboration, we will help every child overcome JM.

As I pass the torch to new leadership, I am deeply thankful for the privilege of serving this community. I look forward to our continued strides in the fight against juvenile myositis.

Thank you for your unwavering support and commitment to our mission.

With heartfelt gratitude,



Nikki Hahn  
Outgoing Chair, Incoming Chair Emeritus  
Cure JM Board of Directors



# 21 Years of Progress and IMPROVING LIVES

**\$27** million  
invested



Largest juvenile  
myositis funder  
on the planet

**10**  
CLINICAL TRIALS

To find better  
treatments & cures



**219**  
RESEARCH  
PROJECTS  
FUNDED



**55**  
Clinical Care  
Network Partners



Reduced time  
to diagnosis by

**75%**

From 12 months to 3 months

Early treatment leads  
to better outcomes



**3,000+**  
FAMILIES CONNECTED  
with other families and  
resources

# POWERING PROGRESS: 2024 HIGHLIGHTS

In this report, we highlight three key pillars of our work that are driving significant progress in the fight against juvenile myositis.

- 1. Improving Patient Care and Outcomes:** There was a time when only a handful of specialists treated juvenile myositis. Thanks to your support, we've expanded care through our Clinical Care Network and clinician education programs. These initiatives ensure that children and young adults receive top-tier care, offering them a brighter, healthier future.
- 2. Advancing Groundbreaking Research:** We've built a global network of JM researchers who are leading cutting-edge research. Through fostering global collaboration, we are driving innovative studies, developing better treatments, and progressing toward a cure.
- 3. Supporting Families Navigating Juvenile Myositis:** We provide essential resources and support for families navigating the complexities of juvenile myositis. Our programs are designed to ease the journey, ensuring families have the guidance and tools they need.

Together, we are entering a new era of progress in the fight against juvenile myositis. Your continued support is transforming lives and bringing hope to children and families.

## Highlights from 2024:

- **\$5 million in active grants** driving research and innovation.
- **71% of the pediatric rheumatologists in the U.S.** participated in our education programs about juvenile myositis care.
- **Expanded the Cure JM Clinical Care Network** to 55 partners.
- **Supported a clinical trial for CAR-T**, a promising "immune system reset" therapy which offers groundbreaking potential.
- **Advanced the trial for a new pill called deucravacitinib**, that shows promise in reducing reliance on steroids and chemotherapy.
- **Provided free 24/7 education and support** to families navigating juvenile myositis.
- **Changed the future for thousands of children, offering hope and improving the quality of life for those affected by JM.**

*"As a board, we are laser-focused on helping children and young adults with JM thrive. Our goal is to improve treatments, care, and support for patients and families. While steroids and methotrexate are life-saving, their side effects can sometimes be worse than the disease itself. We must find better solutions—kids are counting on us."*

Anna Ramsey, diagnosed in 2015  
Chair of Cure JM's Young Adult Advocates Council  
Director, Board of Directors



# IMPROVING CARE FOR PATIENTS: CLINICIAN EDUCATION INITIATIVES

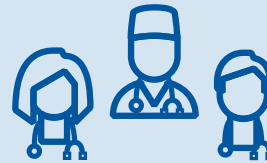
Cure JM's physician education program equips healthcare providers with critical knowledge about juvenile myositis, leading to earlier diagnoses and improved patient care. By training clinicians across specialties, it helps ensure that more children receive timely, effective treatment, ultimately improving outcomes for JM patients.

## EXPANDING THE BEST CARE



3

Global JM Summits  
held annually



500+

Clinicians participated  
in our trainings  
last year



30+

Countries  
represented



## CLINICIAN TESTIMONIALS:

Cure JM's Summits on juvenile myositis research and care are crucial to advance knowledge about juvenile myositis. The Summits bring together experts from around the world, fostering collaboration that directly improves patient care and accelerates research breakthroughs."

*Clinical Care Network Chair Stacey Tarvin, MD, MS, FAAP, FACR*

*University of Indiana School of Medicine, Riley Children's Hospital, Indianapolis*

71%

OF U.S. PEDIATRIC  
RHEUMATOLOGISTS  
PARTICIPATED  
LAST YEAR

## CLINICIAN EDUCATION PROGRAMS



**Three annual summits** bring together the world's foremost JM experts to share cutting-edge knowledge with adult & pediatric providers.




**Our quarterly clinician news** delivers a comprehensive library of the latest resources, giving clinicians easy access to the latest information to provide the best care.



**We foster collaboration among clinicians** through quarterly Clinical Care Network meetings to exchange knowledge, problem-solve, and enhance the quality of care for JM patients.

# IMPROVING CARE FOR PATIENTS: CURE JM CLINICAL CARE NETWORK

Cure JM's Clinical Care Network helps patients get the best care, fosters collaboration among clinicians, and advances better treatments and ultimately, a cure.

 Cities with at least one Cure JM  
Clinical Care Network partner



*"Being able to have Rooney treated at Duke has been the biggest blessing, one that I don't think would have happened without Cure JM's partnership. **Knowing that our daughter's doctor is committed to research and finding a cure means the world to us!"***

Megan R., mom to Rooney,  
who was diagnosed with juvenile myositis in 2023



# IMPROVING CARE FOR PATIENTS: CURE JM CLINICAL CARE NETWORK



**Stacey Tarvin, MD, MS, FAAP, FACR**  
Riley Hospital for Children  
Chair, Cure JM Clinical Care Network



**Sheila T. Angeles-Han, MD, MSc**  
Cincinnati Children's  
Hospital Medical Center



**Bitra Arabshahi, MD**  
Inova Children's Hospital



**Kaveh Ardan, MD, MS**  
Duke Children's Hospital  
& Health Center



**Misha Balmuri, MD**  
The Johns Hopkins Hospital



**Hermine I. Brunner, MD, MSc, MBA**  
Cincinnati Children's  
Hospital Medical Center



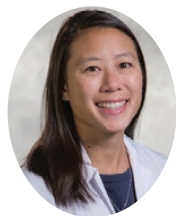
**Ruy Carrasco, MD**  
Pediatric Rheumatology  
Consultants (Austin, TX)



**Angela C. Chun, MD**  
Ann & Robert H. Lurie Children's  
Hospital of Chicago



**Colleen Correll, MD, MPH**  
University of Minnesota



**Lauren Covert, MD**  
Duke Children's Hospital  
& Health Center



**Rodolfo Curiel, MD, FACP, FACR**  
George Washington University,  
GW Myositis Center



**Megan Curran, MD**  
Children's Hospital Colorado



**Alaina Davis, MD**  
Monroe Carell Jr. Children's  
Hospital at Vanderbilt (Nashville)



**Marietta de Guzman, MD**  
Texas Children's Hospital



**Fatma Dedeoglu, MD**  
Boston Children's Hospital



**Vy K. Do, DO**  
Dell Children's Medical Center



**Jeffrey Dvergsten, MD**  
Duke Children's Hospital  
& Health Center



# IMPROVING CARE FOR PATIENTS: CURE JM CLINICAL CARE NETWORK



**Cuoghi Edens, MD**  
University of Chicago Medicine



**Brian Feldman, MD, MSc, FRCPC**  
The Hospital for Sick Children  
Toronto, Canada



**Robert Fuhlbrigge, MD, PhD**  
Children's Hospital Colorado



**Julie Fuller, MD**  
Scottish Rite for Children  
(Texas)



**Amy Gaultney, MD**  
Children's Hospital of  
Orange County (CHOC)



**Beth Susan Gottlieb, MD**  
Cohen Children's Hospital



**Alexei Grom, MD**  
Cincinnati Children's  
Hospital Medical Center



**Aimee Hersh, MD**  
University of Utah Health -  
Primary Children's Hospital



**Adam Huber, MD, MSc**  
IWK Health Centre,  
Dalhousie University



**Ankur Kamdar, MD, FACP**  
McGovern Medical  
School At UTHealth



**Daniel Kietz, MD, PhD**  
University of Pittsburgh Medical Center  
Children's Hospital of Pittsburgh



**Hanna Kim, MD, MS**  
NIAMS, National Institutes of  
Health (NIH), George Washington  
University, GW Myositis Center



**Susan Kim, MD, MMSc**  
University of California  
San Francisco Benioff  
Children's Hospitals



**Marisa Klein-Gitelman, MD**  
Ann and Robert H. Lurie  
Children's Hospital of Chicago



**Bianca Lang, MD**  
IWK Health Centre,  
Dalhousie University



**Aviya Lanis Levy, MD, MS**  
Rady Children's Hospital - San Diego



**Joseph McDonald, MD**  
University of Chicago Medicine



**Diana Milojevic, MD**  
Johns Hopkins  
All Children's Hospital  
(Florida)



**Katherine Moore, MD**  
Children's Hospital Colorado



**Jessica Neely, MD**  
University of California  
San Francisco Benioff  
Children's Hospitals

# IMPROVING CARE FOR PATIENTS: CURE JM CLINICAL CARE NETWORK



**Karen Onel, MD**  
Hospital for Special Surgery  
New York, NY



**Charris Papadopoulou, PhD**  
Great Ormond Street  
Hospital for Children



**Ann M. Reed, MD**  
Duke Children's Hospital  
& Health Center



**Lisa Rider, MD**  
NIEHS, National Institutes of  
Health (NIH), George Washington  
University, GW Myositis Center



**Amanda Robinson, MD**  
University of Utah Health  
Primary Children's Hospital - Lehi



**Kelly Rouster-Stevens, MD, MS,  
PharmD**  
Emory University School of Medicine



**Sara Sabbagh, DO**  
Children's Wisconsin -  
Milwaukee Hospital



**Laisa Santiago, MD**  
Johns Hopkins  
All Children's Hospital (Florida)



**Julia Foster Shalen, MD**  
The Johns Hopkins Hospital



**Susan Sheno, MBBS, MS, RhMSUS**  
Seattle Children's Hospital



**Andrew Shulman, MD**  
Children's Hospital of  
Orange County (CHOC)



**Jacob Spitznagle, MD**  
Children's Hospital of  
Los Angeles (CHLA)



**Melissa Teshler, MD**  
University of Chicago Medicine



**Heather Tory, MD MPH, CPPS**  
Connecticut Children's



**Jessica Turnier, MD**  
C.S. Mott Children's Hospital  
University of Michigan Health



**Dawn Wahezi, MD, MS**  
The Children's Hospital  
at Montefiore



**Lucy Wedderburn, MBBS, PhD,  
FRCP, MRCPCH**  
University College London Great Ormond  
Street Institute of Child Health (UK)



**Meredyth Wilkinson, PhD, BSc, MBBS**  
University College London  
Great Ormond Street Institute  
of Child Health (UK)



**Belina Yi, DO**  
The Johns Hopkins Hospital



# IMPROVING CARE FOR PATIENTS: INVESTING IN OUR CLINICAL CARE NETWORK

Your support allows Cure JM to invest in our Clinical Care Network at the following locations. Through these **Mason's Miracle Grants**, we ensure that clinicians have the resources and collaboration needed to deliver the best, most up-to-date care. These grants are named in memory of Mason Smedley, whose courage and strength in his battle with juvenile myositis have inspired us to improve outcomes and enhance the quality of life for all JM patients.

## Cure JM Clinical Care Network Locations where Cure JM is providing funding:

### Northeast

Boston Children's Hospital  
Children's Hospital at Montefiore (New York)  
Children's Hospital of Pittsburgh  
George Washington University (DC)  
Hospital for Special Surgery (New York)  
Inova Children's Hospital in Northern VA  
Johns Hopkins Children's Center  
(Baltimore)

### Southeast

Duke Children's Hospital  
Children's Hospital of Atlanta  
Monroe Carell Jr. Children's Hospital at  
Vanderbilt (Nashville)

### Midwest

C.S. Mott Children's Hospital (Michigan)  
Cincinnati Children's Hospital  
Comer Children's Hospital (Chicago)  
Lurie Children's Hospital (Chicago)  
Medical College of Wisconsin  
Riley Children's Hospital, Indianapolis  
University of Minnesota

### Southwest

Children's Hospital Colorado  
Scottish Rite for Children (Dallas)  
Texas Children's Hospital (Houston)

### West

Children's Hospital of Los Angeles (CHLA)  
Children's Hospital of Orange County (CHOC)  
Rady Children's Hospital (San Diego)  
Seattle Children's Hospital  
UCSF (San Francisco)

### International

GOSH  
Great Ormond Street Hospital for Children  
(London)  
Hospital for Sick Children (Toronto)



# POWERING PROGRESS: OUR MEDICAL ADVISORY BOARD

Dear Cure JM Community,

As I prepare to step down as Chair of the Medical Advisory Board after 8 years of service, I am filled with deep gratitude and pride for the journey we've taken together. Serving in this role has been one of the most rewarding experiences of my career, and I am honored to have been part of an organization so deeply committed to improving the lives of those affected by juvenile myositis.

Over the past two decades, we have witnessed remarkable progress in research, treatment, and clinical care for patients with juvenile myositis. Thanks to the collaborative efforts of our dedicated researchers, clinicians, and community supporters, we have made significant strides in understanding the complexities of this condition. We have supported efforts to develop new treatment protocols, improved patient outcomes, and most importantly, brought hope to countless families.

I am particularly proud of the role our Medical Advisory Board has played in fostering research in juvenile myositis. We have supported groundbreaking studies that have not only expanded our knowledge but have also led to tangible improvements in the quality of life for our patients. We have also been committed to support the next generation of juvenile myositis researchers and clinicians. The dedication and expertise of our medical community has been truly inspiring, and I am confident that the foundation we have built will continue to propel us toward even greater achievements in the future.

Throughout my tenure, I have been continuously inspired by the strength and resilience of the patients and families we serve. Their courage in the face of adversity has been a constant reminder of why we do what we do. It has been a privilege to advocate for them, and to work alongside such a passionate and committed group of professionals.

I am confident that the Medical Advisory Board will continue to thrive under its new leader, my dear friend and colleague Dr. Brian Feldman. Dr. Feldman is a superb, thoughtful clinical researcher, whose work I greatly admire. The future is bright, with many promising developments on the horizon. I look forward to witnessing our continued progress and the lasting impact it will have on the lives of those we serve, as I continue to serve on the Medical Advisory Board.

Thank you for the opportunity to contribute to this vital work. I leave my tenure with a heart full of gratitude and the knowledge that together, we have made a difference in countless lives.

With warmest regards,

*Lisa Rider*

Lisa Rider, MD  
Outgoing Chair, Medical Advisory Board



# POWERING PROGRESS: CURRENTLY FUNDED RESEARCH

Cure JM is proud to have nearly \$5 million invested in active research commitments.

Our network of researchers spans the globe and is making progress in developing new treatments, understanding the causes of juvenile myositis, and improving care for patients. This research advances our work to improve the treatments, care, and support for juvenile myositis.

**As we say, hope is in the research.**

**Some highlights from our current research grants are:**



**Andy Mammen, MD, PhD**  
Johns Hopkins Myositis Center,  
National Institutes Of Health

Exploring the use and effectiveness of Deucravacitinib (Sotyktu) as a treatment option for juvenile myositis.

### *What is the Desired Outcome?*

To find better treatment options for juvenile myositis, with fewer side effects, that could later be tested in clinical trials.



**Sarah Tansley BSc, MBChB, PhD, MRCP**  
University of Bath, UK (with Prof. Neil McHugh, MBChB, MD)

To use specially adapted detection methods to **identify 'new' myositis specific autoantibodies** that have yet to be discovered in approximately 40% of myositis patients.

### *What is the Desired Outcome?*

To aid in understanding how to treat these sub-types of myositis and improve outcomes for the nearly 40% of JM patients who do not test positive for the current autoantibodies.



**Brian Feldman, MD, MSc, FRCPC**  
Hospital for Sick Children,  
Toronto, Canada

To study the effect of **exercise, creatine, and coenzyme Q10 supplements as treatments for muscle weakness** in juvenile myositis.

### *What is the desired outcome?*

That these treatments could supplement traditional treatments to help patients thrive while living with juvenile myositis.



**Sara Sabbagh, DO**  
Medical College of Wisconsin

For development of a new animal model to **screen new or repurposed drugs for effectiveness and safety in JM**. This is an important step in identifying new treatments for JM.

### *What is the Desired Outcome?*

This study can lead to new, safer, and more effective treatment options with drugs that have been effective in treating other diseases.

# CURRENTLY FUNDED RESEARCH



**Melissa Morales, PhD**  
State University of New York

To investigate deucravacitinib, the newest of the “JAK inhibitor” drugs. These are a new class of drugs that work by stopping the Janus kinases (JAK) from responding to triggers that might cause inflammation. These

drugs are being developed to treat a variety of diseases, including cancer, autoimmune diseases, and inflammatory disease. JAK inhibitors are still under development, but have shown promise in clinical trials. Deucravacitinib shows promise in juvenile myositis and has a low side effect profile.

## *What is the Desired Outcome?*

To investigate deucravacitinib as a potential new treatment for juvenile myositis.



**Sara Sabbagh, DO**  
Medical College of Wisconsin,  
and **Jessica Turnier, MD**  
University of Michigan

To improve the use of observing nailfold capillaries (blood vessels) in diagnosing and treating juvenile myositis.



They will combine a nailfold capillary observation technique that is widely used in many JM clinics with a new technique to examine the cells that line the insides of the vessels.

## *What is the Desired Outcome?*

To deepen our understanding of nailfold image analyses and interpretation to better diagnose patients, identify flares earlier, and determine earlier how patients are responding to medication.



**Andrea Knight, MD, MSCE**  
Hospital for Sick Children,  
Toronto, Canada

To study how childhood-onset of inflammatory diseases impacts the developing brain. Data will be gathered through interview questions and non-contrast brain MRIs.

## *What is the Desired Outcome?*

To determine how the brain is impacted when an inflammatory disease begins in childhood.



**Steve Balevic, MD and  
Kaveh Ardalan, MD, MS**  
Duke University, North Carolina

Funding pre-trial work on vamorolone, an “anti-steroid steroid.” Vamorolone is a new steroid with all the benefits of prednisone and virtually none of the side effects. Cure JM is working with Duke University, the FDA, and the distributors of vamorolone on a clinical trial plan to test the safety and effectiveness of the drug in juvenile myositis patients.



## *What is the Desired Outcome?*

That this project might lead to a clinical trial for an “anti-steroid steroid” (a steroid without the side-effects of current steroids) that could be useful as a first-line treatment option for JM patients.



**Melissa Morales, PhD**  
Binghamton University,  
New York

This project will test and screen potential medications on the effect of Type 1 interferon (a prime factor in inflammation) on muscle function and weakness in myositis.

## *What is the Desired Outcome?*

A better understanding of how to target and more precisely treat muscle inflammation in JM patients.



# CURRENTLY FUNDED RESEARCH



**Jessica Neely, MD**  
University of California  
San Francisco

Using artificial intelligence to analyze data from three sets of participants: JM patients who have received treatment, JM patients who have not yet received treatment, and healthy volunteers.

## *What is the Desired Outcome?*

That this project will help us identify new treatments (with fewer side effects) for juvenile myositis.



**Younghun Han, PhD**  
Baylor College of Medicine,  
Texas

To better understand what drives JDM by identifying which genes and gene combinations predispose patients to JDM.

## *What is the Desired Outcome?*

We aim to expand our knowledge of the causes of JDM to improve treatments and minimize environmental triggers and disease flares.



**Chack Yung Yu, D.Phil**  
Nationwide Children's Hospital,  
Ohio State University (With  
Samantha Coss, MD, PhD)

To study changes in immune cells and proteins in different phases of JDM. We also hope to understand how genetic factors (in particular, a low level of an immune protein known as complement C4) contribute to a higher probability of developing JDM.

## *What is the Desired Outcome?*

To provide new markers to predict disease status and help guide treatment and disease management decisions.

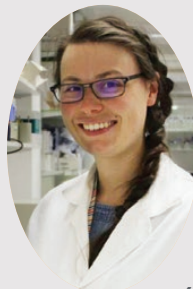


**Jayne MacMahon MB, BCh,  
BAO, LCRP&SI, MRCPCH**  
SickKids, Toronto, Canada

To define a scoring system for a molecule known as interferon to help define how active JDM is. Interferon plays a crucial role in the immune system and is a prime factor in inflammation.

## *What is the Desired Outcome?*

We know that JDM is a variable disease that affects different patients differently. We aim to develop more individualized approaches to disease management and better outcomes for patients. For example, a scoring system for interferon may help clinicians know when to start and stop different medications.



**Meredyth Wilkinson, PhD**  
University College London, UK

Dr. Wilkinson was awarded Cure JM's early investigator grant to study the potential use of drugs categorized as JAK inhibitors. The drugs being studied included Baricitinib (Olumiant), Tofacitinib (Xeljanz), and Ruxolitinib (Jakafi). She will also investigate how problems with the mitochondria might cause inflammation in JDM. We expect this could lead to new targeted treatments to help children recover with fewer harsh medications such as steroids.

## *What is the Desired Outcome?*

To help lay the foundation for future clinical trials to bring new, alternative, and supplemental treatments to patients. Alternative treatments have fewer side-effects and can be less disruptive to a patient's life, which results in better long-term outcomes.

# CURRENTLY FUNDED RESEARCH



**Joanna Parkes, PhD**  
Harwell Science and Innovation  
Campus, Nucleic Acid Therapy  
Accelerator Hub, UK

This project will study **potential “nucleic acid” therapies for JM**, with the goal to identify novel gene therapy interventions. Gene therapy is an emerging field of research with the potential to revolutionize the way we treat diseases.

## *What is the Desired Outcome?*

It is our hope that this might lead to better treatments and early interventions that might stop JM in its tracks.



**Jeff Dvergsten, MD**  
Duke University, North Carolina  
(with George Truskey, PhD and  
Lauren Covert, MD)

As JDM is a rare disease, it can be difficult to have enough patients to test new medications. **This project aims to develop a new muscle model that mimics JDM to test the effectiveness of new drugs.**

## *What is the Desired Outcome?*

To find better treatment options for juvenile myositis, with fewer side effects, that could later be tested in clinical trials.



**Christian Lood, PhD**  
University of Washington

This project aims to understand **how mitochondria contribute to disease in JDM patients**. The mitochondria are the “powerhouses” of the cell, responsible for generating most of the cell’s energy.

## *What is the Desired Outcome?*

Understanding how mitochondria contribute to JDM may allow us to target this process with new therapies. We also hope to develop mitochondrial-related biomarkers to enable preventive treatment of calcinosis, a difficult complication to treat for some patients, and help improve patients’ quality of life.

**CARRA**  CARRA Registry and Biorepository

Funding the juvenile myositis registry and biorepository through CARRA, the Childhood Arthritis and Rheumatology Research Alliance, is crucial. A biorepository is a facility that collects, stores, and distributes blood samples. Our biorepository accelerates JM research by providing researchers with access to JM blood samples that would otherwise take many years to collect.

## *What is the Expected Outcome?*

By supplying these critical samples, researchers can fast-track their studies, leading to quicker research breakthroughs.



*“Every breakthrough in research is more than scientific progress; it is a step towards a future free from the burdens of JM.”*

Andrew Heaton, PhD, Chief Scientific Officer, Cure JM Foundation

# SUPPORTING FAMILIES: EMOTIONAL HEALTH INITIATIVES

We are also proud to be funding three new grants to address the mental health and emotional support needs of the families we serve. This program was generously funded by the RB DenUyl Family Foundation in loving memory of Bruce and Eric DenUyl.



**Misha Balmuri, MD,**  
Johns Hopkins University

**To screen every JM patient for mental health concerns at each clinic visit.** In addition, each patient will have at least one visit with the pediatric psychologist. Finally, the team will develop mental health

awareness videos to help families and patients recognize symptoms of mental health problems and offer some immediate coping mechanisms.

### ***What is the Desired Outcome?***

To determine if integrating mental health support into pediatric rheumatology clinic visits improves anxiety and depression in juvenile myositis patients.



**Alaina Davis, MD,**  
Monroe Carell Jr. Children's  
Hospital at Vanderbilt

**To integrate depression and anxiety screening into the pediatric rheumatology clinic.** An in-clinic therapist will also help patients identify and challenge their negative thoughts and beliefs to develop more helpful thinking patterns and behaviors.

### ***What is the Desired Outcome?***

To improve the mental and emotional health of juvenile myositis patients.



**Andrea Knight, MD, MSCE and  
Ingrid Goh, PhD,**  
Hospital for Sick Children,  
Toronto, Canada

**To implement the use of an in-clinic social worker to screen patients and caregivers for mental health concerns and perform follow-up visits when appropriate.**



### ***What is the Desired Outcome?***

We anticipate that this program will help ensure a better quality of life for juvenile myositis patients by addressing anxiety and depression early.

### Previously Funded:

- **Aviya Lanis, MD**  
**Seattle Children's Hospital, Seattle, WA**  
To develop a narrative medicine intervention program for JM patients
- **Andrea Knight, MD, MSCE**  
**Hospital for Sick Children, Toronto, Canada**  
To implement and evaluate the impact of a mental health screening program in JM clinics
- **Colleen Correll, MD, MPH**  
**University of Minnesota, Minneapolis, Minnesota**  
To create mental health wellness and resilience-building videos to share with our families.



# SUPPORTING FAMILIES: EMOTIONAL HEALTH INITIATIVES



**1 million**  
minutes of peer support  
from those who have been  
down this road before.

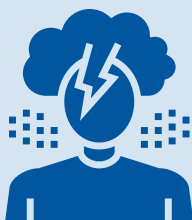


**70** trained peer support  
representatives

Our trained teens support fellow teens, young adults mentor other young adults, and parents offer guidance to other parents, creating a strong network of mutual support.

**24:7 support**

Get the support you need 24 hours a day, 7 days a week by phone, text, or through our online support groups. This support is crucial for managing the physical and emotional aspects of a complex and hard-to-treat disease.



**Emotional check ups at  
your rheumatologist.**

Cure JM has launched a groundbreaking new program to offer emotional health screenings and support as part of routine JM care at your rheumatologist. This program has been implemented in a handful of clinics and will be expanded as resources allow.

**Life-changing information**

Browse hundreds of free resources on treatments, exercise, nutrition, and social support. Resources are available in English and Spanish on our website.

**100+**  
**Free Resources**  
for Families



**20 chapters to educate and  
support families**

Our chapters unite families and local medical professionals to foster learning, sharing, and growth. Together, we create stronger, more connected communities.

**Studying inflammation in the brain.**

Understanding how inflammation affects the brain is the first step to developing strategies to address and reduce its impact.



Visit [www.curejm.org/support](http://www.curejm.org/support) or contact [info@curejm.org](mailto:info@curejm.org) to learn more

# Dear Friends,

As my term as President comes to an end, and I succeed Nikki Hahn as Chair of the Board of Directors, I am especially pleased to share with you some additional progress we have made this year.

Our top priority is – and always has been – to improve the lives of everyone diagnosed with juvenile myositis. You have read a lot about our collective progress in this report.

## **I also wanted to share with you the power of our volunteers.**

First, I want to thank our volunteer councils and committees, who provide on-the-ground leadership in their communities. Volunteers always have been our life-blood, and this year more than 570 of our patients, parents, and grandparents volunteered to move our mission forward. I am so grateful to each of you.

Second, volunteer leaders across the country have reopened our local chapters. Our chapters provide local support, education, and events in partnership with local children's hospitals.

Third, I am so proud of our volunteer network of peer support specialists. These parents, grandparents, teens, and young adults support others and are available 24/7 by social media, phone, and text. We hear every day that learning from others who have been down this road before you is life-changing.

Finally, I encourage you to join us at an upcoming [event](#), including our Family Conference from **June 27-29, 2025** in **Oak Brook, IL**. This 3-day gathering brings together families, clinicians, researchers, industry representatives, and patients of all ages—from toddlers to adults—for a weekend of learning, support, and community. Learn more and RSVP at [curejm.org/conference](https://curejm.org/conference).

I am grateful to each of you – our volunteers, supporters, friends and families. Our progress is a testament to our shared commitment to positive change.

We may be rare, but we are not alone.

Warm regards,



Kristine Alderfer  
Outgoing President, Incoming Chair  
Cure JM Board of Directors



# POWERING PROGRESS: OUR FUNDRAISING SUCCESS

From Cure JM's first fundraiser – a lemonade stand held over 20 years ago – through to today, you are powering our progress.



This is true for most rare diseases: research is powered by friends and families.

## Highlights from our 2024 campaigns:

- **Our walks were back in person, raising \$450,000 for research.** Find a walk near you at [curejm.org/walkstrong](https://curejm.org/walkstrong).
- **Last year's Giving Tuesday Holiday Challenge raised over \$1,000,000 for research.** Visit [curejm.org/hopehero](https://curejm.org/hopehero) to learn more about this year's campaign.
- **Families and friends hosting DIY Fundraisers raised over \$50,000.** Visit [curejm.org/diy](https://curejm.org/diy) to learn more about these fun events, including a bowling event, karate "Kicks for a Cure", a golf event, and others.
- **Our NEW Lemons to Lemonade program raised over \$10,000.** As a tribute to Cure JM's first-ever fundraiser – a lemonade stand – families held their own lemonade stands to raise funds for research and programs. Learn more at [www.curejm.org/lemonade](https://www.curejm.org/lemonade).

*Your participation powers progress.*



These funds raised were put right to work to find cures, and improve treatments, care, and support for the families we serve.



# POWERING PROGRESS: OUR LEADERSHIP

Founded by parents and grandparents of children with juvenile myositis, for 21 years Cure JM has been driven by the passion and commitment of our families.



Cure JM Board of Directors



Medical Advisory Board, Incoming Chair  
Brian Feldman, MD, MSc, FRCP, Head, Division of Rheumatology  
Hospital of Sick Children, Toronto



Clinical Care Network, Chair  
Stacey Tarvin, MD, MS, FAAP, FACR  
University of Indiana School of Medicine  
Riley Children's Hospital, Indianapolis



Cure JM National Leadership Council



Cure JM Young Adults Advocates Council



Cure JM Grandparents Council

"I want to extend my deepest gratitude to our incredible volunteers," says Kristine Alderfer, President, Board of Directors. "Your dedication and hard work are the heart of our mission, and we would not be the global leader in juvenile myositis research without your unwavering support."

Our mission is carried out by:

- **Our Board of Directors**, which leads our work to fulfill Cure JM's mission.
- **Our Medical Advisory Board**, which provides insight, scientific direction, and expertise to Cure JM's work to advance research and care.
- **Our Clinical Care Network**, which provides expertise and direction to Cure JM's work to help kids and young adults get the best care.
- **Our National Leadership Council**, which leads the charge to raise the funds needed to advance our work.
- **Our Young Adult Advocates Council**, which engages our patients aged 18-30 to advance Cure JM's mission.
- **Our Grandparent Council**, which provides a platform for grandparents of patients to get involved, share ideas, and support their families.
- **Our Community Advisory Board**, which provides guidance on ensuring diverse participation in clinical trials and research.
- **Our Staff**, which provides leadership to move our mission forward.

# POWERING PROGRESS: OUR GRANDPARENT SUPPORTERS

Please join us in celebrating the special role that grandparents play within their families and within our community. Since Cure JM was founded by parents and grandparents in 2003, grandparents have always been a special part of Cure JM. We treasure the special role of grandparents and are grateful for their support.

## Cure JM is honored to recognize the following grandparents for their lifetime giving

### \$500,000+

Marge Coffey  
Bruce and Judy Leetz



### \$50,000-\$499,000

Michael and Susan Duke  
Sheila and Harry Harvey  
Nancy Hume  
Rita and Richard Jacoby  
David and Carol Pearson  
Robert and Dixie Slater  
Merrienne Van Ness

## Grandparents who gave \$10,000+ in our Fiscal Year 2024\*

Mike and Patricia Fox

Joel and Laurel Reed

Heather and Mike Weiss

Sheri Grahn

## Grandparents who gave between \$1,000-\$10,000 in our Fiscal Year 2024

Harriette Best

Harold and Eileen Blitz

John and Adri Clapp

Ruth and Wesley Cosand

Kenneth Cutting

Elinor and Andrew Dahill

James and Judie Denton

Patricia Dobson

William and Lynne Elsesser

Dennis and Patricia Grundy

Robert and Karen Hahn

Joanne and Jeffrey Hall

Linda and Randy Hart

Allen and Antoinette Hauser

Mike and Nancy Howe

Rosemary and James Hower

Rita and Richard Jacoby

James and Cheryl Jenkins

Annemarie Kessler

Celene and Michael Marsallo

Larry McFall

Fran McNaught

Sharon and David Naccarati

Lynn and Skip Neuenswander

Marti Peavey

Ginnette Pimentel

Tanja Popovic, MD

Nan and Dan Schaper, MD

Laurette and Michael Shulman

David and Enid Stoms

Terry Tobin

Robert and Julie Wash

This list was accurate at the time of publication. If you have any questions regarding the list, please reach out to  
Betsy Leon at [Betsy.Leon@curejm.org](mailto:Betsy.Leon@curejm.org)

\*October 1, 2023 through September 30, 2024

# POWERING PROGRESS: OUR CORPORATE PARTNERS

*We are incredibly grateful for our corporate partners, whose generous support plays a vital role in advancing our mission to find better treatments and a cure for juvenile myositis. Their commitment helps fund groundbreaking research, expand educational programs, and provide essential resources to families affected by JM.*

*Through their partnerships, we're able to host impactful events, foster innovation in care, and create lasting change in the lives of JM patients.*

*Together, we're forging a future filled with hope, progress, and life-changing scientific breakthroughs.*



## Our Corporate Sponsors:

### PLATINUM PARTNERS



### GOLD PARTNERS



### SILVER PARTNER



### BRONZE PARTNERS



PAUL & MARGARET

PORTER FOUNDATION





## On behalf of the Cure JM Foundation,

Your unwavering support is the heart of our mission. At last year's Cure JM Family Conference, I witnessed firsthand the incredible impact of your generosity. Seeing a young girl joyfully run and play with other children, thanks to a research breakthrough made possible by our community, was truly inspiring. This powerful moment reminded us why our work is so vital.

**As the largest funder of juvenile myositis research, we are committed to fiscal responsibility and maximizing the impact of your contributions.** In the past fiscal year ending September 30, 2024, your generous support of over \$2.2 million enabled us to invest more than \$2 million in promising juvenile myositis research and programs. We have also committed more than \$5 million to ongoing multi-year grants and programs. These investments will positively impact thousands of lives in the years to come. Your support is truly inspiring.

Our mission also extends beyond research. We are also dedicated to ensuring patients receive the best possible care. Our rapidly growing Cure JM Clinical Care Network, now 55 members strong, is a testament to this commitment. These partnerships bring crucial care closer to home for countless patients. With your continued support, we will expand this network even further, reaching more children in need.

Cure JM is committed to supporting families throughout their journey with juvenile myositis. We provide essential resources, 24/7 support, and emotional care programs for patients and their families. We are at the forefront of improving rheumatology care by championing the inclusion of vital emotional support services for all pediatric patients.

While we are proud of our many accomplishments, we recognize that there is still much work to be done. Countless potential treatments await discovery. Your financial support is essential to bringing these treatments to fruition.

Thank you for your partnership in our mission.

With heartfelt gratitude,



Justin Whitney

Outgoing Treasurer, Incoming President, Cure JM Board of Directors



### Cure JM has been recognized with awards for its public accountability, program effectiveness, and cost effectiveness.

Since our inception in 2003, Cure JM has invested approximately 89% of all donations into research and educational programs.

The foundation has received the Top-Rated Award from GreatNonprofits.org every year since 2011, and GuideStar USA has awarded Cure JM the Platinum Seal of Transparency for our commitment to financial transparency and accountability.





Education and support for parents, teaching them how to care for their children

# Your Impact...



Cure JM National and Regional Family Conferences



Tween, Teen, and Young Adult support groups and mentorships from older patients



Live and Virtual Cure JM Town Halls and Family Days



Cure JM Clinical Care Network, helping kids get the best care



Cure JM Medical Symposia



Researchers and families interacting at Cure JM's Family Conference.



Cure JM Advocates Council, for patients aged 18-30



# POWERING PROGRESS: EVERY GIFT HELPS

Join us today and show your support.  
Every gift makes a difference.

## Ways to Give:

- **Online:** Visit [www.curejm.org/donate](http://www.curejm.org/donate) to donate securely using a credit card, PayPal, or Venmo.
- **By Mail:** Send a check made out to "Cure JM" to:
- **Give cryptocurrency:** Visit [www.curejm.org/crypto](http://www.curejm.org/crypto)
- **Other Giving Options:** Please contact Shannon Malloy, our Director of Community Engagement

Cure JM Foundation  
P.O. Box 45768  
Baltimore, MD 21297

Email: [shannon.malloy@curejm.org](mailto:shannon.malloy@curejm.org)  
Phone or Text: (202) 596-6267

Together, let's rewrite the future for juvenile myositis.

Every gift, no matter the size, makes an impact:

**\$5** sends a teen patient to a peer support group

**\$15** gives a children's book about JM to a child

**\$33** provides a 1-hour educational session to a parent, to learn to care for their child with juvenile myositis

**\$47** distributes treatment protocols to doctors

**\$92** provides one dose of medication for a clinical trial to discover treatments that are less harsh than today's treatments of steroids and chemotherapy

Cure JM Foundation is a 501(c)(3) non-profit organization.  
Tax ID number 35-2222262.



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Rosie, receiving an all-day plasma infusion, is just one example of how your support helps kids. Your gift allows kids like Rosie to spend less time in the hospital and more time being kids again!



Top-Rated Since 2011

Platinum  
Transparency  
2024

Candid.

