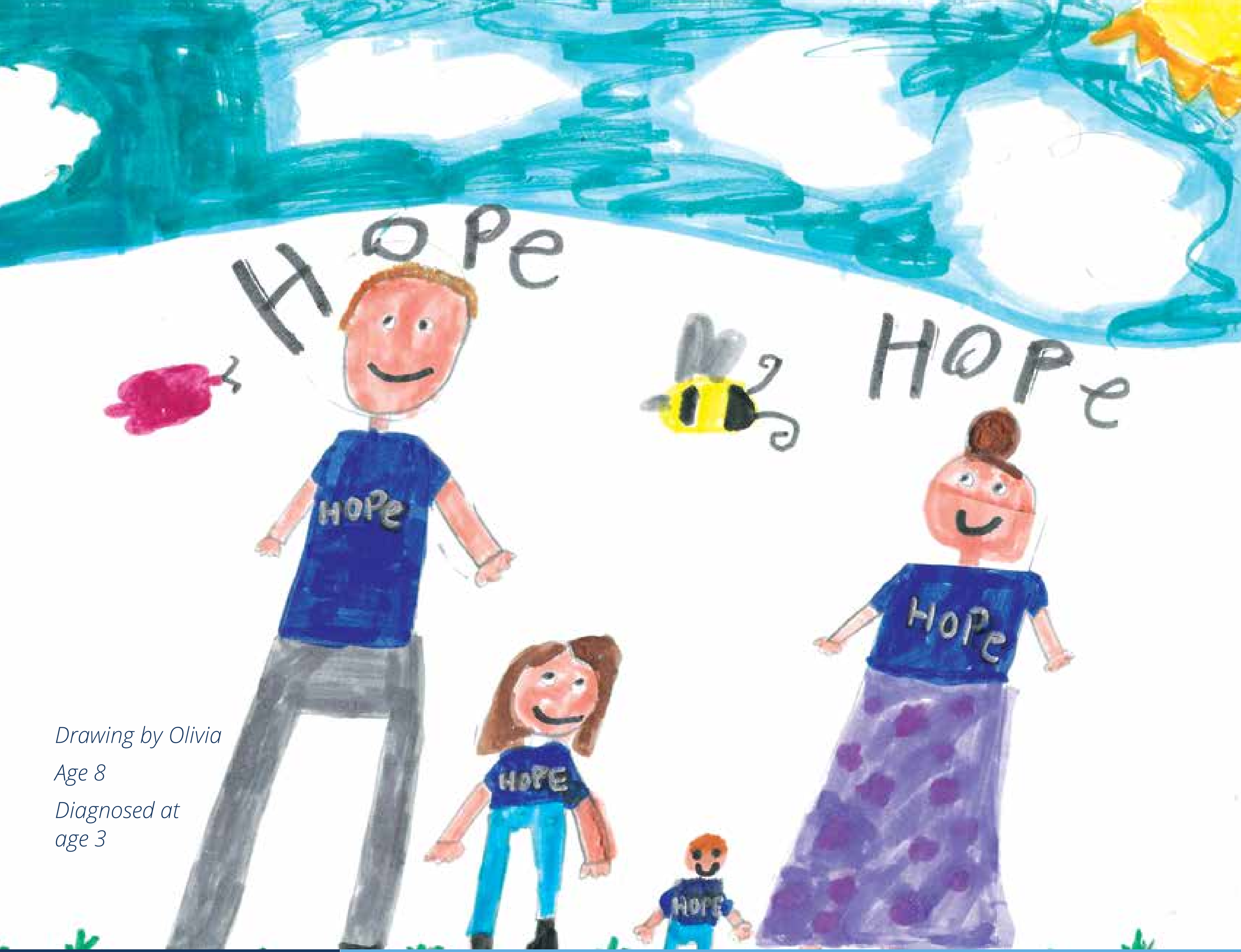


Drawing by Olivia

Age 8

Diagnosed at age 3

IMPACT REPORT 2025

A Defining Moment in the Future of JM Treatment

Cure JM®
FOUNDATION

A Year Like No Other…

A Quick Note from the Executive Director

Dear Friends,

2025 has been an extraordinary year of growth and achievement at Cure JM. I think of it as the year where science fiction took a major turn toward science fact.

We began the year with the hope that a very real potential exists for a cure for juvenile myositis, which once seemed like a far-away aspiration, catapulted to the front and center of our mission through our partnership with a biotech startup that may well hold the key to long-term — and perhaps permanent — remission of JM.

In June, we enrolled the first JM patient in the U.S. in the treatment trial. The patient has completed all treatment procedures without complications. We are awaiting improvement data and should have more to report on the initial results before the end of the year.


Dr. Carl June addresses the 2025 Family Conference

This therapy, known as CAR-T therapy, is currently being pioneered in autoimmune diseases and juvenile myositis by Cure JM and our biotech partner, Cabaletta Bio.

The excitement and progress within the Cure JM research community are building.

Also in June, families attending the Cure JM family Conference in Chicago heard two extraordinary presentations. The first was from Dr. Rebecca Nicolai of Bambino Gesù Children's Hospital, who has treated two children with CAR-T, children with very difficult-to-treat cases of JM. The results were amazing — virtually a complete remission of JM symptoms that had previously been wholly resistant to other treatments.

Moreover, we were honored at the conference to hear from our keynote speaker, Dr. Carl June. Dr. June is often referred to as the father of CAR-T therapy, which first proved successful in oncology. Dr. June's expertise and global stature are helping Cure JM and other organizations navigate a successful transition to JM and other autoimmune diseases, the next frontier for the therapy. Dr. June received an extended standing ovation from our families, recognizing his vision and pioneering breakthroughs that have led to where we are today.

As if CAR-T were not enough, I am equally excited about other major projects funded by Cure JM as a part of our research portfolio. One promising project is Cure JM's investment in "Nucleic Acid Therapeutics" research at the Harwell Science and Innovation Center in the United Kingdom. It is here that the UK has established a national research initiative with a mission to accelerate DNA- and RNA-based therapies, a class of medical treatments that utilize DNA or RNA to treat diseases.

Today, the best-known RNA therapies are COVID-19 vaccines, which provide cells with a set of modified genetic instructions to trigger an immune response to the virus.

Could a similar RNA therapy work in JM? Is it possible to modify genetic instructions to turn off or down-regulate an autoimmune response in JM?

It is a tantalizing possibility.

Cure JM has funded the RNA research of Dr. Joanna Parkes at Harwell. Dr. Parkes, a global expert trained in the U.S., runs the UK lab charged with the responsibility for developing an RNA therapy for juvenile myositis, a mission Cure JM is thrilled to support. As an international funder, we go to where we find the best science.

> *"This kind of progress is made possible only because of the dedication Cure JM receives from supporters like you."*
>
> **Jim Minow**

Dr. Parkes's research successfully identified two leading RNAs that down-regulate or "turn off" interferon pathways leading to JM. The over-expression of interferon is implicated as a cause of muscle and skin inflammation in JM.

This is another example of science fiction heading toward science fact. There is a very real possibility that RNA therapies could lead to the development of a vaccine to control autoimmune reactions, not just in JM, but in a host of related inflammatory diseases in rheumatology. This research is in the early stages. Our next step is to test the efficacy of the RNA therapies in animal models before we can move into human clinical trials as funding becomes available.

This kind of progress is made possible only because of the dedication Cure JM receives from supporters like you. That support has allowed Cure JM to open additional Cure JM Centers of Research Excellence as well as create a coast-to-coast network — the Cure JM Clinical Care Network — of children's hospitals and doctors now trained to provide specialized best-in-class care to patients living with a rare disease — a rare disease that was once largely unknown.

This progress is not accidental. I hope you are as proud as I am of what you and other Cure JM supporters have accomplished over our 22-year history. While the quality of treatments due to Cure JM's years of research investments are ever improving, there is much left to be done.

I cannot thank you, our "family of families," enough for creating a brighter future for JM children everywhere and for providing Cure JM researchers with the necessary support to move therapies from science fiction to science fact.

With appreciation,

Jim

Jim Minow
Cure JM Foundation Executive Director

22 Years of Progress and
IMPROVING LIVES

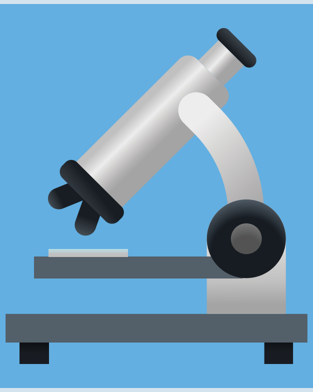
$30 million invested

Largest juvenile myositis funder on the planet

10+

NEW TREATMENTS

to reduce dependance on steroids and methotrexate



219

RESEARCH PROJECTS FUNDED

60

Cure JM Clinical Care Network Partners

Reduced time to diagnosis by more than

75%

From 12 months to under 3 months

Early treatment leads to better outcomes

3,000+

FAMILIES CONNECTED

with other families and resources

Cure JM®
FOUNDATION

POWERING PROGRESS:
2025 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 the Cure JM 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 2025:

- **$5 million in active grants** driving research and innovation.
- **71% of the pediatric rheumatologists in the U.S.** participated in our education programs about JM care.
- **Expanded the Cure JM Clinical Care Network** to 60 partners.
- **Supported a clinical trial for CAR-T**, a promising "immune system reset" therapy which offers groundbreaking potential.
- **Advanced new treatments** that show 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 quality of life.

> *"Cure JM has helped me turn my own hardships into hope. Living with JM isn't easy, but if I can use my experiences to make even one child feel less alone and more hopeful about their future, then every challenge I've faced has been worth it. Knowing I can be that source of comfort and strength for someone else keeps me moving forward."*
>
> Maddy Coffey, Chair, Cure JM Young Adult Advocates Council
> Director, Board of Directors, diagnosed in 2010

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 EDUCATION PROGRAMS

We improve care. Summits, Clinician News, and the Clinical Care Network connect providers and raise standards of care.

We invest in the next generation. Fellowships and training programs like the JM Mastery Series prepare early-career clinicians.

We accelerate research. Collaborations and the Clinical Trial Readiness Bootcamp keep clinicians at the cutting edge of new research.

We bring therapies to families faster. Educating clinicians and families ensures breakthroughs reach patients quickly.

Dr. Andrew Heaton, Cure JM's Chief Scientific Officer, led our Inaugural Clinical Trial Readiness Bootcamp on September 12.
The event brought together 31 participants from 11 institutions, marking a breakthrough step toward advancing new treatments and reducing reliance on today's harsh therapies.

> "The expansion of and investment in Cure JM's Clinical Care Network is a top organizational priority—and it is life-changing for families. It ensures that children with juvenile myositis can access JM expertise care close to home."
>
> *Julie Houpt, Co-Chair, Cure JM Research Committee, mother of a child treated at Cure JM Clinical Care Network partner Scottish Rite in Dallas, TX*

IMPROVING CARE FOR PATIENTS:

THE CURE JM MEDICAL ADVISORY BOARD

Led by Brian Feldman, MD, MSc, FRCPC, the Cure JM Medical Advisory Board (MAB) serves as the principal scientific, medical, and research advisory group to Cure JM Foundation. The Medical Advisory Board is responsible for reviewing Cure JM's strategic research direction and priorities, including investments in research, development, translation, and clinical practice/treatments. They oversee assessments of research grants, the Cure JM Clinical Care Network, fellowship implementation strategies, Cure JM Centers of Research Excellence, and other current and future funding priorities to advance the Foundation's mission.

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

Lisa G. Rider, MD
Chair Emeritus, MAB
Head Environmental Autoimmunity Group, National Institute of Environmental Health Sciences, National Institutes of Health

Lucy R. Wedderburn, PhD, MRCP
Director, Arthritis Research Centre for Adolescent Rheumatology University College London (UCL)

Anne Stevens, MD, PhD
Senior Director, Immunology Janssen Research and Development

Lauren M. Pachman, MD
Professor of Pediatrics Northwestern University Feinberg School of Medicine

Kanneboyina Nagaraju, DVM, MVSc, PhD
Dean and Professor, Pharmaceutical Sciences Binghamton University, State University of New York

Susan Kim, MD, MMSc
Associate Clinical Professor of Pediatrics University of California, San Francisco

Adam Huber, MD, MSc
Professor of Pediatrics Dalhousie University, Halifax, Nova Scotia

Stacey Tarvin, MD
Program Director,
Pediatric Rheumatology Riley Hospital,
Chair, Cure JM Clinical Care Network

Andy Mammen, MD, PhD
Associate Director, Johns Hopkins Myositis Center Investigator, National Institutes of Health

HONORING DR. RODOLFO CURIEL

We want to take this opportunity to recognize and thank Dr. Rodolfo Curiel for his extraordinary leadership at the Cure JM Center of Research Excellence at George Washington University, and for his dedication to helping JM families manage the most difficult phases of this disease. Dr. Curiel is retiring in October.

The Cure JM Center at GW focuses on providing expert second or consulting opinions to families in the U.S. and around the world who often face the most challenging forms of juvenile myositis. Because of Cure JM's financial support, the Cure JM Center at GW has been able to provide this service at no cost to families. We can't tell you how many families have told us over the years how the GW Center "probably saved my child's life."

Dr. Curiel has also served as the principal investigator on several clinical trials, the most recent of which documented the effectiveness of the drug abatacept (brand name Orencia), in treating JM. Children and adolescents who participated in the GW trial showed measurable improvement scores in both muscle strength and skin manifestations. The success of the trial resulted in abatacept's addition to the growing list of newer drugs now in use to treat JM.

IMPROVING CARE FOR PATIENTS:

CURE JM CLINICAL CARE NETWORK

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

> *"We are excited to align clinical care and research to improve the outcomes of patients with JDM today, as we build toward a future that is better and brighter for all children affected by this disease."*

Susan Kim, MD, MMSc, and Jessica Neely, MD,
Cure JM Clinical Care Network Partners at
UCSF Benioff Children's Hospital

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

Angela C. Chun, MD
Ann & Robert H. Lurie Children's Hospital of Chicago
Steering Committee,
Cure JM Clinical Care Network

Dawn Wahezi, MD, MS
The Children's Hospital at Montefiore
Steering Committee,
Cure JM Clinical Care Network

Belina Yi, DO
The Johns Hopkins Hospital
Steering Committee,
Cure JM Clinical Care Network

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

Bita Arabshahi, MD
Inova Children's Hospital

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

Stephen J. Balevic, MD, PhD
Duke University School of Medicine

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)

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

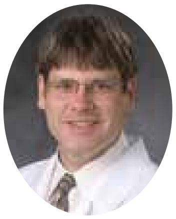
Megan Curran, MD
Children's Hospital Colorado

Alaina Davis, MD
Children's Hospital 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

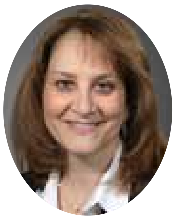
Cuoghi Edens, MD
University of Chicago Medicine

Brian Feldman, MD, MSc, FRCPC
The Hospital for Sick Children

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

Maria Ibarra, MD
Children's Mercy
(Kansas City, MO)

Ankur Kamdar, MD, FACR
McGovern Medical
School At UTHealth

Daniel Kietz, PhD
University of Pittsburgh
Medical Center
(UPMC)

Hanna Kim, MD, MS
NIEHS, 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

Daniel J. Lovell, MD, MPH
Cincinnati Children's
Hospital Medical Center

Joseph McDonald, MD
University of Chicago Medicine

Katherine Moore, MD
Children's Hospital Colorado

IMPROVING CARE FOR PATIENTS:

CURE JM CLINICAL CARE NETWORK

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

Rebecca Nicolai, MD
Ospedale Pediatrico
Bambino Gesù
Rome, Italy

Karen Onel, MD
Hospital for Special Surgery

Julie J. Paik, MD, MHS
Johns Hopkins University School
of Medicine
Baltimore, MD

Charris Papadopoulou, PhD
Great Ormond Street
Hospital for Children

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

Lisa Rider, MD
NIAMS, 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 Shenoi, MD, MS
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 Tesher, 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

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)

IMPROVING CARE FOR PATIENTS:

INVESTING IN OUR CLINICAL CARE NETWORK

Cure JM Clinical Care Network Investment Highlights:

Rady Children's, San Diego

Established a JM Clinic, purchased a nailfold capillaroscopy microscope, and trained staff across physical therapy, emotional health, and dermatology.

UPMC, Pittsburgh

Established a JM Clinic and launched an annual Cure JM Family Day.

Children's Hospital of Los Angeles

Establishing a JM Clinic and purchased a nailfold capillaroscopy microscope.

Montefiore Children's, New York

Purchased a nailfold capillaroscopy microscope.

Johns Hopkins Children's Center & Myositis Center

Purchased a nailfold capillaroscopy microscope and partnering together to expand the JM clinic.

Scottish Rite Children's Hospital, Dallas

Upgraded nailfold capillaroscopy microscope and supporting staff participation in the 2026 Cure JM Texas Regional Conference.

Cincinnati Children's

Educated physicians on using the nailfold capillaroscopy microscope and validated new measures of JM disease activity.

Riley Children's, Indianapolis

Expanded the JM clinic and strengthened the pediatric rheumatology education program for medical students.

Children's Hospital of Orange County

Trained clinicians in JM care and advanced JM research.

Children's Hospital Colorado

Developed a UV education packet for families. This will be shared in the coming months.

Boston Children's

Building a system to help parents measure JM disease activity online.

Hospital for Sick Children, Toronto

Researched the impact of exercise and supplements on JM.

Children's Healthcare of Atlanta

Funded a research assistant to accelerate the CAR-T clinical trial.

Bambino Gesù Children's Hospital, Rome

Advanced CAR-T case studies and shared findings at the Cure JM Family Conference.

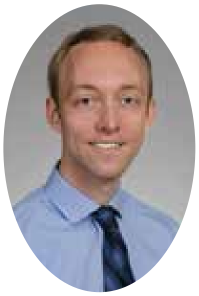
What is a nailfold capillaroscopy microscope?

Abnormal blood vessels can signal active JM. A nailfold capillaroscopy microscope magnifies these vessels **up to 600 times**, allowing doctors to spot flares earlier. Early detection means better outcomes. **By funding this equipment, we are helping kids get the care they need sooner.**

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.

NEW CURE JM FOUNDATION GRANTS AWARDED IN 2025:



Christian Lood, PhD
University of Washington

Sara Sabbagh, DO
Medical College of Wisconsin

Jessica Turnier, MD
University of Michigan

STANDARDIZED PROTOCOL FOR COLLECTING SAMPLES AND MEASURING BIOMARKERS

Collaborating with Dr. Turnier and Dr. Sabbagh, Dr. Lood will lead a project to develop a standardized protocol for collecting samples and measuring biomarkers. This work is critical to improving disease monitoring, identifying new treatment targets, and advancing personalized care. This is important because we know that every child responds differently to treatment and requires an individual treatment plan.

Rie Karasawa, MD, PhD
St. Marianna University School of Medicine, Japan

HOW MYOSITIS-SPECIFIC AUTOANTIBODIES AFFECT PROTEIN EXPRESSION IN INNER CELLS OF BLOOD VESSELS IN JDM

Dr. Karasawa will collaborate with members of Cure JM's Clinician Care Network and work with North American partners, including Dr. Lisa Rider, to share samples. The research will focus on learning how myositis-specific autoantibodies (MSAs) associated with clinical features of juvenile dermatomyositis (JDM) affect protein expression in inner cells of blood vessels in JDM. This study will provide new information on the roles of MSAs in the blood vessel injury, which will offer valuable insights into new therapeutic approaches targeting blood vessels in JDM.

Three new grants have been awarded to implement mental health screening services in rheumatology and juvenile dermatomyositis (JDM) clinics at **Texas Children's Hospital**, the **University of Michigan C.S. Mott Children's Hospital**, and **Children's of Alabama**. These initiatives recognize the stress and emotional challenges faced by children and teens living with a chronic and rare disease. By integrating mental health screening and emotional support into their care, these programs aim to provide comprehensive support for both physical and emotional well-being.

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.

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.

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.

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?

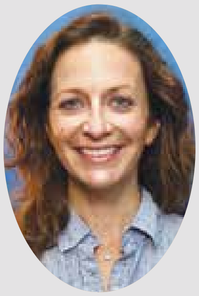
To investigate deucravacitinib as a potential new treatment for juvenile myositis.

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.



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.

VIEW REAL-TIME RESEARCH UPDATES AT WWW.CUREJM.ORG/RESEARCH

CURRENTLY FUNDED RESEARCH

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.

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.

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.

VIEW REAL-TIME RESEARCH UPDATES AT WWW.CUREJM.ORG/RESEARCH

CURRENTLY FUNDED RESEARCH

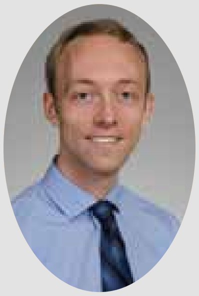
Jayne MacMahon MB, BCh, BAO, LCRP&SI, MRCPCH

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.



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.

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.

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.

> "Our commitment is simple: steward every dollar wisely so that your generosity drives the breakthroughs our families are counting on."
>
> Tim Shelby
> Treasurer, Board of Directors

VIEW REAL-TIME RESEARCH UPDATES AT WWW.CUREJM.ORG/RESEARCH

SUPPORTING FAMILIES:
EMOTIONAL HEALTH INITIATIVES

We are deeply grateful to the RB DenUyl Family Foundation for their generous support, which makes our emotional support program possible.

1.1 million
minutes of peer support from other families, so no one has to walk this journey alone.

77 trained peer support representatives
Our network of young adults, teens, parents, and grandparents provides mutual support and understanding for families facing JM.

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.

Emotional check ups at your rheumatologist

Cure JM is integrating emotional health screenings and support into routine JM care at rheumatology visits, with plans to expand 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

20+ chapters to educate and support families

Together, we create stronger, more connected communities.

NEW Parent and Family Connect Groups

- Our new *Moms' Connect* and *Dads' Connect* Zoom calls give parents a welcoming place to share and connect with others who understand their journey.
- Our *Grandparent Connect* provides support and community for grandparents of JM patients.
- *Young Adult Connect* offers a safe and supportive space for young adults ages 18 - 30.
- Coming soon in the new year: a *Teen Connect* group and a support group for patients ages 30+.

To join the invitation list, visit **www.curejm.org/join**

The American College of Rheumatology Releases First-Ever Guidance Statements to Address Emotional Health in Pediatric Rheumatology

After years of collaboration and leadership from Cure JM, the **American College of Rheumatology** (ACR) has issued official guidance that encourages pediatric rheumatologists to provide education and have ongoing conversations with families about mental health during their appointments.

"This is a milestone for families," says ***Suzanne Edison****, Cure JM's Mental Health Coordinator and a key contributor to the multi-year effort to obtain consensus on these statements. "Living with JDM is filled with ups, downs, and uncertainty. Supporting mental and emotional health is not optional—it's essential."*

Learn more here.

Contact Mental Heath Coordinator Ronda Thorington at **ronda.thorington@curejm.org**

2025 NATIONAL CONFERENCE:
INFORMATION & COMMUNITY FOR JM FAMILIES

The 15th Cure JM Family Conference took place near Chicago in June. Thanks to the generosity of our sponsors, families and clinicians came together for an unforgettable weekend:

- **Families** received the latest updates on cutting-edge JM research from leading researchers and clinicians.
- **Our Leadership Councils** met in-person for strategic planning sessions.
- **More than 40 clinicians** from Cure JM's Clinical Care Network collaborated on how to deliver the best care to patients.
- **Teens and young adults** connected with peers who understand their journey and built lifelong friendships.
- **Younger JM patients and siblings** enjoyed crafts, games, and kid-friendly activities.
- The weekend concluded with a **Volunteer Celebration Banquet**, followed by the **2025 National Walk Strong** fundraiser, a highlight of the weekend!

FAMILY EDUCATION:
INFORMATION & COMMUNITY FOR JM FAMILIES

In 2026, Cure JM is bringing our renowned education and connection to 4 Regional Conferences, more than a dozen local Family Days, and monthly online Town Halls

4 REGIONAL CONFERENCES

Southern California
Saturday, October 18, 2025
Orange County, CA

Texas
Saturday, April 11, 2026
Austin TX

North and South Carolina
Saturday, May 17, 2026
Raleigh-Durham, N.C.

Florida
Save the date:
November 2026

ASK THE DOC TOWN HALLS

Join us for monthly learning sessions with JM Experts. All invitations and recordings are saved at: www.curejm.org/townhalls

12 FAMILY DAYS
and growing!

- Nashville
- Pittsburgh
- Chicago
- San Francisco
- Seattle
- Cincinnati
- Bronx, New York
- Washington, D.C. / DMV-metro
- Boston
- Ann arbor, MI
- Atlanta
- Denver
- *More coming soon!*

> "Families are the heart of our mission. One of our top priorities is to bring education and fellowship to every family, right in their own community."

John Caldwell
Co-Chair, Cure JM National Leadership Council
and Director, 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.

Your participation powers progress.

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

Highlights from 2025:

- **Our signature Walk Strong program raised $600,000 for research.** Find a walk near you at curejm.org/walkstrong.
- **Last year's Giving Tuesday Holiday Challenge raised over $1,000,000 for research.** Visit curejm.org/hopehero to learn more about this year's campaign.
- **Families and friends hosting DIY Fundraisers raised over $10,000.** Visit 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.

> "Cure JM is powered by families and friends who believe in investing in brighter futures for our kids. Thanks to your support, we are funding groundbreaking research and vital family programs that didn't exist just a few years ago."

Zack Harrison, Co-Chair,
Development Committee and
Co-Chair, Southern California Walk

POWERING PROGRESS:
OUR LEADERSHIP

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 Staff**, which provides leadership to move our mission forward.

(click on photos to learn more)

Cure JM Board of Directors

Cure JM Medical Advisory Board Chair
Brian Feldman, MD, MSc, FRCPC
Head, Division of Rheumatology,
Hospital of Sick Children, Toronto

Cure JM Foundation Staff

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

POWERING PROGRESS:
OUR COUNCILS

Founded by parents and grandparents of children with juvenile myositis, for 22 years Cure JM has been driven by the passion and commitment of our families.

Cure JM National Leadership Council

Cure JM Young Adults Advocates Council

Cure JM Grandparents Alliance

Our mission is carried out by:

- **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 Alliance**, 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. Learn more at **curejm.org/cab**
- **Our Chapter and Walk Leaders**, who support Cure JM Fundraising, informational seminars and community activities as a state and local level.
- **Our Family Support Network**, which offers a warm, practical place to meet other parents, grandparents, teens, and young adults who understand the journey.

(click on photos to learn more)

Cure JM Chapter
and Walk Leaders

Cure JM Holiday
Challenge Committee

Cure JM Family
Support Network

Cure JM Community
Advisory Board

POWERING PROGRESS:
HONORING 20 YEARS OF SERVICE

We proudly recognize Denise Koch and Suzanne Edison who are both retiring after 20 years of extraordinary volunteer service.

For two decades, **Denise Koch** has been a driving force in Cure JM's volunteer community. She has served as a trusted leader of the Chicago Chapter and Walk, the Family Support Network, the National Leadership Council, and Board of Directors. Denise's support and mentorship inspired countless volunteers and families to step forward as leaders.

Over two decades **Suzanne Edison** has served on local Chapter and Walk committees, the Family Support Network, as Co-Chair of the Research Committee, on Board of Directors and staff. Suzanne was instrumental in making emotional health a recognized and integral part of JM care. Her advocacy and commitment have provided families with vital resources, support, and hope, helping children and parents navigate the emotional challenges of living with JM.

Take the Baton

Inspired by Denise and Suzanne's example? To get involved, contact our Director of Community Engagement, Shannon Malloy, at shannon.malloy@curejm.org. She will help you explore ways to plug into our community in a way that fits your busy life.

> "We each carry the baton for a while hoping to make a bit of difference for the next family, and then we pass it on to someone else. Some carry the baton for a short time, some for a longer time, but the amount of time is not the important part, it's that you've carried it all. Carry on."
>
> Suzanne Edison, Cure JM Family Conference, June 28, 2025

Thank you, Kristine Alderfer, for a decade of service as Conference Organizer, connecting hundreds of families and clinicians. We are grateful for your leadership and look forward to your continued service on the Board of Directors.

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

$1,000,000+

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
Merrianne Van Ness

Grandparents who gave $10,000+ in our Fiscal Year 2025*

Mike and Patricia Fox
Heather and Mike Weiss
Charles Allen
Joel and Laurel Reed
Janet and Allen Cumbie
Rosemary and James Hower

Grandparents who gave between $1,000 -$10,000 in our Fiscal Year 2025

Cathy Allen
Jim Austin
Harriette Best
Bill and Connie Brewer
John and Ann Burns
Sheryl and Stuart Chuzmir
Elinor and Andrew Dahill
Phuoc Dang
William and Lynne Elsesser
Carl and Carolyn Erite
Josie Garcia
Sheri Grahn
Dennis and Patricia Grundy
Robert and Karen Hahn
Joanne and Jeffrey Hall
Linda and Randy Hart
Patti Hawley
Mike and Nancy Howe
Danny Hwang
Michael Kenawell
Annemarie and Grant Kessler
Chuck and Laurel Krider
Kimberly Lawson
James Macklin
Celene and Michael Marsallo
Larry McFall
Mike and Francine Mule
Sharon and David Naccarati
Lynn and Skip Neuenswander
Lousie Nielson
Susan and David Sangid
Nan and Dan Schaper, MD
Linda Sestak
Laurette and Michael Shulman
Barbara and Jacob Spigelman
David and Enid Stoms
Terry Tobin
James and Dorothy Triquet
Becky and Donald Whitt

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

*October 1, 2024 through September 30, 2025

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:

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Innovators in Specialty Infusion

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 to donate securely using a credit card, PayPal, or Venmo.
- **Give cryptocurrency:** Visit www.curejm.org/crypto
- **By Mail:** Send a check made out to "Cure JM" to:

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

- **For more ways to give click** here

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.

Cure JM®
FOUNDATION

*Since our inception in 2003, Cure JM has invested approximately **89%** of all donations into research and educational programs, and has been recognized with awards for its public accountability, program effectiveness, and cost effectiveness.*

GREATNONPROFITS
2025 TOP-RATED
NONPROFIT

Top-Rated Since 2011

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