

POWERED BY YOU



2016 IMPACT REPORT

CURE JM FOUNDATION®

With Deep Gratitude...

“For 13 years, we’ve fought side by side with heroic JM families and dedicated supporters to find better treatments and a cure for JM. We are humbled by the courage of all those who suffer from JM, as they are the inspiration and driving force behind everything we do at Cure JM. Together, we can create a world without JM.”

Tom and Shari Hume

Dear Cure JM Families and Friends,

Thanks to you, 2016 was a year of significant momentum for Cure JM Foundation® in the fight against Juvenile Myositis (JM).

[Our accelerated progress would not be possible without you, our dedicated supporters.](#)

You helped advance our life-changing work through generous contributions. And, many of you volunteered your time and talents, participated in Cure JM events and research studies, and worked hard to spread the word about our important cause. Collectively, you all made the recent advances that have brought us closer to solving the puzzle of this complex disease possible. **We are humbled by your support, and truly grateful.**

In this report, you will see the profound impact your contributions have made on the children, adolescents, adults, and their families affected by this devastating disease.

Research Highlights

Thanks to your generosity, Cure JM has invested over \$11 million in research and educational programs and supported over 140 research studies since 2004. Cure JM is currently funding critical research at 18 world-class research institutions, including our two research and treatment centers located in Washington, D.C. and Chicago. This promising research includes studies on biomarkers, genetics, calcinosis, and heart disease related to JM. Our steadfast progress continues to improve the outcomes for JM patients.

Drug Development

A special thanks to Cure JM grandmother Marge Coffey, who made possible Cure JM’s investment in a 3-year drug development program at National Center for Advancing Translational Science (NCATS). The NCATS team will screen hundreds of thousands of potential drugs, as well as existing drugs for other diseases, and perform follow-up studies on the most promising drugs. The expected result is a short list of new and repurposed drugs that have the potential to improve the prognosis for JM.

Drug Trials

We saw an increase in the number of drug trials this year for JM, with three active drug trials, plus one new drug was available for “compassionate use.” Two of these drug trials took place at one of Cure JM’s research and treatment centers — the George Washington University Myositis Center in Washington, D.C.

New Chapters And Walks

To better serve the JM families and continue our successful growth, we established Cure JM chapters in 5 regions: Austin, Chicago, New York, Seattle and Washington, D.C. Each chapter held its first “Meet & Greet” event where local Cure JM families joined together to provide mutual support and hear the latest research updates from prominent local researchers and Executive Director, Jim Minow. Each chapter hosts an annual **Walk Strong to Cure JM™**, a family fundraising walk.

Cure JM mom, Kalen, said, "The walk was our first time meeting any other families affected by JM. When my son was first diagnosed, I felt so alone because of the rarity of this diagnosis. After joining the online Cure JM community, it was a huge relief to have others to be able to relate to. And then to be able to meet them at the Seattle **Walk Strong™** event was even better!"

New chapters are planned for 2017, and with continued success, the expansion will continue in future years.

Family Support

Thanks to you, Cure JM has been providing vital resources, information, and support to JM families for 13 years. Your profound impact on JM families is crystal clear in the countless stories we hear from them.

As one parent stated, "I found the Cure JM site at 3:00 a.m. through tear-filled eyes on the floor of the hotel bathroom while my son slept that first night of diagnosis. It was the best source of information I found. It gave me hope and guidance. I don't feel like we are fighting this alone. Our family will forever be grateful for the Cure JM Foundation."

Financials

We use your contributions wisely, and this year, **87% of donations went directly to research and educational programs.** Cure JM Foundation's independently audited financials are posted on our website.

Cure JM received 2 prestigious awards given to fewer than 1% of over 1 million nonprofit organizations in the United States. For financial transparency and demonstrating a commitment to measuring progress and results, Cure JM received the *Platinum Award*, the highest ranking possible from Guidestar. Plus, Cure JM received the Independent Charities "*Best in America*" seal for meeting the highest standards of public accountability, program effectiveness, and cost effectiveness.

Give Hope

We have many reasons to **HOPE**.

Our vital supporters are one of those reasons. A JM child's life, a family's hope for the future, would not be possible without you.

Our JM patients and families are another reason to hope. Their courage and resilience in the face of adversity are the driving force and inspiration behind everything we do at Cure JM.

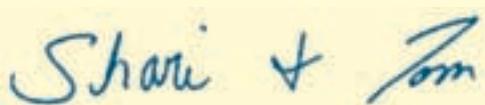
Despite our momentum, we still have work to do.

JM can take away a child's carefree childhood and replace it with needles, doctors, and hospital rooms. JM can be life-long or life-ending, unless a cure is found.

You can change this. You can rewrite the future for all of those battling JM.

Their future is in our hands. Together, we can create a world without JM.

With deep gratitude,



Shari and Tom Hume
Co-founders

James Minow
Executive Director

Power Points

New Research and Programs Powered by YOU



11th National Family Conference
Austin, 2017



National Walk Program
Walk Strong to Cure JM™



7th JM Medical Forum
Austin, 2017



Drug Development Program



Teen and Young Adult Portal



First Five Regional Chapters



Early Diagnosis Initiative



E-book of Myositis and You



Medical Network for Healthcare Pros

And Since its Inception, Cure JM has...



Invested \$11 Million in
Research/Educational Programs



Supported Over 140
Research Studies



Helped to Create & Support Two
Research and Treatment Centers

Power of Love: The Smedley Family

Mason ('little man') Smedley always enjoyed life to the fullest, a lesson he taught to the many people he touched during his short life.

Mason was diagnosed with Juvenile Dermatomyositis, a form of Juvenile Myositis (JM), in August of 2003 when he was 17 months old. He struggled with the disease most of his life and spent more than half of his life bound to a wheelchair.

Mason was the third of four children, with a little sister and two big brothers who always loved him dearly. Mason loved to eat Snow Cones, learn about sharks and tell jokes with his brothers and sister. Mason lived life to the fullest -- once he even swam with dolphins. His love of life touched all who met him.

Mason's Courageous Fight

Due to his JM, Mason endured countless surgeries and infections. Over the years, calcium invaded his little body, not only under his skin, but his organs as well. He spent much of his young life in the hospital, but his will, determination, and positive attitude kept him going.

Mason fought a very courageous battle with JM, but lost his fight on June 19, 2012.

Taking Action

Mason's parents, Damon and Kristen, have vowed to continue to raise money and awareness for this horrible disease in hopes that a cure will be found, so no other child will have to suffer like Mason.

Mason's parents — along with his siblings, Abby, Brock and Alec — have mobilized the city of Hillsboro, Oregon and raised over \$300,000 and logged thousands of volunteer hours for Cure JM. The Smedley family and hundreds of community volunteers have organized six "Cure Kids Jam Festivals" and five annual dinner and auction events. The Smedleys have been recognized as Cure JM Heroes for their relentless efforts to spread awareness of Juvenile Myositis and raise funds for research.

Mason's Miracle Award

Four years ago, Cure JM established a special award in memory of Mason, called "Mason's Miracle Award". Mason was, and continues to be, an inspiration to everyone. Mason showed great courage and strength in his battle with JM, and despite his challenges, he had an amazing sense of humor. His charm instantly won over everyone he met.

He was, and will always be, a true hero and has made a difference in countless lives. This award is now given annually to someone who carries on the spirit of Mason, and demonstrates the unfaltering courage, optimism, and perseverance that Mason showed us all. Mason's spirit and love of life will continue to inspire our community.

Mason had a vibrant, positive personality. Regardless of the battles he faced, there was always a smile on his face."

Damon Smedley
Mason's Father



Mason

February 25, 2002 - June 19, 2012

Empowering Families

“Chapter meetings are an ideal way for Cure JM families to connect with JM specialists and researchers in their own region.”

Denise Koch

Greater Chicago Chapter President

Regional Chapters

Greater Chicago Chapter

(Illinois, Indiana, Iowa, Wisconsin, Michigan)

President Denise Koch

denise.koch@curejm.org

Pacific Northwest Chapter

(Washington, Oregon, Utah, Montana, Idaho)

President Suzanne Edison

suzanne.edison@curejm.org

Washington, D.C. Chapter

(Washington, D.C., Virginia)

President Michelle Best

michelle.best@curejm.org

Texas Chapter

(Texas, Oklahoma)

TBA

walks@curejm.org

New York Chapter

(New York, New Jersey, Connecticut)

Presidents Kevin and Doreen Coffey

kevin.coffey@curejm.org,
doreen.coffey@curejm.org

In 2016, Cure JM Foundation introduced regional chapters to bring exceptional education and support to families in their local communities.

Cure JM launched its first five regional chapters in Austin, Chicago, New York, Seattle, and Washington, D.C. Each chapter hosts Meet & Greet social events and educational events where families and patients can learn about JM from local physicians and JM researchers. Cure JM Chapters also hold our new signature event, **Walk Strong to Cure JM**,™ a family fundraising walk to bring communities together and raise funds for Juvenile Myositis research.



Cure JM's Washington, D.C. Chapter at its first Meet & Greet in May 2016

“In the first year, Cure JM Chapters will hold 25 events, connect over 200 Cure JM families, and raise several hundred thousand dollars for JM research.” says Jim Minow, Executive Director of Cure JM Foundation. “Our first five chapters have been a great success due to the outstanding families and volunteer leaders in these regions.”

Chicago Chapter President: Denise Koch

One of our exceptional volunteer leaders is Denise Koch. Since 2013, Denise has been the Cure JM Family Support Network (FSN) Representative for the Midwest states. Through her role as FSN Representative, Denise has empowered hundreds of families with the critical knowledge and emotional support they need in their journey with JM.



Chicago Chapter
President
Denise Koch

In 2016, Denise stepped up to a new role at Cure JM as President of Cure JM’s first-ever Regional Chapter in Chicago, IL.

“Our regional chapters provide a powerful way to build a community among those affected by JM,” says Denise. “Families can meet others like themselves and share in the support of others who understand the challenges of coping with this devastating disease. Chapter meetings are an ideal way for Cure JM families to connect with JM specialists and researchers in their own region.”

Cure JM is very excited to expand the regional chapter program in 2017. Visit www.curejm.org/chapters or contact info@curejm.org to learn more.

Power of Community

Cure JM Foundation launched its **Walk Strong to Cure JM™** program in 2016 with kick-off events in Seattle, WA and Austin, TX (early 2017). During these events, Cure JM families, friends, neighbors and other supporters in the local community band together to raise money for JM research through a family-friendly fundraising walk. These family fun festivals also help to raise awareness of JM in communities across the nation.

Julie Shevlin, Cure JM mom and Walk Strong Chair for Seattle said, "It has been incredible to see what the **Walk Strong to Cure JM™** program has been accomplishing around the country. Hundreds of families are bringing their communities out in force to help us fund and find the cure."



Tessa, diagnosed at age 4, enjoys the post-walk festivities.

In Seattle, over \$60,000 was raised by walk teams to honor their loved one with JM. Plus, JM families and friends experienced firsthand the excitement and power of this event.

Future walks are scheduled for 2017 in Chicago, Long Island, and Washington, D.C., and we plan to expand the program to even more communities in 2018. Cure JM invites you to **Walk Strong,™** and to join the fight for a cure.



Julie Shevlin crosses the finish line at the inaugural Walk Strong to Cure JM event in Seattle, WA.

Walk Strong to Cure JM™

Chicago, IL

Sunday, May 7, 2017
Busse Woods, Elk Grove Village, IL
Walk Chair Jennifer Coe
jennifer.coe@curejm.org

New York, NY

Saturday, May 13, 2017
Eisenhower Park, Long Island, New York
Walk Chair Tracy Van Ness
tracy.vanness@curejm.org

Washington, D.C.

Sunday, June 4, 2017
RIO Washington Center, Gaithersburg, MD
Walk Chair Simonetta D'Onofrio
simonetta.donofrio@curejm.org

Seattle, WA

Saturday, October 7, 2017
Marymoor Park, Redmond, WA
Walk Chair Julie Shevlin
julie.shevlin@curejm.org
More events coming soon!



Over 500 people registered to Walk Strong™ in Austin. I am humbled by the overwhelming support of our community."

April Duley

Austin, Texas
Walk Strong Chair



Fun for all ages:
The Peters Family enjoys their local Walk Strong™ event.

Kid Power

“I want all the kids with JM to know they are not alone, and we can beat this.”

Layla
Diagnosed at Age 5



Layla was diagnosed with Juvenile Myositis in April of 2015 when she was five. Always a bright and compassionate little girl, she knew right away she wanted to do something for other kids. She wanted to make a difference for everyone fighting JM. Inspired by Layla's courageous fight against JM and her desire to help others with JM, Layla's friends and family teamed-up for the "Love for Layla" fundraiser. 150 friends, family, and supporters gathered for a family night out in Chicago last summer.



Layla: Finding Strength in Numbers

"It made me feel special," recalls Layla, now six years old. "Because all those people came to help me — and everyone with JM — fight."

Layla's courage and compassion inspired her community, and in just one night the "Love for Layla" event raised nearly \$10,000 for Cure JM's research program.

"I was happy "Love for Layla" got money for scientists," explains Layla. "Because then scientists can find a better cure."

But Layla's influence doesn't end there. In addition to helping raise money for research, Layla also has made a special point of encouraging other kids with Juvenile Myositis. Layla and her family are members of Cure JM's Chicago Chapter and also attend Cure JM's National Family Conferences, where Layla and her parents meet other families fighting JM.



"When kids can meet other kids, they will know that together we are strong," Layla says with undeniable conviction.

"I want all the kids with JM to know they are not alone, and we can beat this."

Power of Peers: Cure JM Teen Portal

In 2016 Cure JM Foundation launched a new portal for teens and young adults with guidance from our new Teen Ambassadors. It includes helpful resources for living with JM.

Meet Anna, one of our Cure JM Teen Ambassadors:

I always knew I was different, but never imagined I was one-in-a-million. I was diagnosed with JM when I was 15, two weeks before I started 10th grade. I began having symptoms in 7th grade after participating on the track team in the high jump. I hurt my knee and had to go to see an orthopedist who diagnosed me with bursitis.

Not Just "Growing Pains"

After that, I started having pain in my joints and I noticed my energy level was never the same. The pain worsened, with weakness in my upper arm muscles. Within three months, it escalated to weakness over my entire body, joint pain, and a rash on my elbows. Those three months were filled with different doctor's appointments, MRIs and confusion. I knew something was very wrong and yet the doctors did not seem to understand and kept trying to write it off as growing pains, though I had not grown in three years.

At the end of the three months, my mom and I went to Cabo San Lucas, Mexico. She thought it would be good for me to relax and get away from all the stress. Cabo in August is the hottest place ever, and if you know anything about JM, you know that heat and sun are not what you want. Our trip was cut short when I got so sick that I could barely move.

Diagnosis

We came home and went directly to a rheumatologist. He quickly diagnosed me and I have never felt such relief in my entire life. Sure, I had a life threatening disease, but I finally had an answer and treatment.

My doctor automatically started me on Methotrexate and Prednisone, which I am still on four years later. I was also prescribed a bunch of other meds, plus every four months I get two rounds of Rituxan IVs two weeks apart.

By the end of my senior year of high school, I was starting to feel almost like my old self again and now I am in my sophomore year of college all the way on the other side of the country. This means I am in charge of my own meds, doctors and infusions. It is a challenge to make sure I do not push myself too hard while still having fun and taking in the college experience.

My Opportunity

Life since being diagnosed has not been easy, but I have matured in countless ways over the past four years. Facing mortality at age 15 did that. Whereas I once saw this disease as a curse, I now see it as an opportunity for continued change and growth. I know it will be part of all that I accomplish in life.

Learn more about Cure JM's Teen Ambassadors and discover resources for teens and young adults at www.curejm.org/teens

Whereas I once
saw this disease
as a curse, I
now see it as an
opportunity for
continued change
and growth.”

Anna
Diagnosed at
Age 15



Power of Progress



NCATS Drug Development Program

Jim Inglese, Ph.D.

Principal Investigator, Division of Pre-Clinical Innovation at National Center for Advancing Translational Sciences (NCATS), National Institutes of Health

Cure JM has invested in a 3-year drug development program at NCATS led by Jim Inglese, Ph.D. Cure JM's funding supports the team's efforts to screen hundreds of thousands of new drugs, as well as existing drugs currently used in the treatment of other diseases, to determine their possible usage in the treatment of JM. They will then perform follow-up studies on the most promising drugs, with a goal of developing a short list of new and re-purposed drugs that have the potential to improve the prognosis for JM patients.



Interferons in Juvenile Dermatomyositis: Pathogenic Role and Correlations with Disease Characteristics at Onset and Long-Term Course

Rebecca Nicolai, M.D.

Division of Rheumatology, Babino Gesu Hospital, Rome, Italy

Dr. Nicolai aims to measure type I and type II interferon gene expression in JDM muscle, potentially leading to the discovery of additional biomarkers to measure disease activity. This is important because the pathogenesis of JDM is not understood, although it is likely that aberrant interferon expression plays a major role. If so, this could open up the possibility for new drug treatments that inhibit interferon expression in JM.



Novel Genomics Study in Juvenile Dermatomyositis

Paul J. Norman, Ph.D.

Senior Research Scientist, Department of Structural Biology,
Stanford School of Medicine

Dr. Norman is investigating the entire HLA genomic region using a new and powerful method he developed that will shed new light on the genetics of JM. Previously uncharacterized genes may interact with HLA genes to become risk factors for disease. Proper understanding of these risk factors opens the door for new diagnostic indicators, treatment targets and, in the long-term, prevention of the disease through directed gene-therapy approaches.



Heterogeneity of Juvenile Myositis, with a Focus on Therapies and Responses

Takayuki Kishi, M.D., Ph.D.

Environmental Autoimmunity Group, National Institute of Environmental Health Sciences,
National Institutes of Health

Dr. Kishi's goal is to investigate clinical response to therapies in patients with JDM from a large JM registry. He will examine the impact of initial medications and other factors on achievement of inactive disease, complete clinical response, and remission. He will also compare different treatment regimens and examine differences in their response rates. These analyses should provide new information on response rates to therapies and predictors of responses to therapies in JDM.



Physical Activity Monitors as Outcome Measures in Juvenile Myositis

Emily Brunner, D.O.

Pediatric and Adult Rheumatology Fellow, University of Pittsburgh Medical Center,
Division of Rheumatology and Immunology

In this pilot study, Dr. Brunner is evaluating the use of Personal Activity Monitors (Fitbits) as a validated measurement tool for physical activity and strength measurement among JM patients. This easy to use tool could be used as a supplement to existing scoring measures and could provide better outcome measurement of a patient's physical function and response to treatment.

Selected Research and Programs Funded in 2016 Thanks to YOU!



Validation of Patient Reported Outcomes Measurement Information System (PROMIS) in Juvenile Myositis

Kaveh Ardalan, M.D., M.S.

Attending Physician, Division of Rheumatology,
Ann & Robert H. Lurie Children's Hospital
of Chicago;

Instructor of Pediatrics and Medical Social Sciences,
Northwestern University Feinberg School of Medicine

Dr. Ardalan's study aims to validate the use of PROMIS (Patient Reported Outcomes Measurement Information System) to improve Quality of Life data collection. This long-term longitudinal data is needed to assess emotional distress, pain, fatigue, and physical function allowing clinicians to better target interventions —pharmacologic, exercise-related, or psychological. This information would enable JM patients who are struggling with disease management to be more easily identified for intervention.



Genetic Risk Factors in Juvenile Dermatomyositis

Claire Deakin, M.D.

Post-Doctoral Fellow, University College, London

Dr. Deakin is studying genetic risk factors for JDM using samples from a large number of North American and UK patients with JDM. This project may also be able to determine genetic risk factors for developing specific features, such as the formation of calcium deposits. It will also help us find out whether the age patients are when they get disease influences the role of genetic differences in JDM or its subgroups.

The biological effect of these genetic differences will also be studied in order to help us better understand the cause of this disease. This research may lead to more information about the causes of JDM and why certain patients develop certain features.



Plasma Exosomes in Juvenile Dermatomyositis

James Jarvis, M.D.

Professor of Pediatrics, University of Buffalo, NY

Dr. Jarvis aims to understand how blood vessels become injured in JDM. He is culturing exosomes from children with JDM with blood vessel cells to determine if small RNA molecules are capable of causing blood vessel wall damage. By comparing what is seen with JDM exosomes to the exosomes of healthy

children, we will have new ways to understand how blood vessels are injured in JDM.

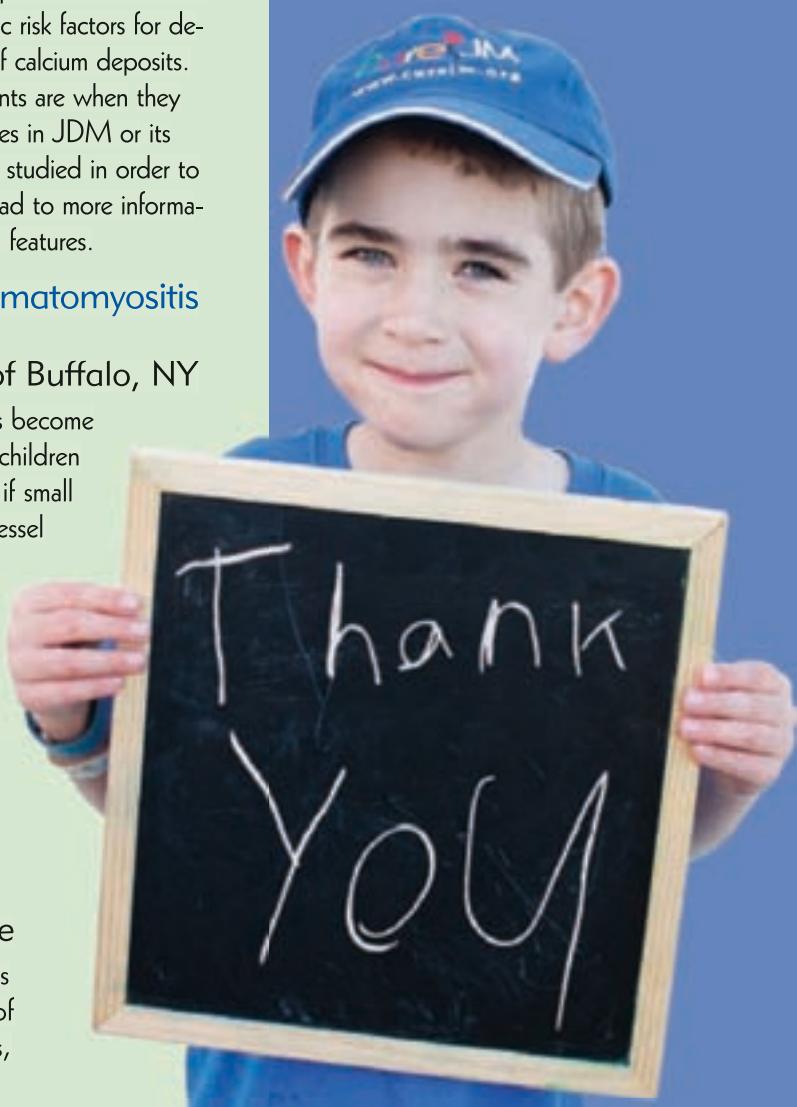


The Use of Metabolomics to Develop Novel Biomarkers for Juvenile Dermatomyositis

Jeffrey A. Dvergsten, M.D.

Assistant Professor of Pediatrics,
Duke University School of Medicine

Dr. Dvergsten aims to identify aberrant patterns of metabolite expression in blood and muscle of children with JDM to develop new biomarkers for help in diagnosis, assessment of disease activity and response to treatment in JM.



Quentin, diagnosed at age 3

Power of Your Partnership

“As a board member and a parent of a child affected by JM, it’s important to me to know my donations and those I ask of my friends and family are spent in the best way. Cure JM Foundation leadership provides complete transparency and decisions are thoughtfully made where each dollar is spent.”

Rhonda McKeever
Chairman of the Board

Because of you, Cure JM Foundation is the leading global nonprofit funder of JM research. We have invested more than \$11 million in research and educational programs to date, making significant strides towards our ultimate goal of a cure.

Cure JM is committed to using your contributions responsibly and efficiently to have the greatest impact on the families affected by JM. To this end, we invested 87 cents of every dollar towards our mission. We are also focused on providing full accountability and transparency. Our independently audited financials and IRS Form 990s since inception are available on our website.



Top-Rated Since 2011

FY2016 Total Revenue: \$1,109,965

Expenses:



Fiscal Year Ending September 30, 2016

Full Financials are available on Cure JM Foundation's website
www.curejm.org

* A portion of this amount will be applied to 2016-2017 Research and Programs currently underway.

Power Forward

Moving into 2017, Cure JM looks forward to another landmark year where we will focus on drug repurposing, drug development, genomics, and translational research.

We believe progress in these four areas will have the greatest impact on the lives of your loved ones. Cure JM will continue empowering families with the critical resources they need in their daily battle with JM. Additional initiatives for 2017 include:

Research Programs and Medical Community Outreach

- Expansion of new Cure JM Medical Network for healthcare professionals
- Development of a more robust patient registry in partnership with CARRA* to collect longitudinal patient data and advance research
- Continuation of Cure JM's research grant program, to identify better treatments and ultimately find the cure for JM
- Expansion of Physician education initiative to accelerate patient diagnosis times and improve patient outcomes
- Supporting the 2nd Global Conference on Myositis for Medical Professionals in May 2017, where leading myositis researchers from around the world will present their latest research and future research directions for JM will be discussed with Cure JM leadership
- Hosting 8th Annual Cure JM Conference for Medical Professionals in 2018

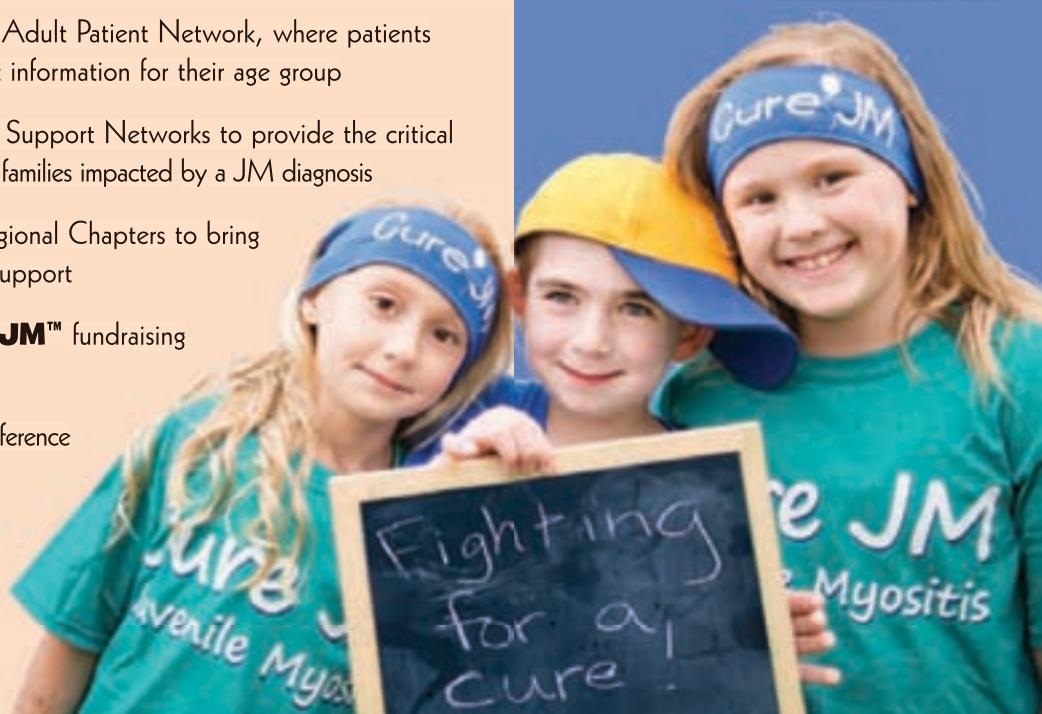
Patient/Family Support

- Funding of 2nd Edition of *Myositis and You*, a comprehensive book about Juvenile Myositis for patients, families, and physicians
- Further development of Teen and Young Adult Patient Network, where patients can share their stories and access relevant information for their age group
- Continuation of Family and Grandparent Support Networks to provide the critical resources and support for patients and their families impacted by a JM diagnosis
- Establishment of additional Cure JM Regional Chapters to bring JM families together for education and support
- Expansion of **Walk Strong to Cure JM™** fundraising and family fun events
- Hosting 12th Annual Cure JM Family Conference in 2018

*CARRA is the Childhood Arthritis and Rheumatology Research Alliance, a North American organization composed of over 400 physicians, researchers, and healthcare professionals involved in pediatric rheumatology research.

To say Cure JM has made a difference in our family would be an understatement. I cannot even imagine the past four years without the resources Cure JM provides. We are forever grateful."

Michelle B.



Power to Make a Difference

Never give up,
never give in.
**Everyone involved
at Cure JM
has given of
themselves to
help our JM
Warriors fight the
good fight.”**

Marissa P.

Madison,
diagnosed age 7



Thank you for making a profound impact on the lives of those battling Juvenile Myositis. Because of you, Cure JM has made game-changing strides in research and provided vital patient and family support programs for over 13 years.

Despite this, Juvenile Myositis can still take away a child's precious childhood and replace it with needles, doctors, and hospital rooms.

You can change this. You can rewrite the future for all of those battling JM.

Cure JM Foundation is the only organization in the world that solely supports the JM community. As we expand our research program worldwide, we rely on private donations like yours to fund the studies necessary to improve the prognosis for JM patients, and to develop the tools necessary to help JM families cope with this devastating disease.

Can you help us today?

Easy ways to give:

Donate by check

Simply use the envelope included with this report.

Donate by credit card or schedule an automated monthly donation

Visit www.curejm.org/donate or call 760-487-1079

For other ways to donate, including bequests, stock gifts, employer matching donations or the federal employee Combined Federal Campaign (CFC # 94746), please visit www.curejm.org/donate or call 760-487-1079.

To volunteer your time and talents, please contact us at info@curejm.org.

*“Sometimes superheroes
reside in the hearts of young
children fighting big battles”*

People Power

Cure JM Foundation Medical Advisory Board

Cure JM Foundation's Medical Advisory Board (MAB) is comprised of internationally renowned researchers and clinicians in the field of Juvenile Myositis. The MAB provides insight, scientific direction, and expertise to Cure JM's Board of Directors and Staff. The MAB also consults with clinicians who request guidance in the treatment of a patient.



Lisa G. Rider, M.D.
Chairman, Cure JM Foundation MAB
Deputy Chief of the Environmental Autoimmunity Group, National Institute of Environmental Health Sciences, National Institutes of Health



Lauren M. Pachman, M.D.
Professor of Pediatrics, Northwestern University's Feinberg School of Medicine
Head, Cure JM Center of Excellence in JM Care and Research, Stanley Manne Children's Research Institute



Ann M. Reed, M.D.
William Cleland Professor of Pediatrics Chair, Department of Pediatrics
Physician-in-Chief, Duke Children's Duke University Medical Center



Adam Huber, M.D.
Pediatric Rheumatologist and Professor of Pediatrics at the IWK Health Centre and Dalhousie University in Halifax, Nova Scotia, Canada



Susan Kim, M.D., MSc
Associate Professor UCSF School of Medicine Department of Pediatrics

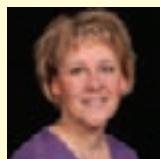


Brian Feldman, M.D., MSc, FRCPC
Professor of Pediatrics & Medicine, Faculty of Medicine, and the DLSPH University of Toronto Head, Division of Rheumatology, Sick Kids

Cure JM Foundation Board of Directors



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Director
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Cure JM Foundation Staff



Executive Director
James Minow
james.minow@curejm.org



Fundraising and Operations
Shannon Malloy
shannon.malloy@curejm.org

Cure JM Foundation

was founded in 2003 by parents and grandparents of children battling Juvenile Myositis (JM).

A 501(c)(3) nonprofit organization, Cure JM is the only foundation dedicated solely to supporting JM research and JM families. Thanks to you, Cure JM has invested in more Juvenile Myositis research and programs than any other charitable organization.



JM, which includes Juvenile Dermatomyositis (JDM) and Juvenile Polymyositis (JPM), is a group of rare and life-threatening autoimmune diseases. In the United States, approximately two to four children in a million are diagnosed with JM each year.

The primary symptoms of JM are weak or painful muscles, skin rash (with JDM) and fatigue. Children with more severe courses of the disease may also suffer from heart and lung complications, calcinosis (the development of small lumps of calcium under the skin or in the muscles), vasculitic ulcers (holes in the skin or gastrointestinal tract), complications with the digestive tract, contractures (shortened muscles that can limit movement and/or cause a joint to stay in a bent position), and lipodystrophy (a damaging loss of body fat).

Some children experience a mild form of the disease and may go into remission, while others will fight JM their entire lives. Some will lose the ability to walk. Complications of the disease can result in ongoing pain, disfigurement and even death.

But whether the course of the disease is mild or severe, a JM diagnosis is life-changing for all of these children and their families.

Our mission is to find better treatments and a cure for Juvenile Myositis, and improve the lives of families affected by JM.

Our ultimate goal is to never, ever let another child suffer from Juvenile Myositis. With your help, we believe this goal is within our reach.

Cure JM®
FOUNDA TION

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