TO our Cure JM Foundation® patients and families, your fight is our fight. Why else are we here? You are inspirational, humbling, and courageous. Your stories of victory — about overcoming adversity, connecting with new JM friends, and finding JM medical experts — inspire us to reach further.

TO all of you who financially supported Cure JM, we wouldn’t be here without you. Cure JM has invested nearly $10 million in research and educational programs since our inception in 2003. A combination of your generous gifts and your passionate support has profoundly impacted the lives of children and adults battling JM.

This past year, JM research experienced unprecedented momentum. Critical research investments, made possible by your support, have led to the identification of the major genetic risk factor for all forms of Myositis. Several other immune response genes have been identified as specific risk factors for Juvenile Dermatomyositis.

Cure JM Foundation continued funding its two research and treatment centers in Chicago and Washington, D.C. We also funded promising research at eight additional prestigious research centers and hospitals making every effort to get answers. Thanks to your generous contributions, Cure JM has supported over 120 research studies, accelerating progress toward a cure.

Your contributions are put to work in the most effective and efficient way possible. Cure JM Foundation is staffed primarily by unpaid volunteers and does not have a physical office, so overhead expenses are low. In fact, approximately 91% of your contribution goes directly to research and educational programs.

Your generosity directly changes the course of children’s lives and futures. When parents say their child received a diagnosis, is doing better, or lived longer because of Cure JM, we think of YOU, our supporters.

This year, Cure JM received the Independent Charities “Best In America” Seal of Excellence that is only given to 0.2% of over 1 million nonprofits in the U.S. This seal is awarded on an annual basis to charities that meet the highest standards of public accountability, program effectiveness, and cost effectiveness.
Additionally, Cure JM has made strides in shortening the length of time to diagnosis, which is critical because research shows that early and aggressive treatment leads to the best outcomes. Your collective efforts at spreading the word about JM, as well as your generous support of educational and outreach programs for both physicians and patients, have been instrumental in shortening the time to diagnosis.

As one parent told us, “My husband and I were able to diagnose our daughter before her doctors because the information and images on Cure JM’s website were an EXACT match to her condition.”

Because of YOU, this child, and many others like her, received a prompt, possibly life-saving diagnosis. And their families no longer have to fight this disease alone.

Together, we are making tangible strides toward our goal of curing JM and transforming lives of JM patients and families.

However, we still hear heart-wrenching stories of pain and suffering—having a child go undiagnosed for years, feeling isolated and alone—and the unimaginable suffering no one should ever experience, losing a child to JM.

We know there are still daunting challenges ahead of us.

**This drives us every day.**

So, we need ‘you’ to help us achieve the next breakthrough. To push research further than we have ever been.

We invite you to join our crusade to give hope to all children and adults fighting for victory.

With you in our corner, we know we’ll win.

Please enjoy this booklet to see the impact you have made, the hope you have provided, and the lives you have changed in such a profound way.

We hope you will continue to support Cure JM, where every gift is an opportunity to directly impact research and improve the lives of children and adults with Juvenile Myositis.

In gratitude,

Shari & Tom

Shari and Tom Hume
Parents of Parker
Diagnosed with JM in 2002

“Thanks to your generous contributions, Cure JM has supported over 120 research studies, accelerating progress toward a cure... In fact, approximately 91% of your contribution goes directly to research and educational programs.”
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. Since its inception, Cure JM has invested more money into 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 increase awareness of all forms of JM, provide support to the families battling this disease and fund research into better treatments and an eventual cure for 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 brought us HOPE during the scariest time in our lives, JDM diagnosis."

Courtenay E.
Cure JM Top Ten

1. 3 Million Dollar Grant received in collaboration with 4 nonprofits

2. NEW Awards “Best of America” - Independent Charities of America “Top-Rated” - Great Nonprofits, 5th year in a row

3. Support groups with nearly 2,500 members
   Patients, Family Members, Grandparents

4. Months cut from average diagnosis time since 2009

5. JM symposium for the medical community held at Stanford University

6. Social media sites with over 16,000 followers

7. Time champion of fundraising/voting contests winning over $1,000,000 for research

8. Research studies and 2 research/treatment centers currently funded

9. Annual JM Family Conference to be held in Florida in 2016

10. Million dollars raised since 2003

Sophia, grateful for your support of her little sister Brielle
The length of time for patients to be diagnosed has almost been cut in half over the past 6 years.\textsuperscript{1}

The diagnosis time has decreased from 9 months in 2009 to 5 months in 2015. This is crucial because research shows that early diagnosis and aggressive treatment leads to the best outcomes. This is dramatically shorter than the average diagnosis time for rare diseases of 7.6 years.\textsuperscript{2}

Thanks to your support of educational and outreach programs for physicians and patients, as well as your efforts to spread the word about Juvenile Myositis, children are now diagnosed faster. \textit{You are literally saving lives of children and adults affected by JM.}

\textbf{Patients and families affected by Juvenile Myositis are finding Cure JM faster than ever before.} In 2015, 70\% of our registered patients found Cure JM in the first month after diagnosis.

\textit{This is a 280\% increase versus 2006.}

In fact, a full 39\% discovered Cure JM within the first week following diagnosis. This is a 179\% increase over 2006.

Connecting with Cure JM Foundation quickly is beneficial for patients and families because they receive vital educational materials and emotional support. Plus, one of our 15 regional Family Support Representatives reaches out to each new family to provide support and encouragement.

Research shows that JM patients and families who are active in a patient support group report a better quality of life.\textsuperscript{3}

\textbf{“The day we found Cure JM, we found help, hope and healing. Cure JM took us out of isolation and has been like family since day one.”}  
\textit{Rich M.}
Marge Coffey is, by profession, a registered nurse, and for many years owned a home health agency, serving clients in the New York area. But in 2010, her world was turned upside down when her seven-year-old granddaughter was diagnosed with JM.

“Having your grandchild diagnosed with JM is a double-edged sword,” says Marge. “You are watching your grandchild suffer while also watching your child suffer. As a grandparent, this is incredibly difficult.”

At diagnosis, Madison had a severe case of JM and remained in the pediatric intensive care unit for three months, followed by inpatient rehabilitation for three months. Marge played an integral role in Madison’s treatments, attending hospitalizations, infusions and appointments. But through it all, Marge had a nagging feeling in the back of her mind. She had a feeling that because JM is a rare disease, more needed to be done to research better treatments and a possible cure.

Marge wasn’t content to wait for someone else to make a difference for her granddaughter, and she decided to get involved. “I understand the value of research,” says Marge. “Orphan diseases like JM need more research.”

Over the next few years, Marge would become a grandparent who was making a difference.

Marge joined the Cure JM Grandparent Support Network and connected with other grandparents. She attended several of the Cure JM National Conferences and became a valued member of the Cure JM Advisory Council. Marge made critical investments in research, helping Cure JM make significant advancements. For her important role in moving research forward, Marge was awarded the first-ever Cure JM Champion Award at the Cure JM National Conference in Baltimore in 2012.

Marge credits Cure JM’s Research and Treatment center at George Washington University in Washington, D.C. for helping Madison turn the corner. Cure JM funding enables the center to provide free consultations from one of the world-leading JM experts, Dr. Lisa Rider. After several visits with Dr. Rider, Madison was able to taper a few medications and has improved dramatically. Marge says, “I got to see Maddy dancing at her sister’s birthday party, and there was not a dry eye in the house!”

“Getting involved and supporting Cure JM gives me a sense of hope,” says Marge. “Having been involved with Cure JM, I have seen first-hand the great work they do. Cure JM is investing in research that directly impacts our family and gives our family hope.”

“Cure JM is investing in research that directly impacts our family and gives our family hope.”
Julie Garst’s daughter Adelyn was just seven years old when she was diagnosed with Juvenile Dermatomyositis (JDM) -- a form of Juvenile Myositis (JM).

Newly diagnosed and feeling alone, Julie wasn’t sure where to turn. A year after her daughter’s diagnosis, she connected with Cure JM Foundation, and through Cure JM, Julie met other families also dealing with JM.

“I wish I would’ve found this group when my daughter was first diagnosed. Meeting the other families brought us out of the dark,” says Julie. “We felt a sense of hope, a sense of camaraderie, and we believed we could do this. The other families we met were regular families just like us and they could do it, so we were confident we could too.”

Through the Cure JM online support network, Julie met Haley who lived close to her.

“Meeting another mom who knew what we were going through meant everything to me,” said Julie.

“I wish I would’ve found this group when my daughter was first diagnosed. Meeting the other families brought us out of the dark.”

Julie and Haley talked over the phone and realized that they both wanted to make a difference for their daughters – so they joined forces and hosted a party at a local boutique to benefit Cure JM Foundation. Dozens of families came together at the event to support Julie and her family.

“Feeling that support from our friends and family gave us the boost we needed to get through the hard times.”

“Hosting the event made me feel empowered,” says Julie. “I can’t control this disease, my daughter’s blood test results, the side effects of the medication, or all the other things that go with JM. But I can control how we react to it. Getting involved made me feel better and that I was making a cure possible.”

Now Julie is the one answering the calls of the newly diagnosed families. Julie has become one of Cure JM’s fifteen volunteer Family Support Network representatives and covers the states of Kansas and Missouri.

“I am so honored to be a peer-support representative for Cure JM,” says Julie. “I hope to be able to show other families that they aren’t alone and help them find the hope I have found through Cure JM.”
Earlier this year, five-year-old Gracey was diagnosed with Juvenile Myositis. She had lost the ability to walk and was immediately hospitalized and put onto a life-saving regimen of corticosteroids and other intense treatments.

“We were lost and scared. Our lives had been turned upside down by this disease we had never heard of,” says Gracey’s mom Alanna. “Thankfully, things began to turn around for us when we found Cure JM.”

Through the Cure JM peer support network and Family Support Network, Alanna began to learn about JM, common treatments and coping strategies. And most importantly, she learned that her family wasn’t alone in their battle with JM.

“Meeting other families who understood and supported us got us through our darkest hour,” says Alanna. “I was so inspired by the passion and commitment of the Cure JM community that we were inspired to get involved and do our part to raise funds for JM research.”

Soon after Gracey’s JM diagnosis, Alanna reached out to a friend of her family who owned a winery and together they hatched the idea for Graceyfest. Alanna had never held an event like this before, so she reached out to two Cure JM Fundraising Coaches, Shannon & Lindsay, who are also parents of children with JM. Together, the team planned the event and had a lot of fun along the way, including phone calls, video calls and a lot of laughs. Alanna had so much fun that Graceyfest is now an annual event.

But the best part?

“Gracey had so much fun at Graceyfest. She was so proud of all the friends and family that came out to support her and we all felt great that we were making a difference.”

The second annual Graceyfest is scheduled for spring of 2016 in Mount Washington, Kentucky.
Fiscal Year ending September 30, 2015

Full financials are available on Cure JM Foundation’s website

We are grateful for your support of Cure JM Foundation, and we are committed to allocating your generous donations as effectively and efficiently as possible. As the leading charitable funder of Juvenile Myositis research, we are focused on achieving the greatest impact for the children and adults fighting JM.

A 501(c)3 nonprofit organization, Cure JM is managed by unpaid volunteers and a single employee. We all have a personal connection to someone battling Juvenile Myositis, so we have a vested interest in making certain that the funds we raise are utilized as efficiently as possible. Our primary goal is always the discovery of better treatments and eventually a cure for JM.

As a result, Cure JM is able to invest 91 cents of every dollar directly to research and educational initiatives.

Our dedication and urgency to find a cure and improve the lives of patients with Juvenile Myositis is as strong as ever.

Thank you for being part of the cure!
“Rare disease research is difficult to fund. Thanks to Cure JM and its generous donors, JM research studies like mine are able to ask and answer the most critical questions to help us better understand JM. Continued funding will ultimately lead us to better treatments.”

Ann Reed, MD
Chair, Department of Pediatrics, Duke University School of Medicine
Cure JM Medical Advisory Committee

Cure JM Program of Excellence in JM Research at Stanley Manne Children’s Research Institute, affiliated with Ann & Robert H. Lurie Children’s Hospital of Chicago

Dr. Lauren Pachman, the Principal Investigator and Director, has cared for over 600 children with JDM and other forms of inflammatory myopathy. Dr. Pachman has patients who travel from around the country to see her for a diagnosis and/or treatment. She has seen patients from 23 states in the last 12 months. Dr. Pachman is also called upon for consults and referrals from other doctors. Her team is working to discover the biomarkers of JM activity to guide the utilization and/or creation of more effective therapies. They have already identified a variety of genetic and environmental factors that not only play a role in the onset of symptoms, but also govern the child’s outcome.

George Washington University Myositis Center in Washington, D.C.

Under Dr. Rodolfo Curiel, this Center is a multidisciplinary effort made possible by a grant from Cure JM Foundation. As a national referral site for inflammatory muscle diseases, the Center is often called upon to establish a diagnosis, provide a second opinion, assist with severe cases of Myositis, and provide periodic reviews. The pediatric rheumatology consultation with JM expert, Dr. Lisa Rider of the National Institutes of Health, is provided at no charge to the patient. Ancillary providers (e.g. dermatology) or testing, such as an x-ray, is covered by insurance or self-pay. The GWU team has seen patients from 24 states and 8 countries in the last 12 months. Working in collaboration with the NIH, the Center also specializes in JM research and education. They are currently analyzing data from 450 patients from previous studies.

With funding from Cure JM, the GWU myositis team, under Dr. Rodolfo Curiel, is preparing to launch a new small clinical trial of a biologic therapy for patients with treatment-resistant juvenile dermatomyositis.
Genetic Risk Factors for Calcinosis
Elizabeth Mellins, MD
Stanford University
This research study utilizes previously collected blood samples to look at certain genes and potentially determine their role in the development of calcinosis.

Gastrointestinal Bacterial Tract in JM Patients
Anne Stevens, MD
Seattle Children’s Hospital
This study aims to determine if the proliferation of oral and intestinal pathogens could lead to the activation of JM.

Predictive Model of Disease Outcomes using Computational Biology Modeling in Children with Inflammatory Muscle Disease
Tim Niewold, MD, Mayo Clinic & Ann Reed, MD
This research study aims to determine associations between disease outcomes and various features of JDM, which may lead to the prediction of which patients would benefit from particular treatment choices. The team has already predicted changes in disease activity using predictive models for overall disease activity, muscle disease and extra muscular involvement, which allows more informed treatment choices to be made.

Premature Atherosclerosis in Juvenile Dermatomyositis
Dawn Wahezi, MD
Albert Einstein College of Medicine
This study aims to identify which risk factors may be the most significant indicators of early heart disease in children with JDM.

Lymphocyte Repertoire in Juvenile Dermatomyositis
Susan Kim, MD
Boston Children’s Hospital
This study uses “next generation sequencing” to help decode the complicated “immune repertoire” in patients with JDM. Initial analysis has shown there are differences in the T cell repertoire, and that regulatory T cells may play a role. Further studies and analysis are planned at different phases of disease, as well as in other JDM samples such as skin and muscle.

These findings are leading to a better understanding of the changes in the immune system in JDM, and will potentially lead to improved outcomes.

Complement C4 in Disease Risk and Pathogenesis of Juvenile Dermatomyositis
Chack-Yung Yu, MD
Nationwide Children’s Hospital and The Ohio State University
This study uses cutting-edge techniques to analyze whether variations of C4A genes and changes of C4 proteins can be used to reveal the severity of JDM and how the illness may develop. They hope, through their research, to be able to develop better and more specific ways to diagnose and treat the disease, and to find a cure in the future.

Novel Biomarkers Associated with Disease Activity in JDM
Hanna Kim, MD
National Medical Center and National Institutes of Health
This research study compares and contrasts serum markers and gene expression patterns in JDM with those of other closely related disorders (CANDLE and SAVI) with the hopes of better understanding the cause(s) of JDM and possible treatments. By developing a better biomarker, Dr. Hanna Kim and the research team hope to better predict who will respond to a particular therapy, determine when to stop and start therapy, and develop more JDM-specific therapies in the future.
Why We Keep Fighting

Up to 40% of patients will have calcinosis (painful calcium deposits)

Up to 40% of patients will have functional disability

Up to 40% of patients will suffer from lipodystrophy (damaging loss of body fat)

Zero FDA approved drugs developed for JM

Up to 69% will have cumulative disease damage after average of 7.7 years

Cure JM is the ONLY organization solely supporting JM research and families.

With your support, we will keep fighting until we find a cure.


Moving into 2016,
Cure JM looks forward to driving our research progress forward and having an even greater impact on the lives of children and adults battling Juvenile Myositis. Cure JM will continue empowering families with the resources they need to fight this disease on a daily basis. Initiatives for 2016 include:

Research Initiatives and Medical Community Outreach

- JM Symposium for the Medical Community in Florida - January 2016
- Collaboration with the Arthritis Foundation, Lupus Foundation of America and several other nonprofits in a research initiative linking researchers, patient communities, clinicians and health systems in productive research partnerships
- Two grant cycles awarding up to six grants for clinical and translational research proposals; Cure JM has partnered with CARRA (Childhood Arthritis and Rheumatology Research Alliance), an organization of more than 400 pediatric rheumatologists and researchers, to determine the most promising research studies to pursue
- Physician education initiative to accelerate patient diagnosis times and improve patient outcomes
- Targeted research to identify better treatments and discover the cure for JM

Patient/Family Support

- JM Family Conference in Florida - January 2016
- Teen/Young Adult web pages for patients to connect and share stories and gain easy access to unique resources such as college transition information
- E-book version of *Myositis and You*, a 450-page book with contributions from over 75 medical professionals (patients and parents often refer to this book as their “roadmap to recovery”)
- Welcome Kits, educational and support materials for all JM families
- Family Support Network and Grandparent Support Network for crucial one-on-one and group support
- Webinars to educate and support patients
- Personalized information cards for patients that explain JM and provide emergency contact information for their parent/caregiver

Help Create a World without JM by Continuing Your Support

Make a donation by check using 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.

Donate through the federal government’s Combined Federal Campaign:
Visit www.curejm.org/cfc

Donate stock, securities or vehicles:
Visit www.curejm.org/donate, call 760-487-1079 or email info@curejm.org

Set up a bequest or planned gift from your trust or estate:
Visit www.curejm.org/future or call 760-487-1079.

Employer Matching Donations:
Check with your employer or visit www.curejm.org/donate

Volunteer:
To learn how you can get involved, contact us at info@curejm.org
“Cure JM has been a lifesaver for our family... Cure JM is an amazing group of family and friends working together for one goal, one dream - a cure for Juvenile Myositis”

Kristen P.

Maura, diagnosed with JM at age 3