



2021 Impact Report



Our Mission: To find a cure and better treatments for Juvenile Myositis and improve the lives of families affected by JM.





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An Organization Like No Other

Cure JM family and friends,

I have never known an organization quite like the Cure JM Foundation. We are one of a kind.

To explain: Cure JM was founded 19 years ago by a small group of volunteers—parents and grandparents—who wanted to change the world for children with a rare disease few had ever heard of—Juvenile Myositis, or JM.

Most organizations would struggle to survive or have any impact at all. Not Cure JM. Under the focused and intentional leadership of co-founders Tom and Shari Hume, Cure JM set its sights on fulfilling a mission with two seemingly monumental objectives.

First, as very little was known about JM, what caused it or how to effectively treat it, Cure JM created and funded a research program designed to attract the world's foremost researchers in JM and related autoimmune diseases. **Objective #1: find better treatments and a cure.**

Second, little was also known about how to diagnose and treat JM, even among pediatric rheumatologists. It often took months to diagnose (or misdiagnose) JM, and precious time was lost to arrest the progress of the disease, which resulted in longer and more difficult courses of treatment. **Objective #2: engage more doctors to improve their knowledge, familiarity, and experience in diagnosis and treatment, resulting in higher quality care and support to families struggling with JM.**

And while the founders brought extraordinary vision and leadership to Cure JM, it was our families banding together in common purpose to drive our success. You found ways to support the early pioneers in research and clinical care. You funded medical training for pediatric rheumatologists, bringing more of them into the fold as JM specialists. You provided the resources for Cure JM's first Center of Excellence, first biorepository, first medical and research conferences.

Most importantly, you provided the passion that meant Cure JM could successfully recruit the world's leading JM doctors and researchers to our Medical Advisory Board, meaning that we had the "best of the best" as our partners in medical progress.

That we have succeeded in becoming one of the most effective rare disease research organizations anywhere is no accident. The simple truth is that without you, our families, being with us, side by side and step by step in our journey, we would have never come this far.

In 2022, Cure JM is launching the Cure JM Clinical Care Network and funding our fifth Center of Excellence. We have almost \$4 million committed to research and new drug development, including several clinical trials that, if successful, will bring improved treatments to our children. As COVID recedes, our chapters around the country will soon meet again and parents, children, and teens can congregate and share in that mutual support that has always defined Cure JM as such a special and welcome place for all families.

I am privileged to be a part of this exceptional organization—the Cure JM Family.

As you page through this 2021 Impact Report, please know that our accomplishments are a result of your strength, resilience, and thoughtful engagement as parents, grandparents, and patients. I am most indebted for your service.

With appreciation,



James Minow
Executive Director

Our Mission: To find a cure and better treatments for Juvenile Myositis and improve the lives of families affected by JM.

Objective #1: Find better treatments and a cure for JM.



Research and Partners

Cure JM is currently providing almost \$4 million in research investments to advance treatments and improve the quality of JM care.

Research projects and outcomes include:

- The identification of several new drugs to treat JM through our funded partnership with the National Center for Advancing Translational Sciences at the NIH.
- The continuing development of clinical trials to test three drugs, baricitinib, abatacept, and vamorolone, for safety and effectiveness in treating JM.
- Ongoing support to four Cure JM Centers of Excellence in research and clinical care at Lurie Children's Hospital (Chicago), George Washington University (DC); Duke Children's Hospital (NC); and Seattle Children's Hospital (WA).
- The expansion of Cure JM's global network of clinician/researchers at leading pediatric hospitals around the world and providing JM education and training through Cure JM's annual Medical Symposium.
- Ongoing support for two JM patient registries and biosample repositories to collect data critical to understanding the causes of JM and to test and develop new drugs through clinical trials.
- Bringing JM families and patients to the FDA to educate FDA policymakers on JM and the urgent need for better treatments in working together to develop clinical trial plans for new FDA-approved drugs.

2021: Research and Partners



Dr. Andrew Heaton, Ph.D, Chief Scientific Officer
Cure JM Foundation



Dr. Andrew Heaton, Chief Scientific Officer at Cure JM discusses progress with Research and Partners in 2021.

<https://youtu.be/scwAw2TXzQo>

CURE JM TOWN HALL MEET WITH THE RESEARCHERS BEHIND TWO NEW EXCITING JM DRUGS



Featuring Dr. Kaveh Ardalan of Duke University
Dr. Travis Kinder of the NIH



At a Town Hall in November 2021, Dr. Kaveh Ardalan and Dr. Travis Kinder discussed details of the new treatments and what these drugs could mean for patients with JM.

<https://youtu.be/k8ZZIfVFrhE>

Objective #2: Engage more doctors to improve their knowledge, familiarity, and experience in diagnosis and treatment, resulting in higher quality care and support to families struggling with JM.

Family Support

- **Provided vital resources and connections** for over 3,000 patients and families.
- **Supported four major Centers of Excellence** to advance JM research and deliver the highest quality of care to patients, including second opinions.
- **Provided support to newly diagnosed families** through peer support groups and one-on-one support programs.



Cure JM provided education to families through monthly Town Halls with topics such as Research for New Treatments, Mental Health and JM, and Information for Newly Diagnosed Families.

To view all of the Town Halls, please visit <https://curejm.org/videos/index.php>



This Cure JM Town Hall from April 2021 explores the importance of exercise in the management of JM. It was presented by Sue Maillard, a specialist physiotherapist at Great Ormond Street Hospital, London. Sue has specialized in Pediatric Rheumatology Physiotherapy for over 30 years and has a specialist interest in Juvenile Myositis.

<https://youtu.be/XAZrIZnUvTo>

Volunteer Leadership

Cure JM is 3,000 families strong across the U.S. and the leadership you have brought to our success is nothing short of extraordinary. Because Juvenile Myositis is a rare orphan disease, family leadership is the most critical ingredient to our ability to raise the resources needed to fund the research to meet our mission.

Every organization needs a driving force. For Cure JM, that force is our families who provide vision, inspiration, and leadership through your engagement with local chapters, the National Leadership Council, and the Grandparent Council, all of which help guide Cure JM and our Board of Directors.



Meet Rachelle, Scott, and John Veenstra

Scott and Rachelle Veenstra are parents to John. Their son was diagnosed with JM at 18 months of age and continues to be treated at Duke, one of our Cure JM Centers of Excellence. During Walk Strong Across America, 2021, John hiked to the top of Mt. Mitchell with his parents and Jim Minow, Cure JM Executive Director. For John, this was a great accomplishment. We appreciate the deep dedication that the Veenstras have for supporting the mission of Cure JM. Recently, Rachelle became the co-chair of the Cure JM Research Committee.

To learn more about the Veenstras, view this short video: https://youtu.be/b_GOJ8Y9Of0



National Leadership Council

The National Leadership Council (NLC) powers Cure JM's mission in local communities across the country. The NLC's charter is to advance Cure JM's mission by raising funds, connecting families, and building relationships with local healthcare providers. If you would like to be involved in the kind of leadership involvement that moves our Cure JM mission forward, please raise your hand and become a member of the NLC.

We are honored to recognize the leaders of the NLC who drive Cure JM's fundraising forward. If you would like to volunteer with Cure JM, contact Shannon.Malloy@CureJM.org

Chair: Denise Koch

First Vice-Chair: Dave Maher

Second Vice Chair: Maggie Choy

To learn more about the NLC, please watch this short video.

<https://youtu.be/VC3gQCSZBEc>

Join Us...

Cure JM National Leadership Council



Committees:

- Giving Tuesday Holiday Challenge
- Northeast Chapters, Walks, and Fundraising Committee
- Midwest Chapters, Walks, and Fundraising Committee
- Southern Chapters, Walks, and Fundraising Committee
- Western Chapters, Walks, and Fundraising Committee
- Family Fundraiser Committee
- Auction Committee

Cure JM NLC Members

This is a partial list, as new members are joining all the time.

https://curejm.org/organization/leadership_council.php

Kristine and Alan Alderfer
Bobbie and Matt Bernhardt
Carrie Bernhardt and Rick Bernhardt, MD
Michelle and Lang Best
Amy and Jeff Blitz
Jeff Bornemiss
Cristal Brinker
Danielle and Bruce Britten
Stephanie and Jason Brown
Leslie and Glenn Budnick /Westrom
John and Tiffany Caldwell
Sue Carpenter
Maggie Choy
Suzy and Lenny Clement / Gonzalez
Brian and Eleanor Clements
Kevin and Doreen Coffey
Marge Coffey
Christy Coss, MD and David Coss, MD
Kelly and Kevin Culver
Erin Curtis
Elinor Dahill
Debbie and John Daum
Katie and Charlie Dean
Jacquelyne DenUyl
Clark DenUyl
Jessica Doherty
Veronica and Jim Douglas
Warren and Cecily Durbin
Melissa and David Eisenreich
Michael Eisenreich
Kate and Dave Ettingoff
Kelly and Raymond Florida
Candy Fortier
Gary and Patricia Fox

Erin and Ralph Garcia
Joy and Kelly Garcia/Kapp
Rebecca and Darrin Gengler
Amanda Gibson
Julie Golob
Naomi Gonzalez
Kim and Adam Gorman
Thomas Grant, PhD
Joanne Hall
Zack and Sandi Harrison
Holly and Brandon Howe
James and Rosemary Hower
Christina Hunstad and Michael Hunstad, PhD
Jeff and Jessica Jennings
Jason and Joleen Johnson
Leah and P.J. Kania
Brian and Rebecca Karsten
Elizabeth Kasselberg
Mike and Andrea Kenawell
Talita and Paulo Kiper/Vanieri
Denise and Roger Koch
Jessica and Cindy Cicchino/Kovacs
Margaret and Miles Lee
Judy and Bruce Leetz
Lindsay and Matthew Llauguet
Giovanni and Stefanie Loria
David and Kathryn Maher
Colleen and Chuck Marchetta
Sarah and Troy McClintock
Meaghan McGregor
Loralee and Doug McIntosh
Veronica and Todd Montero
Gary Moore
Kathleen Newman
Rachel Newman, MD

Chanelle Nickerson
Nick and Lori Parker
Michael and Erin Parnell
David and Carol Pearson
Ronald and Diane Perel
Jason and Brandynn Phelps
Stacy and Jason Povlish
Randy and Jennifer Putt
Laura Quigley-Wysocki
Anna Ramsey
Anahi Renteria
Karen and Robert Roe
Luke and Liz Ryan
Jana and Bryan Sall
Mark and Norah Sangid
Caesy and Zack Sauder
Carol and Rob Schwartz/Ramsey
Bud and Ryane Sheffield
Tim and Melissa Shelby
Julie and Justyn Shevlin
Robert Slater
Damon and Kristen Smedley
Sarah and William Smiddy
Eric Snyder, MD
Jason and Mary Beth Stafford
Scott and Shannon Taylor
David and Allison Taylor
Charles and Molly Tereck
Rebecca and Jim Tighe
Scott and Rachelle Veenstra, PhD
Kirsten Warr
Sue and Paul Weiss
Justin and Amy Whitney
Ashley Whitt and John Whitt, MD

Major Donors and Fundraising Success

- Cure JM Foundation has been recognized with **awards for its public accountability**, program effectiveness, and cost effectiveness.
- Since inception, Cure JM has invested more than **90% of contributions directly into research and programs** to move our mission forward.
- Since inception, Cure JM has invested over **\$19 million to find better treatments and improve the care** for children with JM.



In 2021, Cure JM families and friends came together to raise and donate more than \$2 million for research and programs. For a rare disease group, this is a phenomenal accomplishment, and each member of the Cure JM community should be very proud of this extraordinary result.

More than 600 families participated in raising funds for research and programs through our two signature events, Walk Strong Across America in July and Giving Tuesday Holiday Challenge in November.

Additionally, in March 2021, we are pleased to report that we held the first ever Rare Experiences Auction. This virtual auction allowed supporters from across the country to bid on unique experiences while supporting Cure JM.

Fundraising Success in 2021

Rare Experiences Auction: \$25,000

Giving Tuesday Holiday Challenge: \$850,000

Walk Strong Across America: \$650,000

We are so grateful to all of the families and supporters who participated in these important events.

We couldn't do it without you!



National Grandparent Council



**Committee Chair:
Randy Putt**

Please watch this short video to learn more about the Grandparent Council.

<https://youtu.be/sNWISypuWNo>

Join Us...

Cure JM Grandparent Council



Please join us in celebrating the special role of grandparents as critical partners in Cure JM's mission. Since Cure JM was founded by parents and grandparents in 2003, grandparents have always been a special part of Cure JM. Their support, guidance, and wisdom is formidable and appreciated.

Thank you for actively participating to help find better treatments and a cure for JM.

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

\$500,000+

Marge Coffey

Bruce and Judy Leetz

\$50,000-\$499,000

Sheila and Harry Harvey

Nancy Hume

Rita and Richard Jacoby

Robert and Dixie Slater

Merrienne Van Ness

National Grandparent Council



In addition, Cure JM would like to recognize those members of the Grandparent Council who gave between \$1,000-\$10,000 in our Fiscal Year 2021 (October 1, 2020 through September 30, 2021).

*Harriette Best
Harold and Eileen Blitz
Fiorella Brown
Lynn and Timothy Buescher
Aaron Coldiron
James and Judith Denton
Patricia Dobson
Carl and Carolyn Erite
Josie Garcia
Robert and Karen Hahn*

*Joanne and Jeffery Hall
Linda and Randall Hart
Allen and Antoinette Hauser
Timothy and Diane Hewitt
Michael and Nancy Howe
Rosemary and James Hower
Rita and Richard Jacoby
Joe and Lori Kania
Charles and Laurel Krider
Emma Lee Mayeaux*

*Larry McFall
Kathleen Newman
Thomas and Virginia Packard
Sally and William Phelps
Ray and Virginia Reilly
Ilene and Bill Schlicher
Laurette and Michael Shulman
Barbara and Jacob Spigelman
David and Enid Stoms
John and Pamela Strasser*

And, our sincere thanks to the hundreds of other grandparents who made generous contributions to Cure JM In 2021.

If you have questions about this list please contact Susan O'Brien at Susan.OBrien@CureJM.org



Cure JM Board of Directors

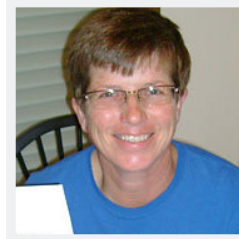
The Cure JM board of directors has the vision for our organization and sets the pace for moving our mission forward. This past year was an extraordinary year of transition, as Nikki Hahn, former Cure JM board president passed the torch to Kristine Alderfer, our current Cure JM president. Additionally, Mitali Dave transitioned out of her chair position and Nicki Hahn has become our new Cure JM board chair. Thank you to Nikki and Mitali for your years of service, and thank you to our Cure JM board of directors for all of your hard work and dedication to the mission of Cure JM.



Nikki Hahn, Chairman



Kristine Alderfer, President



Denise Koch, Secretary



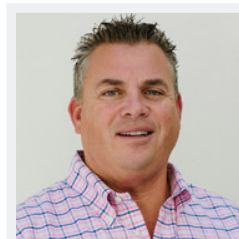
Brent Hauser, Treasurer



Shari Hume, Co-Founder



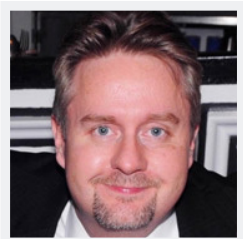
Tom Hume, Co-Founder



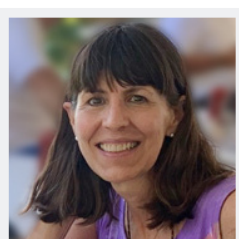
Kevin Coffey, Director



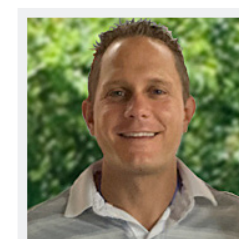
Tracy Van Ness, Director



Tim Shelby, Director



Karen Berman, Director



Zachary Harrison, Director



Randy Putt, Director



Mitali Dave, Chairman Emeritus

To learn more about Shari and Tom Hume, co-founders of Cure JM, watch this short video:

https://www.youtube.com/watch?v=aJ07B_yENDQ



Medical Advisory Board

Cure JM Foundation's Medical Advisory Board is comprised of internationally renowned researchers and clinicians in the field of juvenile myositis.



Lisa G. Rider, M.D.

Chair, Cure JM Foundation Medical Advisory Board
Head of the Environmental Autoimmunity Group
National Institute of Environmental Health Sciences
National Institutes of Health



Kanneboyina Nagaraju, DVM, MVSc, Ph.D.

Founding Chair and Professor Pharmaceutical Sciences
Binghamton University, State University of New York



Brian Feldman, M.D., MSc, FRCPC

Professor of Pediatrics & Medicine, Faculty of Medicine
DLSPH University of Toronto Head
Division of Rheumatology, Hospital for SickKids



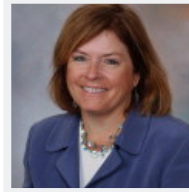
Lauren M. Pachman, M.D.

Professor of Pediatrics
Northwestern University Feinberg School of Medicine



Adam Huber, M.D., MSc.

Pediatric Rheumatologist and Professor of Pediatrics
IWK Health Centre and Dalhousie University



Ann M. Reed, M.D.

Chair of the Department of Pediatrics
Duke University School of Medicine



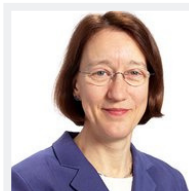
Susan Kim, M.D., MMSc

Associate Professor, Associate Clinical Professor
University of California San Francisco Department of Pediatrics



Anne Stevens, M.D., Ph.D

Senior Director, Immunology
Janssen Research & Development, LLC
Clinical Professor, University of Washington
Department of Pediatrics
Attending Physician, Seattle Children's Hospital



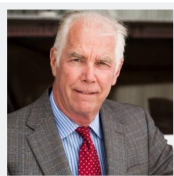
Lucy R. Wedderburn, Ph.D., MRCP

Professor and Consultant of Pediatric Rheumatology
NIHR Senior Investigator
Director, Arthritis Research
UK Centre for Adolescent Rheumatology at UCL
UCLH and GOSH
Deputy Director, NIHR Great Ormond Street Biomedical Research Centre

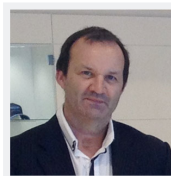
The Cure JM Medical Advisory Board provides insight, scientific direction, and expertise to Cure JM's Board of Directors and staff. The Cure JM Medical Advisory Board also consults with clinicians who request guidance in the treatment of a patient.

To learn more about the Cure JM Medical Advisory Board, visit:
<https://www.curejm.org/organization/mab.php?id=medpro>

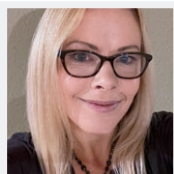
Cure JM Staff



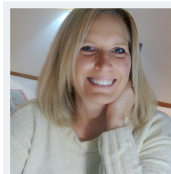
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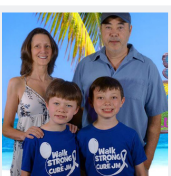
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Lauren Alvord
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Lauren.Alvord@CureJM.org



Betsy León
Associate, Development and Family Engagement
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Dawn Moltzan
Family Engagement Associate
Dawn.Moltzan@CureJM.org

Closing Thoughts from Nikki Hahn, Chair of the Cure JM Board of Directors

As we look ahead to 2022, our goals are to...

- Continue improvement in quality of care.
- Validate newer and better drugs to treat JM.
- Lead to more individualized patient-centered treatments.
- Reactivate Cure JM's national chapter leadership structure to support families and children and young adults.
- Drive our mission and reach higher levels of success in 2022.

Thank you for your support of Cure JM. We could not do this great work without you!



CONTACT US

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