

Family Support Guide

For Families of Children and Young Adults Affected by
Juvenile Myositis

including Juvenile Dermatomyositis and Juvenile Polymyositis



Cure[®] JM

F O U N D A T I O N

www.curejm.org

RAISING AWARENESS - SUPPORTING FAMILIES - FUNDING RESEARCH - FINDING A CURE

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

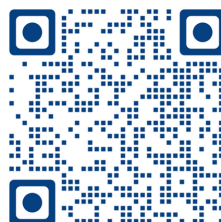
Cure JM Foundation is a 501c3 Organization

Our goal is to never, ever let another child suffer with Juvenile Myositis.
With your help, we believe it's a goal that's well within our reach.

Join the Cure JM Family to learn more about research for new treatments plus how to get involved, and we'll connect you with a network of support, encouragement, and resources.

Sign up to become part of a fantastic support network!

curejm.org/quickjoin



Cure JM Contact Information

For information about how to get involved at Cure JM, contact Shannon Malloy, Director of Development and Family Engagement
shannon.malloy@curejm.org



For information about Emotional and Mental Health issues, contact Suzanne Edison, Mental Health Coordinator
suzanne.edison@curejm.org



To connect with a Cure JM Chapter in your area, visit:
curejm.org/chapters



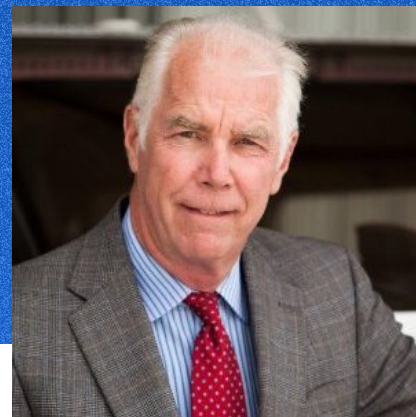
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info@curejm.org

Social Media
[@curejm](https://www.instagram.com/curejm)



Welcome to Cure JM



Jim Minow, Executive Director

Greetings,

Welcome to the Cure JM Family. The most important thing to know about our organization is that we are a great support network for all of our families, as well as a force in the Rare Disease community. It is truly our goal to find better medications and a cure for JM.

To offer you a little background on the Cure JM Foundation, there is an inspiring story to share. The Cure JM Foundation was established in October 2003 by Shari Hume, Tom Hume and Lisa Felix, all parents of children with JM, and by Harriet Bollar, grandmother of a child with JM. They were brought together only by circumstance, but with the same determination to find a cure for Juvenile Myositis. Their ultimate goal was to eradicate JM, so that no child would ever have to suffer from this insidious disease again.

Cure JM's first fundraiser was a modest lemonade stand in Encinitas, California. Soon after, the Foundation established a website to increase awareness of the disease and provide information and emotional support for families impacted by the disease.

Over the years, the organization has grown substantially. Through nationwide grassroots fundraising efforts, Cure JM Foundation has raised over \$19 million for JM research and education. These funds have been used to help establish JM Research and Treatment Centers of Excellence at the Ann & Robert H. Lurie Children's Hospital of Chicago, George Washington University in Washington, D.C., Duke Children's Hospital and Medical Center, and Seattle Children's Hospital. In addition, Cure JM Foundation has funded a wide range of genetic and JM treatment studies, as well as fellowships. Cure JM also co-produced the first-ever book on JM, *Myositis and You*, featuring contributions from over 80 experts and medical professionals. Most recently, in 2022, we have started our Cure JM Clinical Care Network, which you will read more about in this Welcome Kit, as well as on our website, curejm.org.

I hope you find this guide helpful, and a source of comfort. You will always have support through the network at Cure JM. Contact us at anytime. We are always here to help.

All my best,

A handwritten signature in black ink that reads "Jim".

Jim Minow, Executive Director
Cure JM Foundation

TOP TIPS

From JM Parents and Patients

These ideas come directly from parents of JM kids or from patients themselves. The first days after diagnosis can be overwhelming, as well as the journey to find the right care and treatment. We hope these tips help you!

- **Find a pediatric rheumatologist who has experience treating JM.** You may want to refer to our listing of the physicians in the Cure JM Clinical Care Network, as well as at our Cure JM Centers of Excellence. **Learn more at: curejm.org/care and curejm.org/centersofexcellence**
- **Keep track of the following in a binder or electronic device, and take all of this information to doctor appointments:**
 - a. Questions for the doctor and other providers with room for their answers. Include dates on all notes
 - b. Copies of everything
 - c. Treatment changes
 - d. Medication Chart
 - e. Insurance Information
 - f. Nutrition or other medication information
 - g. Daily observations
- **Ask your Primary Care Physician to help you mediate or communicate between specialists.** If you are in a system with a case manager, contact one as soon as possible.
- **Create a Family Health History.** Autoimmune diseases and other illnesses can run in families, so it's important to gather health information from at least three generations of your family.
- **Create an information packet about JM** and what your child specifically needs for your child's school/teachers, such as:
 - Look into a 504 plan or an IEP.
 - Describe side effects of medications to teachers—most kids with JM are on steroids which cause a variety of physical and emotional changes, i.e. weight gain, mood swings, etc.
 - Make sure all teachers and parents of students in your child's class inform the school when their child is ill with a bad virus, infection or other illness. Your immune-suppressed child can more easily catch contagious illnesses, and can get more severe forms of an illness.
 - If needed, get a handicapped parking sticker/sign for your car. It will allow you to park closer to an office, school, or store when your child has muscle weakness, and it will minimize sun exposure when traveling from the car to the building.

TOP TIPS

From JM Parents and Patients

- **Get support.** Having a child with JM is stressful for everyone in the family. Join a Cure JM support group, follow Cure JM on social media to connect with other JM families, and attend a JM event. Also, talk to a social worker at the hospital where your child is treated or another therapist. Reach out to your network of family and friends as well. Do not be afraid to ask for help. Help can take many forms, from having meals provided, to driving your other children to their activities, to just listening.
- **Investigate all the family resources at your hospital.** Most hospitals have many resources designed to help families. Contact Child Life for age-appropriate coping techniques. Contact the hospital social worker for help navigating the health care system. Contact Pain Management Services at your child's hospital if there are problems with IVs, side effects of medications or other issues related to pain.
- **Find time to do fun things.** Your child may be sick, but he/she is still a child and needs to play when possible. Also, include siblings in some special outings as well, because they might feel left out.
- **Be a “Mama Tiger” or “Papa Tiger”.** You are your child's best advocate—you know your child best. Trust your instincts.
- **GET INVOLVED** in raising awareness and fundraising for Cure JM. It is one of the best ways for you and your child to stay positive and take back some control. Additionally, taking action is one of the best ways to channel feelings of helplessness, frustration and grief. Learn more and get involved at curejm.org.
- **Make time for yourself.** As a parent, you want to do everything possible to help your child get better. But life with JM is a marathon, not a sprint. If you truly want to give 100% for your child, every now and then you need to take some time to recharge.



Sample Journal Page

Feel free to adapt this journal in whatever way you need. It is just a way to get you started. In the beginning, it is important to keep track of many things: how your child is feeling; what hurts and how severely (use a pain scale—either numbers or faces like in the doctor’s office); any reactions to the medications; skin, muscle or intestinal changes; what they do or don’t do; what they eat or can’t eat, etc. Record not only what you notice, but what they tell you. It may not be important, but you never know. Use the journal to help you form questions for the doctors or other providers.

Date	Description of Behavior, Symptom, or Observation (Pain Scale)	Treatment Changes	Questions for Doctor	Responses from Doctor

Sample Medication Chart

This chart is just one example of how you can keep track of your child's daily doses of medications.

DATE																				
Name of Medication and Dose	AM	PM	AM	PM	AM	PM	AM	PM	AM	AM	PM	AM	PM	AM	PM	PM	AM	PM	AM	PM

Checklist for Doctor's Appointments

These are things you should think about taking to ALL doctor appointments, whether it's the rheumatologist, pediatrician, gastroenterologist or another specialist. This will help you and your child prepare for the visit, and help to minimize stress and worry for everyone concerned.

- Collected information in your binder or electronic device (refer to Top Tips)
- Daily journal entries
- Questions for the doctor
- Extra copies of medication charts to provide to doctors, nurses, etc.
- Family health history
- Any forms needed for school or insurance
- Games or books as distractions
- Extra food and/or drink

Empower your child to participate during doctor's visits. See the sample checklists on the following page.



Sample Checklists for Children

One of the ways you can help your children cope with JM is by giving them a sense of control over their doctor visits and treatments. Giving children their own checklists makes them a part of the process and helps them to remember to address any concerns they might have.

**Kids: write down your questions before you go to the doctor.
Check off your questions after you ask them.**

Q: _____

A: _____

Q: _____

A: _____

Nurse Check In

- Tell your nurse your name, age, and birthday
- Take off shoes and coat
- Measure your weight
- Measure your height
- Take blood pressure on arm
- Take your temperature
- Tell the nurse if you have any pains
- Answer the nurse's questions

Once all the boxes are checked, you will see the doctor.



Doctor Exam

- Ask questions you wrote down
- Tell the doctor how you are feeling and answer the doctor's questions
- Tell the doctor how many pills you take daily
- Let the doctor look at your body and hands
- Let the doctor listen with the stethoscope
- Let the doctor wiggle and waggle your joints
- Walk or run down the hall

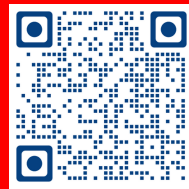
Once all of these boxes are checked, you will be done.

Resources

Join the Cure JM Family to learn more about research for new treatments plus how to get involved, and we'll connect you with a network of support, encouragement, and resources. Sign up to become part of a fantastic support network!

Joining is free and takes less than one minute.

curejm.org/quickjoin



Connect on social media!

@curejm



Check out this page for support as well:

Cure JM Caregivers

facebook.com/groups/125974597456217

Grandparents have always been an important part of Cure JM. We invite all Grandparents of JM patients to join the Cure JM family at curejm.org/quickjoin

Resources

Myositis and You

Written by medical experts for families like yours.

Co-edited by one of our founders, this comprehensive guide features over 450 pages with contributions from over 80 experts and medical professionals.

By reading this book, you will:

- Learn what Juvenile Myositis (JM) is and how to explain it to children
- Understand the symptoms of JM, tests used to diagnose it, and how to find medical help
- Find strategies to help your child adjust to physical limitations and to cope with JM as a family
- Understand treatment options and how health professionals track your child's progress
- Gain information on different aspects of JM, including long-term outcomes
- Discover a number of resources to assist you in the fight against your child's myositis

To receive your free digital copy of *Myositis and You*, join Cure JM at curejm.org/quickjoin

***Myositis and You* is also available on Amazon.com**

Caroline's Infusion Day

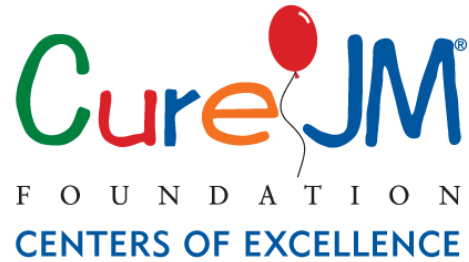
Infusions can definitely be a bit scary for children, particularly the first time. This book is a wonderful resource, and it is written by one our own Cure JM Moms about her daughter who has JM.

You can purchase it at:

amazon.com/Carolines-Infusion-Day-Kelly-Brennan/dp/1737617900



Resources



Cure JM Centers of Excellence are recognized for the extraordinary care they provide to Juvenile Myositis patients and families. Center of Excellence staff and physicians bring the highest level of clinical experience and knowledge to the JM community and are world-class leaders in JM care and research. Cure JM Centers of Excellence enjoy strong organizational support from their respective institutions, assuring that Cure JM's investment in clinical care and research is matched by an institutional commitment to building a robust JM program.

To learn more, visit: curejm.org/centersofexcellence



The Cure JM Clinical Care Network was launched in 2022 and expands excellent JM care to more children around the country

The Cure JM Clinical Care Network:

- Connects families and physicians so families know where to access the highest quality care
- Recognizes physicians who treat JM patients
- Provides a platform for more physicians to access grant funding from Cure JM to advance clinical care and research
- Provides physicians with resources for patients and families

To learn more, visit: curejm.org/care

Resources

Emotional Health and JM

Adolescents and young adults with Juvenile Myositis experience depression at rates two to three times higher than peers in the general population.* Researchers do not know yet whether mental health problems in JM are caused by the underlying illness (from inflammation), the treatments, genetics, or the challenge of living with a chronic and rare disease. What we do know is that patients, parents, clinicians, and researchers rank mental health as a critical research priority for Cure JM.

Cure JM Foundation recommends that mental health assessment and treatment be an integral component of comprehensive care for patients with JM, including those in remission. To this end, Cure JM is currently developing resources to help pediatric rheumatologists screen for mental health issues and recommend further evaluation or treatment if warranted. Additionally, a special committee of the Childhood Arthritis and Rheumatology Research Alliance (comprised of physicians, behavioral health specialists, patients and parents) is currently working on Consensus Statements for Assessment and Treatment of Mental Health to be published and shared with the broader rheumatology community.

The following information will help you better understand the signs and symptoms of depression and anxiety and how to find support.

Know the Signs of Depression+

Depression (major depressive disorder or clinical depression) is a common but serious mood disorder. It causes severe symptoms that affect how you feel, think, and handle daily activities, such as sleeping, eating, or working. You may be suffering from depression if you have been experiencing some of the following signs and symptoms most of the day, nearly every day, for at least two weeks.

- Constantly feeling sad, anxious, or even “empty,” like you feel nothing
- Feeling worthless, hopeless, or like everything is going wrong
- Spending more time alone and withdrawing from friends and family
- Not doing as well at school
- Losing interest or pleasure in activities and hobbies that you previously enjoyed
- Eating or sleeping more than usual or less than usual
- Feeling tired always (and not related to JM)
- Having trouble concentrating, remembering information, or making decisions
- Having aches or pains, headaches, or stomach problems (not related to JM)
- Thinking about dying or suicide or trying to harm yourself



Resources

Know the Signs of Anxiety+

Generalized anxiety disorder leads to excessive anxiety or worry most days, for at least 6 months, about a number of things such as personal health, work, social interactions, and everyday routine life circumstances. The fear and anxiety can cause significant problems in social interactions, school, and other areas of life.

Generalized anxiety disorder symptoms include:

- Feeling restless, wound-up, on-edge, or irritable
- Having sleep problems or being easily fatigued (and not related to JM)
- Having difficulty concentrating; mind going blank
- Having muscle tension
- Difficulty controlling feelings of worry

JM-Specific Factors Contributing to Depression and Anxiety:

- Worrying about flares
- Feeling distressed about changes in appearance
- Living with a chronic and unpredictable disease
- Fighting pain, fatigue, weakness, and other disease symptoms
- Taking multiple medications with emotional and physical side effects
- Coping with hospitalizations, infusions, injections, procedures, and surgeries
- Transitioning from pediatric to adult care
- Feeling alone / isolated due to rarity of JM
- Lack of understanding from friends and relatives about JM

Sources:

* Knight, Andrea. Mental Health Needs of Juvenile Myositis Patients & Potential Interventions. 2018 Update on JM Care & Research. June 2018.

* Prevalence of Depression in Adolescents. National Institute of Health. 2016. www.nimh.nih.gov/health/statistics/major-depression.shtml

+ National Institute of Mental Health

This material is for informational purposes only, and is not a substitute for medical advice, diagnosis or treatment provided by a qualified mental health or health care provider.

How to Get Help

Seek professional care:

- Find a mental health provider or treatment center at the Psychology Today website: www.psychologytoday.com/us/therapists
Providers can be sorted by zip code, insurance, issue, type of therapy desired, language spoken, etc. "Talk Therapy", medications, and a variety of other therapies are available to treat depression and anxiety
- Speak to a social worker or psychologist (if available) at your rheumatologist's or primary doctor's office, or at the hospital
- Consult a guidance counselor, psychologist, social worker or nurse at school

Find Support Systems:

- Family and friends
- Cure JM support groups / local support groups
- Cure JM regional chapters
- Cure JM conferences, walks, and events

Practice Self-Care:

- Mindfulness / meditation / yoga / massage
- Exercise & fun activities
- Good sleep habits
- Nutritious foods

Crisis Hotlines in the U.S.

Call 911 in the event of a mental health crisis (urgent threat of self-harm or harming others)

Suicide Lifeline: 800-273-TALK (8255)

The Suicide Lifeline provides 24/7, free & confidential support for people in emotional distress, as well as prevention and crisis resources for you or your loved ones.

Crisis Text Line: Text HOME to 741741

TXT 4 HELP: Text the word "safe" and your current location (address, city, state) to 4HELP (44357) which allows you to text live with a mental health professional:

nationalsafeplace.org/txt-4-help

National Help Line for Substance Abuse:

(800) 262-2463

National Institute on Drug Abuse Hotline:

(800) 662-4357

Eating Disorders Awareness and Prevention:

(800) 931-2237

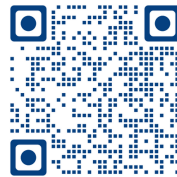
National Youth Crisis Hotline: (800) 442-HOPE

Resources

MENTAL & EMOTIONAL HEALTH RESOURCES for CURE JM FAMILIES

- Facebook group: Cure JM Emotional & Mental Health Support Group. This is a place to get support from other families, receive educational articles, information about events, and mental health tips. [facebook.com/groups/curejmemotionalsupport](https://www.facebook.com/groups/curejmemotionalsupport)
- Find information about signs and symptoms of depression and anxiety and places to get help, nationally, including a downloadable flyer available on the Cure JM website: [curejm.org](https://www.curejm.org)

There are many resources available to you through the Cure JM network.
Make sure to join today: [curejm.org/quickjoin](https://www.curejm.org/quickjoin)





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