

# Welcome Kit

for Families of Children Affected by Juvenile Myositis

*including Juvenile Dermatomyositis and Juvenile Polymyositis*



Cure JM  
FOUNDATION

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

"Cure JM has taken us out of isolation and connected us to a world that understands what we go through on a daily basis."

*Sissy T.*



"I was lost until I found Cure JM."

*Sasha S.*

"Cure JM Foundation has been so helpful, beyond measure. They open the doors of hope and help to anyone affected by this terrible disease."

*Jennifer L.*



"We were so fortunate to connect with Cure JM shortly after my daughter's diagnosis. Cure JM instantly became a part of our extended family and they immediately provided the overwhelming support and resources that we desperately needed."

*Lake C.*



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**We are** a 501(c)(3) nonprofit organization created and managed by families of children affected by Juvenile Myositis (JM). We are dedicated to, and assisted in our efforts by, the JM community.



**Our mission** is to provide support for families coping with JM, raise awareness of JM, and fund research that will ultimately lead to a cure for JM.

**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.



# Welcome...

Welcome to Cure JM! Cure JM Foundation is the center for information and support in your family's battle with Juvenile Myositis (JM), including Juvenile Dermatomyositis and Juvenile Polymyositis. Whether you were just diagnosed or have been coping with JM for years, you will find encouragement and support from other families on our Cure JM message board, Facebook page and at our events and fundraisers.

Cure JM Foundation was founded in 2003 by families of children battling JM. Through the generosity of the JM community, friends and family, Cure JM has helped establish JM research centers in Chicago and Washington, D.C., and has funded the first-ever book just about JM. Through our website, [www.curejm.org](http://www.curejm.org), the organization provides information and support to families, like yours, battling this rare disease. However, there are still children suffering, so there is still work to do.

Various studies estimate that between one and five children per million will develop Juvenile Myositis each year. Due to the rarity of the disease, there is little government funding of JM research, so private fundraising is absolutely crucial if we are to find the cause, best treatments and an eventual cure for Juvenile Myositis. Cure JM is primarily managed by volunteers with minimal staffing, giving us the ability to direct well over 95% of donations towards research and educational programs. Please let us know if you are interested in helping with a fundraiser so we can continue our fight for the cure. And, if you would like to make a tax-deductible donation, go to [www.curejm.org](http://www.curejm.org).

If you haven't done so already, please visit [www.curejm.org/registration](http://www.curejm.org/registration) and complete the Cure JM Patient Registration process, so you can receive a welcome kit, news updates, event information and be connected to other JM families in your area.

In the meantime, let us know if there is anything we can do to help. You'll definitely want to visit our online community, *Cure JM Connect!* (go to [www.curejm.org/fsn](http://www.curejm.org/fsn) and click on *Cure JM Connect!*), or visit our home page [www.curejm.org](http://www.curejm.org) for other social media options, including Facebook. And, make sure to watch the educational and fundraising videos available on our website at [www.curejm.org/videos](http://www.curejm.org/videos).

Warmest regards,

**Shari Hume**

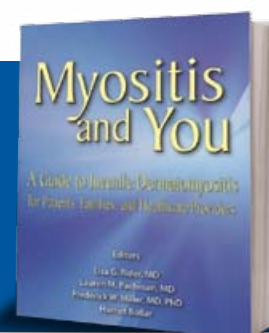
Co-founder, Cure JM Foundation

Mom to Parker, diagnosed in 2002 at age 4

*P.S. Cure JM is the ONLY organization that solely supports Juvenile Myositis. Please consider making a donation today to help us continue our search for the cure.*

Cure JM Foundation funded *Myositis and You*, the first book ever published to focus exclusively on Juvenile Myositis.

This comprehensive guide features over 450 pages with contributions from over 75 experts and medical professionals and was co-edited by one of our founders. Visit [www.curejm.org/book](http://www.curejm.org/book) for more information.



# Top 12 Tips from JM Parents and Patients

These ideas have come directly from parents of JM kids or from the patients themselves. The first few days, weeks and months after diagnosis are often overwhelming, and we hope these ideas will help you find ways to organize and support yourself and your child as you begin this new journey.

1. **Find a pediatric rheumatologist who has experience treating JM.** Trust your instincts and ask questions until you are comfortable with what the doctor is telling you. If you are unsure about your child's treatment, get a second opinion.
2. **Get a 3-ring binder to keep track of the following:**
  - a) Questions for the doctor and other providers with room for their answers. INCLUDE DATES ON ALL NOTES.
  - b) Copies of EVERYTHING! Ask for and keep copies of all clinic/hospital visits, summary notes and lab reports. It's oftentimes easier to get extra copies of labs, medical reports and notes in the chart during the appointment or hospital stay, rather than going through medical records later.
  - c) Treatment Changes
  - d) Medication Chart
  - e) Insurance Information
  - f) Nutrition or Other Medication Information
  - g) Daily Observations
3. **Take your binder to all doctor appointments.** Have additional copies of medication chart available for EVERY appointment, surgery, etc.
4. **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.
5. **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. Write it down and create a "Family Health History" or even design a family tree with health information. This will come in handy at doctors' appointments for your child or anyone in your family.

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.

6. **Create an information packet about JM** and what your child specifically needs for your child's school/teachers, etc.
  - a) Look into a 504 plan or an IEP—see [www.curejm.org/fsn](http://www.curejm.org/fsn) for more details
  - b) Describe side effects of medications to teachers and ask them to discuss these with students depending on the age of your child—most kids with JM are on steroids which cause a variety of physical and emotional changes, i.e. weight gain, mood swings, etc.
  - c) 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.
  - d) 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.
7. **Get support.** Having a child with JM is stressful for everyone in the family. Join a Cure JM support group, visit the Cure JM message board, and attend a national Cure JM conference. 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 other kids somewhere, to just listening.
8. **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.
9. **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.
10. **Be a "Mama Tiger" or "Papa Tiger".** You are your child's best advocate—you know your child best. Trust your instincts.
11. **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 [www.curejm.org/teamjm](http://www.curejm.org/teamjm).
12. **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 (Use Pain Scale)	Treatment changes	Questions for doctor	Responses from doctor

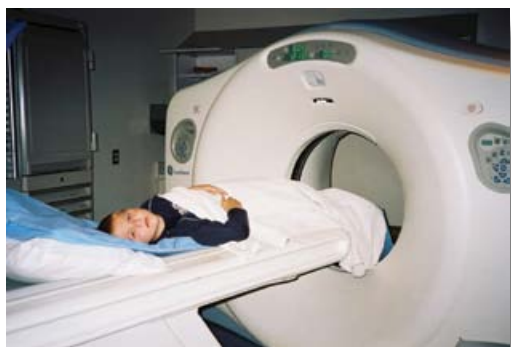


# Checklist for Doctor's Appointments

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.

- ☐ 3-ring binder  
(as described in Top Twelve Tips)
- ☐ Daily journal pages  
(if separate from binder)
- ☐ Questions for doctor
- ☐ Extra copies of medication charts to provide to doctors, nurses, etc. (see page 7)
- ☐ Family health history
- ☐ Any forms needed for school or insurance
- ☐ Games or books as distractions
- ☐ Extra food or drink


Being  
well-prepared  
for your child's  
medical  
appointments  
is a great way  
to reduce  
stress for both  
you and your  
child.



Empower your child  
to participate during  
doctor visits.  
See the sample "Child's Checklist"  
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. To download a copy of these checklists that you can customize for your child, visit [www.curejm.org/fsn](http://www.curejm.org/fsn)



## Nurse Check In

When all of the boxes have a check we will go to see the doctor


- ☐ Tell nurse your name, age and birthday
- ☐ Take off shoes and coat
- ☐ Measure your weight (stand on scale)
- ☐ Measure your height (stand against wall)
- ☐ Take blood pressure on arm
- ☐ Take temperature across forehead
- ☐ Tell nurse if you have any pains
- ☐ Answer the nurse's questions



## Doctor Exam

When all of the boxes have a check we will be done

- ☐ Ask questions you wrote down (see next page)
- ☐ Tell the doctor how you are feeling
- ☐ Tell the doctor how many pills you take daily
- ☐ Answer the doctor's questions
- ☐ 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



## My Questions

Kids: write down your questions before you go to the doctor.  
Put a check mark next to each question after you ask the doctor.

- ☐ Question: \_\_\_\_\_  
Answer: \_\_\_\_\_
- ☐ Question: \_\_\_\_\_  
Answer: \_\_\_\_\_
- ☐ Question: \_\_\_\_\_  
Answer: \_\_\_\_\_

[illegible]

This medication chart is just an illustrative example. Actual medications used for JM patients can vary significantly. To download a copy of this chart that you can customize for your child, visit [www.curejtm.org/fsn](http://www.curejtm.org/fsn)

# Cure JM Highlights



**CURE JM BEGINS**  
IN 2003 WITH A LEMONADE STAND IN  
ENCINITAS, CA



SINCE THEN, JM FAMILY  
AND FRIENDS HAVE RAISED  
**MORE THAN \$8 MILLION**  
FOR JM RESEARCH AND EDUCATION



CURE JM FOUNDATION HAS HELPED  
ESTABLISH  
**TWO JM RESEARCH CENTERS,**  
ONE AT CHILDREN'S HOSPITAL OF CHICAGO  
RESEARCH CENTER...



...THE OTHER AT GEORGE  
WASHINGTON UNIVERSITY IN  
WASHINGTON, D.C.



AND WE HELPED TO SECURE A  
**\$1.9 MILLION NIH GRANT**  
FOR THE CHICAGO PROGRAM OF EXCELLENCE IN JM RESEARCH



WE FUNDED THE  
**FIRST-EVER BOOK ABOUT JM,**  
*MYOSITIS AND YOU,*  
 WITH CONTRIBUTIONS FROM  
 OVER 75 MEDICAL PROFESSIONALS

OUR WEBSITE HAS OVER  
**100 PAGES OF INFORMATION**  
 AND AN ACTIVE MESSAGE BOARD FOR JM FAMILIES



WE'VE HOSTED  
**SEVEN ANNUAL  
 EDUCATIONAL FORUMS**  
 FOR JM FAMILIES



IN CONJUNCTION WITH  
**7 ANNUAL NATIONAL  
 FUNDRAISERS**



AS WELL AS  
**FOUR MEDICAL  
 CONFERENCES**  
 FOR THE JM MEDICAL  
 COMMUNITY



CURE JM FAMILIES HAVE GENERATED  
**350 NEWSPAPER ARTICLES**  
 AND **100 TV STORIES**



WE'VE REGISTERED **OVER 1,500 JM FAMILIES** FROM **32 COUNTRIES**  
 IN THE CURE JM FAMILY SUPPORT NETWORK

AND ENGAGED **13,000+ PEOPLE** IN THE  
 CURE JM SOCIAL MEDIA COMMUNITY





# 10 Easy Ways to Raise Awareness of Juvenile Myositis and Cure JM

One of the best ways to channel feelings of helplessness, frustration and grief is to take action. This page and page 11 provide some ideas. You may be better at one than the other. Do whatever seems right for you.

1. Take Cure JM brochures and newsletters to your doctor's office, hospital, etc. Ask them to distribute these to patients with JM. Brochures can be printed from our website's literature link or requested by contacting us at **info@curejm.org**
2. Share the links to the Cure JM educational and fundraising videos with your family, friends and everyone you know: **www.curejm.org/videos**
3. Ask if it's okay for you to post Cure JM brochures and flyers in your break room at work, local coffee shops, bagel shops, grocery stores, etc.
4. Speak at your child's school to educate them about JM and Cure JM.
5. Connect with Cure JM on social media. Visit **www.curejm.org** to link to Cure JM on Facebook, LinkedIn, Twitter and more. Invite your friends and family to join the cause!
6. Add the Cure JM website address to any family and social networking websites; ask your friends to do the same.
7. Include a signature line on every e-mail with the following:  
**Help find a cure for my child battling Juvenile Myositis at www.curejm.org**
8. Write a letter to your family/friends to let them know about Juvenile Myositis and Cure JM.
9. Contact your local newspaper(s) and television stations. You can usually send a story about your experience with JM via e-mail to the newspaper or television station. You can find the appropriate e-mail addresses for newspapers/TV stations on the internet.
10. Hold a fundraising event to benefit Cure JM (see the next page for fundraising ideas).



# 10 Easy Ways to Fundraise for Cure JM

1. Hold a fundraiser to benefit Cure JM. Consider a golf outing, dinner/auction or jog-a-thon.
2. Write a letter to family/friends about your child's experience with Juvenile Myositis and explain how they can help find a cure by donating to Cure JM. . Sample emails and letters can be found at [www.curejm.org/teamjm](http://www.curejm.org/teamjm).
3. Set-up a personal fundraising page and send the link to family and friends. To learn more, visit [www.curejm.org/teamjm](http://www.curejm.org/teamjm).
4. Add a signature line to your emails with a link to your fundraising page or use this line:  
**Help us find a cure for my child battling Juvenile Myositis at [www.curejm.org](http://www.curejm.org)**
5. Be a participant or a volunteer for the next Cure JM conference/marathon. Learn more at [www.curejm.org/conference](http://www.curejm.org/conference). Fundraise on behalf of your child with JM.
6. Support Cure JM while you shop at Amazon and thousands of other online retailers! Check out all of the details at [www.curejm.org/shop](http://www.curejm.org/shop). It's that easy!
7. Ask for donations to Cure JM in lieu of presents for birthday parties and holidays. Direct friends and family members to [www.curejm.org/donate](http://www.curejm.org/donate) for more information on the numerous support options available, including automatic monthly donations, stock donations, employer matching gifts and more.
8. Keep a coin collection jar by your door. Every time you walk in, empty your pockets or purse with your spare change. Ask local stores to set out collection jars for Cure JM.
9. Give up one latte, cappuccino (or other treat) each week and you could donate over \$200 in one year.
10. Donate the proceeds from your next garage sale or lemonade stand to Cure JM.

For over 50 fundraising ideas, turn-key fundraising toolkits and a network of fundraising coaches, visit [www.curejm.org/teamjm](http://www.curejm.org/teamjm)

*For over 50 more fundraising ideas and complete turn-key fundraising toolkits, go to [www.curejm.org/toolkits](http://www.curejm.org/toolkits). Cure JM has a network of fundraising coaches standing by to help you every step of the way! Email [fundraising@curejm.org](mailto:fundraising@curejm.org) to get started today!*



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