

# Welcome Kit

*for Families of Children Affected by Juvenile Myositis  
including Juvenile Dermatomyositis, Juvenile Polymyositis and Juvenile Amyopathic Dermatomyositis*



CureJM  
FOUNDATION  
[www.curejm.org](http://www.curejm.org)

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F O U N D A T I O N

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*We are an all-volunteer foundation 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.*

*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! The Cure JM Foundation is the center for information and support in your family's battle with Juvenile Myositis. (This includes Juvenile Dermatomyositis, Juvenile Polymyositis, or Amyopathic Dermatomyositis). 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 and at our events and fundraisers.

The Cure JM Foundation was founded in 2003 by families of children battling JM. Our non-profit organization is run by ALL volunteers and we all are associated with a child affected by 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.

With the rarity of this disease (three to four children in 1 million), fundraising is vital to permitting further studies into finding the cause, best treatments and a possible cure for Juvenile Myositis (JM). Since we are an all-volunteer organization, nearly 100% of every donation goes straight to research or 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).

In the meantime, let us know if there is anything we can do to help; and definitely, visit our message board and share your story about your journey with JM. If you haven't done so already, please register on the Cure JM Patient Registry so you can receive news updates, event information and be connected to other JM families in your area. And, make sure you watch our new educational and fundraising videos available on our website:

Newly diagnosed video: [www.curejm.com/family\\_support/video\\_for\\_newly\\_diagnosed.html](http://www.curejm.com/family_support/video_for_newly_diagnosed.html)

Fundraising video: [www.curejm.com/teamjm/video.htm](http://www.curejm.com/teamjm/video.htm)

Warmest regards,

**Shari Hume**

Co-founder

Cure JM Foundation

Mom to Parker, diagnosed in 2002 at age 4

**Suzanne Edison**

Family Support Director

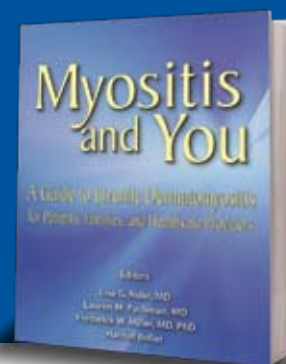
Cure JM Foundation Advisory Board

Mom to Flora, diagnosed in Jan. 2007 at age 6

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.

The Cure JM Foundation funded the first book ever published about Juvenile Myositis: *Myositis and You*.

This comprehensive guide features over 450 pages with contributions from over 80 experts and medical professionals. The book was co-edited by one of our founders and can be ordered directly from [www.amazon.com](http://www.amazon.com)



# Top Ten 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 yourself 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.

*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.*

5. Create an information packet about JM and what your child specifically needs for your child's school/ teachers, etc. See [www.curejm.org](http://www.curejm.org) or *Myositis and You* for more details.
  - a) Look into a 504 plan or an IEP—see [www.curejm.org](http://www.curejm.org) for more details under **Family Support Network**.
  - 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.
6. 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.
7. 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.
8. 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.
9. Be a "Mama Tiger" or "Papa Tiger". You are your child's best advocate—you know your child best. Trust your instincts.
10. 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.



# Sample Journal Page

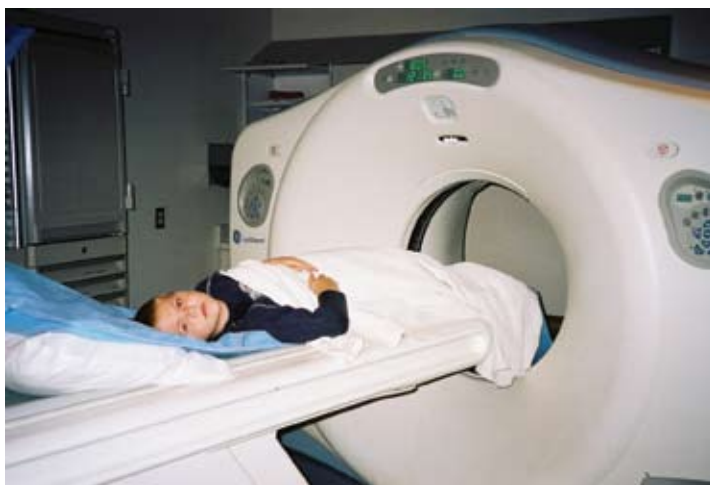
Feel free to adapt this in whatever way you need. It is just a way to get you started. In the beginning it is important to keep track of many things: how your child is feeling; what hurts and how severely (use a pain scale—either numbers or faces like in the doctor’s office); any reactions to the medications; 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.

<b>Date</b>	<b>Description of Behavior, symptom or observation (Use Pain Scale)</b>	<b>Treatment changes</b>	<b>Questions for doctor</b>	<b>Responses from doctor</b>

# Checklist for Doctor's Appointments

These are things you should think about taking to ALL doctor appointments whether it's the Rheumatologist or your pediatrician, a GI specialist or a naturopath.

- 3-ring binder-the one we described in Top Ten Tips
- Daily note Journal (if separate from binder)
- Questions for Doctor
- Extra copies of medication charts to provide to doctors, nurses, etc.
- Any forms needed for school or insurance
- Games or books as distractions
- Extra food or drink





# 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 10 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.com](mailto:info@curejm.com)
- 2) Share the links to the Cure JM educational and fundraising videos with your family, friends and everyone you know:  
Newly diagnosed video: [www.curejm.com/family\\_support/video\\_for\\_newly\\_diagnosed.html](http://www.curejm.com/family_support/video_for_newly_diagnosed.html)  
Fundraising video: [www.curejm.com/teamjm/video.htm](http://www.curejm.com/teamjm/video.htm)
- 3) Post brochures in your break room at work, your local coffee shops, bagel shops, grocery stores, etc.
- 4) Speak at your child's school to educate them about JM and Cure JM.
- 5) Join the Official Cure JM Cause and fan pages on Facebook. Invite your family and friends to join the cause. [www.facebook.com/curejm](http://www.facebook.com/curejm)
- 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](http://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 page 10 for fundraising ideas).



# Cure JM Highlights



Cure JM begins with a lemonade stand in Encinitas, CA in 2003



Families and friends raise over \$3 million through grassroots fundraisers



Cure JM helps establish two JM research centers, one at Chicago Children's Memorial Research Center under the direction of Dr. Lauren Pachman (in center of photo on left)...

...and the other at George Washington University in Washington, D.C.





Cure JM funded the first-ever book on Myositis, called Myositis and You.



Cure JM holds annual educational forums and fundraisers in conjunction with major marathons in

- Austin, Texas
- Carlsbad, California
- Chicago, Illinois
- Washington, D.C.



In August 2010, Cure JM wins 1st place and \$250,000 for research in the Pepsi Refresh Project.



# 10 Easy Ways to Fundraise for Cure JM

- 1) 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.
- 2) Set-up a personal fundraising page at [www.firstgiving.com/curejm](http://www.firstgiving.com/curejm) and send the link to family and friends.
- 3) Add a signature line to your e-mails 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).*
- 4) Be a participant or a volunteer for the next Cure JM conference/marathon and set-up your personal fundraising page at [www.firstgiving.com/curejm](http://www.firstgiving.com/curejm). Send the link to family and friends.
- 5) Ask for donations to Cure JM in lieu of presents for birthday parties and holidays.
- 6) 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.
- 7) Give-up one latte, cappuccino (or other treat) each week and you could donate over \$200 in one year.
- 8) Donate the proceeds from your next garage sale or lemonade stand to Cure JM.
- 9) Shop on-line from over 680 stores at [IGive.com](http://IGive.com) and register Cure JM as your charity. Up to 26% of your purchase will go to Cure JM! To register, go to [www.curejm.com/order\\_pages/gifts.htm](http://www.curejm.com/order_pages/gifts.htm).
- 10) Hold a fundraiser to benefit Cure JM—consider a golf outing, dinner/auction, jog-a-thon, etc.  
For over 50 fundraising ideas, fundraising guidelines and more, go to [www.curejm.com/teamjm/fundraising\\_start.html](http://www.curejm.com/teamjm/fundraising_start.html)

*Check with your company to see if they match donations!*





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