Fundraising Toolkit

for Families of Children Affected by Juvenile Myositis

including Juvenile Dermatomyositis, Juvenile Polymyositis and Juvenile Amyopathic Dermatomyositis





www.curejm.org

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

Table of Contents

Welcome to Team JM1
Cure JM Overview & Highlights2
Fundraising Guidelines4
54 Fundraising Ideas6
10 Easy Ways to Fundraise for Cure JM11
Sample Donation Request Letter12
Sample Press Release
Sample Fundraising Flyer14



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 to Team JM!

Welcome to Team JM, the fundraising arm of Cure JM. Team JM is a nationwide network of volunteers dedicated to finding a cure for JM. Team JM works to raise money for research while promoting community awareness of juvenile myositis diseases. The Cure JM Foundation supports these efforts with wristbands, brochures, posters and other tools.

Team JM is made up of people touched in one way or another by JM. We are parents, grandparents, family and friends. Our members plan events that range from lemonade stands and garage sales to major marathons.

This booklet will help you get started with all of the tools you will need to hold a fundraiser. First, choose an event that you are passionate about, whether it's a golf tournament, a jog-a-thon or a bake sale. We have 54 ideas for fundraising events in this booklet, so you can start there. Then, sign and return the Fundraising Guidelines, and a Cure JM team member will contact you to provide any guidance you might need.

Visit the Cure JM Foundation website often (www.curejm.org) for updates and upcoming events in the battle against JM and the latest strategies for raising funds and awareness.



Cure JM Overview & Highlights

The Cure JM Foundation was founded in 2003 by families of children battling Juvenile Myositis. Juvenile Myositis (JM) is an orphan autoimmune disease affecting approximately 2-3 children out of a million and can be debilitating and life-threatening.

Our non-profit organization is run by ALL volunteers and we are all associated with a child affected with JM. Cure JM Foundation's mission is to increase awareness of all forms of JM, provide support to the families battling this disease and fund research into a cure for JM. Cure JM is the only organization that solely supports JM research and JM families. Thanks to the Juvenile Myositis community, family and friends, Cure JM has:

- 1. Raised nearly \$4 million through grassroots fundraisers throughout the country.
- Helped establish 2 JM research centers, one at Chicago Children's Memorial Research Center (Cure JM Program of Excellence in JM Research) under the direction of Dr. Lauren Pachman; and the other at George Washington University in Washington, D.C.
- 3. Helped secure a 4-year grant totaling \$1.9 million from NIH in 2010 for the Chicago team due to the progress already underway at the Cure JM Program of Excellence in JM Research.
- 4. Funded (and continue to fund) wide range of genetic and JM treatment studies, as well as fellowships.
- 5. Funded the first-ever book about JM, "Myositis and You", written by over 100 doctors.
- 6. Created targeted educational materials (video and welcome kit) for newly diagnosed families.
- 7. Garnered local and national media attention...at least 300 local newspaper articles and 50 television stories.
- Connected over 1,000 families in 20 different countries to provide mutual support in their battle against JM – includes having regional JM family support representatives in the U.S.





- 9. Provided a comprehensive website, as well as an active message board where families can post questions and connect with other families affected by JM.
- Provided educational forums where leading JM researchers speak to families affected by this disease and facilitated JM educational forums for medical community.
- 11. Provided welcome kits, newsletters, brochures and videos for JM community.
- 12. Provided guidance to families to help them navigate the health care system and work with insurance companies, doctors, schools, etc.

We are proud of our accomplishments; however, there is still work to do...especially in terms of awareness and research efforts. Some children die because they do not receive a diagnosis until it's too late. Other children receive a delayed diagnosis which affects their prognosis. These delayed and missed diagnoses are regrettably common. Most pediatricians will never see a case of Juvenile Myositis in their lifetime. And, even though JM can be debilitating and life-threatening, pharmaceutical companies are not motivated to develop treatments for a disease that affects such a small portion of the population. We are proud of our accomplishments; however, there is still work to do...especially in terms of awareness and research efforts.

Our ultimate goal is to never, ever let another child suffer from Juvenile Myositis. Please visit www.curejm. org for more information about Cure JM.





Fundraising Guidelines

Thank you for considering holding a fundraiser to benefit the Cure JM Foundation.

It is through the generosity of individuals like you that we are able to continue supporting the much-needed research and educational programs for JM. Before starting your fundraising efforts, please review and follow the guidelines listed below.

After filling-out this form, please sign and return this document to Cure JM. We look forward to working closely with you to ensure your event is a big success!

Please provide the following information about your fundraiser:

Name
Address
Email address
Phone number(s)
Name of event
Type of event
Event address
Date/time of event
Expected revenue

Please adhere to the following fundraising guidelines for Cure JM:

- 1. All fundraising materials must use the terminology: TO BENEFIT THE CURE JM FOUNDATION or BENEFITING THE CURE JM FOUNDATION. It must be clear that fundraising events are held to benefit Cure JM, and they are not a Cure JM event.
- 2. All materials bearing the Cure JM name or logo need to be approved by Cure JM prior to the production, distribution, broadcast, or publication of any printed materials, publicity releases or advertising related to the event. The Cure JM logo may not be altered in any way. All materials should include the Cure JM website: www.curejm.org



- 3. Donations for your fundraising event can be made by check, cash or credit card. All checks should be written out to the Cure JM Foundation. Please deposit cash donations and send a check or money order to Cure JM for the total amount. Credit card donations can be made on-line at the Cure JM website. Donors can specify to which fundraising event they are donating. All net proceeds from your fundraising event should be mailed to the Cure JM Foundation within thirty days of the event.
- 4. All necessary insurance, licenses and permits should be obtained. You must agree to indemnify and hold the Cure JM Foundation harmless from any and all claims of any kind or nature whatsoever arising out of, or in any way related to the event.
- 5. All services and items required for your event ideally should be donated so your expenses are minimal. Cure JM can provide "sponsorship request letters" to help in your acquisition of these services and items. Your fundraising event should not result in any costs or expenses for Cure JM, unless expressly agreed in writing in advance by a Cure JM Foundation Board member.
- 6. Cure JM is here to help! Cure JM can guide you in your fundraising efforts and help provide some of the literature and materials you will need. For large events, Cure JM can also help you with media contacts and template press releases to generate interest in local TV and newspaper coverage.
- 7. Please sign and return this document to Cure JM. By signing this document, you are providing your consent to abide by the Cure JM Guidelines.

Cure JM looks forward to working with you to ensure your fundraiser is a BIG success! We sincerely appreciate your help in increasing awareness and funding for Juvenile Myositis research!!!!

I agree to follow the Cure JM Fundraising Guidelines as provided in this document.

Name: _____

Date: _____

Please mail, fax or scan and email this completed and signed form to the Cure JM Foundation.

Cure JM Foundation 836 Lynwood Drive Encinitas, CA 92024 Fax number: 760-230-2243 E-mail address: shari.hume@curejm.com

54 Fundraising Ideas

School fundraising

- 1. Read-a-thon: Elementary school student and JM patient Austin raised over \$800.00 for Cure JM when he implemented his very own fundraising idea, "Read for a Cure with Cure JM". We have taken Austin's concept and further developed it so a single child or an entire school can use it. The forms are easy to use and everything is explained for the donor. It is as easy as gathering pledges for each minute (or each book) a child reads.
- 2. Jog-a-thon: This is ideal for schools that wish to raise money for Cure JM. Students collect pledges from friends and family based on how many laps they might run...or flat donations can be collected prior to the race. Cure JM families have raised over \$50,000 through jog-a-thons!
- 3. Change A Life Campaign: Ask your family, friends and your child's school to collect their spare change for one week in honor of your child, to benefit the Cure JM Foundation and JM research. One school collected \$4,000 in PENNIES!
- 4. Restaurant Nights: Many restaurants will donate a percentage of sales to Cure JM on a predetermined date. Create a flyer and distribute to your fellow students and enjoy a fun evening that benefits Cure JM.
- 5. Special Dress Days: Choose from Crazy Dress Day, Backwards Dress Day, Wacky Hat Day, etc. Students donate from \$1.00-\$5.00 to dress the part.
- 6. Special Snack Days: Sell a special snack to kids at recess and donate the proceeds to Cure JM. Some snack ideas include popcorn, bread sticks, hot chocolate, ice cream...
- 7. Paper Airplane Contest: Students donate \$1.00-\$5.00 for a chance to create and throw a paper airplane into a basket or goal. Ask local vendors to donate prizes for the winners. A Cure JM family raised over \$200 with this event.
- 8. School dance or dance-a-thon: Students purchase tickets to attend dance party...proceeds go to Cure JM. Alternatively, you could hold a dance-a-thon where students ask their friends and family to donate based on how many dances, or how many minutes they can dance.
- 9. Jump rope-a-thon: This is good for the younger kids. The students ask friends and family for donations based on how many minutes they can jump-rope. Hula hoops are another possibility.



- 10. Art Sale: Have the students make their own artwork and "sell" it to the parents or grandparents.
- 11. Concession Stands: Hold these at school events to benefit Cure JM.
- 12. Rock/Paper/Scissors Contest: Charge entry fee and use brackets like in basketball.

Office fundraising:

- 13. Casual for a Cure: Employees pay \$5.00-\$10.00 to dress in casual clothes.
- 14. Dinner parties: Hold a company party on-site or at someone's home. Ask for a \$25 donation to attend.
- 15. Cocktails for a Cure: Hold a cocktail party at a restaurant or home and either require a flat donation or a donation per drink.
- 16. United Way Donations: Ask fellow employees to donate to Cure JM through United Way.

Community fundraising:

- 17. Walk-a-thon or Bike-a-thon: Ask your friends to participate in one of these events, and collect donations beforehand from friends and family. Donations can be flat or based on length of time, miles covered, etc.
- 18. Bowl-a-thon: Find a local bowling alley to sponsor the event; and invite friends and family to bowl in exchange for a donation to Cure JM. Gilson Lee and his family raised over \$5,000 with a bowl-a-thon!
- 19. Cash for Trash: Line up all your family, co-workers, schools and organizations. Have them save the soft drink can tabs or even better, the whole can! Save them up and then turn them in for valuable research dollars. Have the reclamation center make the check out to Cure JM Foundation and send it to us with a note that it is from your recycling efforts.
- 20. Car Wash: Get your friends together and wash cars in exchange for donations to Cure JM.
- 21. Just for Fun Team Games: Get your friends and neighborhood involved in various team games, such as baseball, kickball or volleyball. Participants make a donation to Cure JM to play.
- 22. Golf Fore a Cure: Hold a golf tournament to benefit Cure JM. Three Cure JM families hold these on an annual basis and have raised a significant amount of money!

www.curejm.org

- 23. Kicks for a Cure: Hold a Field Goal contest or a Karate Kick Contest: Ask for donations to enter the contest. Winner receives prizes donated from local vendors.
- 24. Homerun Derby: Hold a homerun contest or even a Free Throw contest.
- 25. Neighborhood Yard Sale: Ask your neighbors to join in for a neighborhood yard sale and donate all of the proceeds to Cure JM. Get a realtor involved to sponsor the event, run an ad in the paper and create maps/flyers.
- 26. Poker Party: Invite your friends over for a fun night of poker in exchange for a donation to Cure JM.
- 27. Dog Wash: This is a great one for kids. Offer to wash the dogs in your neighborhood for a \$5.00-\$10.00 donation.
- 28. Lemon-aid Stand or Sno-Cone Stand: Set these up with a few friends on a warm summer day.
- 29. Bake Sale: Ask friends and family to bake some of their favorite goodies and sell them at a sporting event or in front of a store (get store permission first!)
- 30. Bakeless Sale: Here's a 21st Century take on an old classic. Friends, relatives and co-workers, are invited to NOT spend hours baking a cake, pie or cookies and to NOT stand in the sun all day trying to sell those baked goods. Instead, ask that they take the money they would have spent baking or buying those treats and donate it directly to the Cure JM Foundation. Click here for a poem that you can give to family and friends to start your own bakeless bake sale.
- 31. Creations for a Cure: Have kids make bracelets, necklaces, etc. and ask for donations for their masterpieces.
- 32. Theatre Benefits: Ask a local theatre to hold a benefit performance for Cure JM.
- 33. Concert for a Cure: Find a band who will hold a benefit concert for Cure JM.
- 34. Picture a Cure: Find a professional photographer who will donate his/her time to take holiday pictures for families and donate the proceeds to Cure JM.
- 35. Product Promotions: Find friends who hold in-home sales parties for companies such as Mary Kay Cosmetics; and ask them to sponsor a sales night to benefit Cure JM.
- 36. Cuts for a Cure: Ask a local hair salon to give a portion of their proceeds to Cure JM for a predetermined date. Bring in a well-known hair stylist if possible.



- 37. Carnival for a Cure: Hold a carnival with jump tents, food and games. Find local vendors to sell food items and donate prizes.
- 38. Cure JM Literature: 'The Cure JM Foundation has brochures, posters, and flyers available for your fundraising and awareness efforts in the Literature section of this website. You can download and print these items for distribution to family and friends (and strangers!) Please take these to your pediatrician, rheumatologist, dermatologist, etc. and ask them to display them in their offices or waiting room so that other JM families can find their way to us.
- 39. Kids' Camp: Kids run a neighborhood day camp for 2 hours with arts and crafts. Fees benefit Cure JM.

At-Home Fundraising:

- 40. Friends and Family Letter: This is the single most effective fundraising piece and one of the simplest. Cure JM can help you prepare an appropriate letter for your friends and family, explaining JM and the need for research. These campaigns can be done at any time of year but are especially useful during the holidays and for birthdays to request a donation in honor of a child battling JM.
- 41. Coin Collection Jar: Leave a jar by the door to drop spare change into. You'll be surprised how fast this change adds up to a big donation to Cure JM!
- 42. Give-it-Up: Everyone in the family gives up something such as coffee, candy, ice cream, etc. The money they would have spent on these items goes into the Give-it-Up jar.
- 43. Stay-in-Night: Instead of going out to dinner and a movie, stay home and donate the money you would've spent to Cure JM.
- 44. Birthday Wishes for a Cure: Request donations to Cure JM in lieu of birthday gifts. This works for holiday gifts and wedding gifts as well.

On-Line Fundraising:

45. First Giving: If you are planning an event to raise money for the Cure JM Foundation or just want to help raise money for Cure JM in honor of your child, please consider using the First Giving site. Firstgiving.com provides an easy way to accept and track donations, and you get instant feedback on who is donating! Visit www.firstgiving.com/curejm to find out how you can set up a personalized First Giving page for a new or existing Cure JM Foundation fundraising event.

- 46. Family Websites: Add a link to the Cure JM donation page from your family website.
- 47. I Give Shopping: Do all of your shopping at iGive. Go to www.igive.com and register with Cure JM as your charity. Then, every time you make a purchase from any of the 700+ stores through their link on iGive, our organization receives a gift of up to 26 percent of the total purchase price. An extra \$5 is donated to Cure JM for each registrant who shops at iGive within 45 days after signing up.
- 48. I Search: Search the Web with http://isearch.igive.com/toolbar.cfm. After you sign up, one cent is donated to Cure JM for each search. If every Cure JM family searched the Web just 10 times a day through this tool, Cure JM would receive \$22,000 in a year!
- 49. eBay: Sell unwanted items on eBay and donate the proceeds to Cure JM.
- 50. Facebook/MySpace Pages: Provide a link to Cure JM donation page from your personal page. Also, add Cure JM to your "Causes", as Cure JM is registered with both sites as an official cause. Ask others to join your cause and add Cure JM to their page.
- 51. Twitter: Include Cure JM when you use this site.
- 52. Email Sign-off: Always include a special sign-off on your emails. An example: My child is battling a rare autoimmune disease called Juvenile Dermatomyositis. Please consider making a donation to help find a cure: www.curejm.org
- 53. On-line Auction: Start thinking about what items you could provide for a Cure JM on-line auction in the near future
- 54. Friends and Family Email: Send an email to your friends and family requesting donations to Cure JM in honor of your child.





10 Easy Ways to Fundraise for Cure JM

- Write a letter to family/friends about your child's experience with Juvenile Myositis and how they can help find a cure by donating to Cure JM.
- 2. Set-up a personal fundraising page at http://www.firstgiving.com/ curejm and send the link to family and friends.
- 3. Add a signature line to your emails with a link to your fundraising page or with this: Help us find a cure for my child battling Juvenile Myositis at 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 http://www.firstgiving.com/curejm Send the link to family and friends.

Check with your company to see if they match donations!

- 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 www. IGive.com and register Cure JM as your charity. Up to 26% of your purchase will go to Cure JM! 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: http://www.curejm.com/teamjm/ fundraising_start.html

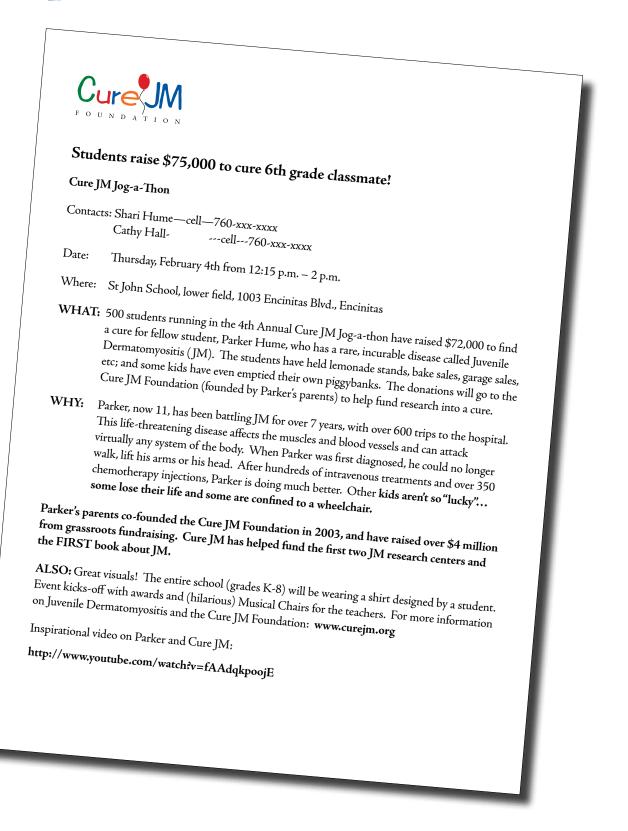
Watch and share the link to our Cure JM Fundraising video http://www.curejm.com/teamjm/video.htm

Sample Donation Letter

The Cure JM Foundation is looking for generous sponsors who can be	
the Cure JM Foundation, a non-profit organization searching for a cure for a rare and life-threatening disease called Juvenile Myositis. Event:to benefit the Cure JM Foundation	
When: date and time	- 1
Where: location	
Why: JM is extremely rare (3 children in a million) and can attack any system of the body. Funding is desperately needed to continue with research and ultimately find a cure for the children suffering from this disease.	I
Your contribution will help us reach our goal and get closer to a cure. May you feel honored to know that you have made a direct difference in the lives of many children. Warmest regarde	
Warmest regards,	
Your Name	
Event Director	
Phone number and email	
Tax ID # 35-2222262	
Contribution:	



Sample Press Release



www.curejm.org

Sample Fundraising Flyer

It's Time for a Cure!

Help us find a cure for Juvenile Dermatomyositis by donating today.

Juvenile Dermatomyositis (JM) is a rare and life-threatening disease that attacks the muscles and skin. There is not a cure YET! With your help, we can get closer to the cure!

All proceeds will be donated to the Cure JM Foundation, a non-profit organization that increases awareness, provides family support and funds research to find a cure for JM.







Cure JM Foundation 836 Lynwood Drive, Encinitas, CA 92024 phone: 760-487-1079 fax: 760-230-2243 email: info@curejm.com

www.curejm.org

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