



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 \$4 million through grassroots fundraisers throughout the country.
- 2) 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) Funding research study with Duke University and CARRA to determine the best treatment approaches for JM.
- 5) Funded (and continue to fund) wide range of genetic and JM treatment studies, as well as fellowships.
- 6) Pending funding includes extension of the two existing research center grants and the establishment of additional Cure JM Centers of Excellence in JM Research.
- 7) Funded the first-ever book about JM, "Myositis and You", written by over 100 doctors.
- 8) Created targeted educational materials (video and welcome kit) for newly diagnosed families.
- 9) Garnered local and national media attention...at least 300 local newspaper articles and 50 television stories.
- 10) 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.
- 11) Provided a comprehensive website, as well as an active message board where families can post questions and connect with other families affected by JM.
- 12) Provided educational forums where leading JM researchers speak to families affected by this disease and facilitated JM educational forums for medical community.
- 13) Provided welcome kits, newsletters, brochures and videos for JM community.
- 14) 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.

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.