



CURE CMD

Congenital Muscular Dystrophy



SUMMER '09 EDITION

Together with you, funding our way to a treatment and cure for the CMDs

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www.curecmd.org



Cure CMD Launches International Registry

Unlike more common forms of muscular dystrophy, congenital muscular dystrophy is extremely rare, often misdiagnosed and there is not a single source of information on affected individuals. As a result, it is difficult for researchers to plan for CMD clinical trials because the accurate numbers and characteristics of the CMD patient population are not entirely known. In an effort to help solve this problem, Cure CMD will launch an international database (CMDIR) on August 14th, 2009. CMDIR stands for Congenital Muscular Dystrophy International Registry. Known as a patient registry, the CMDIR will allow those children and adults with congenital muscular dystrophy and their families to identify themselves, and creates a central database of CMD patients. This registry will collect patients' contact information, medical records and health survey responses. It will register kids and adults with a diagnosis of CMD and LGMD who have a genetic mutation in a CMD gene. Establishing an international registry is a crucial step in achieving clinical trials leading to a treatment and cure.

Fundraising:

In order to find a treatment or cure, Cure CMD must fund research. Cure CMD is looking for volunteers to help organize and host fundraising events and serve on a fundraising board. We have many ideas and templates to work with. We will use funds raised in combination with grants from the MDA, US Government and European Union to focus efforts on research for the congenital muscular dystrophies. We have made good progress, but we must come together as a group of dedicated parents, friends and affected individuals in order to make a treatment or cure possible. In the section below, there are two examples of fun fundraising events that family friends have organized. If you are interested in helping, please contact Rich Cloud at rich.cloud@curecmd.com.

To donate: www.curecmd.org/donate



Family and Friends Raise Funds for Cure CMD

Emily Ludolph, family friend of Kyra (with CMD), organized a mud volleyball and bean bag toss tournament at Swanny's Bar and Grill, in Pipestone, Minnesota on June 27th. Over 200 people participated. "Kyra's Crusaders" raised over \$1800!

The family of Joel and Ginger Brady, friends of Aubrey (with CMD), held a combination birthday party/Cure CMD fundraiser on June 27th. In lieu of bringing birthday gifts for the Bradys' one-year old son, guests were asked to bring a donation to Cure CMD. This celebration of both Will and

Aubrey raised over \$1,000!



Meet CMD: OWEN'S STORY

Owen will be six years old in August. He begins kindergarten in the fall. Owen has had many challenges of late, especially with trying to grasp why he is unable to walk. He has started asking questions and we have done our best to be completely honest with him. Even with this and other issues pertaining to his disease, he is a very happy, loving and social child. We are constantly amazed at his lack of fear with strangers; this works especially well for those who might stare a bit too long or who may ask an inappropriate question. Owen is able to break the ice with these individuals completely on his own with amazing grace and fortitude. Our hope is that he will continue to show this strength well into his future.



Owen has a six month old brother named Aiden who he is very much involved with and whom he adores. Owen loves to help with bathing and feeding his brother, but is having a hard time getting used to baby slobber!

Owen's latest pastime is playing baseball. He has played on a local "challenger" team for two years in a row. Owen enjoys being part of the team and loves racing around the bases. We took Owen to see the Cincinnati Reds vs. Chicago Cubs game at his request and he has not stopped talking about it since the game over a month ago. Owen will begin playing TOPPS (let me check this to see if it is correct) Soccer in the fall.

We are very proud of the person that Owen is proving himself to be, but we do look to the future for a treatment for his disease.

Written by Trish Gustafson, (Owen's mother)



[To read more CMD stories, click here](#)

Cure CMD Scientific Conference Is A Huge Success

Cure CMD's first annual Therapeutic Targets Conference took place at Emory University, in Atlanta, Georgia, from July 9 - 11. Working with Cure CMD, Dr. Carsten Bonnemann, of the Children's Hospital of Philadelphia, received substantial financial grants from both The National Institutes of Health and the MDA to fund this groundbreaking conference. Over 80 participants from around



the world attended, including scientists, clinicians, pharmaceutical companies, and representatives of the US government and European Union. Experts in CMD participated in a 3 day conference that included sharing up to the minute CMD research results and knowledge, spanning all of the CMD subtypes. An especially important element of the conference was discussion of potential future treatments for the CMDs and how to get those treatments to human clinical trials more quickly. Central ideas communicated included gene therapy, muscle regeneration, and stem cell therapy. It was truly inspiring to see the passion and dialogue of this group as they worked together to share information and discuss treatments for those afflicted with CMD. To read more about the conference [click here](#); to understand the research roadmap: [click here](#).

Announcement: Cure CMD announces CMD Translational RFA, www.curecmd.org/scientists with deadline for submission: Sept 15th. Review by Cure CMD SMAB, funding by Jan 1st, 2010.

Important Topic: Special Needs Trust

In order to qualify for public assistance programs, including Medicaid coverage, an individual must meet certain income and asset limitations. If a person's assets or income exceeds these limitations, he or she will be required to spend down his or her resources until they are low enough for the government program to begin payment. Consequently, making a gift to a disabled family member, either during lifetime or under your will, may cause that family member to become ineligible for public assistance. Only after basic living and medical expenses consume the gift will your family member be eligible again for public assistance. In many cases, leaving a gift to a disabled family member, either directly or in a traditional trust, is akin to writing a check to your state's Medicaid program.

However, assets held in certain trusts created for the benefit of a disabled family member, commonly called Supplemental Needs Trusts (or Special Needs Trusts), do not count against a person's income and asset limitations. These trusts supplement benefits from public assistance programs and provide a more comfortable life for your family member without jeopardizing public assistance payments.

Federal regulations recognize Supplemental Needs Trusts, but specific requirements for these trusts vary from state to state. Therefore, if you are interested in learning more about Supplemental Needs Trusts it is important that you consult with a lawyer licensed in your state and experienced in these matters.

The supplemental needs trust was written by Attorney David Westbrook, a Minnesota/Wisconsin estate attorney.

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2009 - 2010 Calendar of Events

What	Event	When	Where	Who
Fundraiser	Hillsborough International Oyster Festival S.A.M. (Struggle Against Muscular Dystrophy)	Sept 3 - 5, '09	Hillsborough, Co. Down, Northern Ireland	Enjoy the World Oyster Eating Championships as well as a fashion show, family fun day, live entertainment and competitions throughout the village during the festival. Fashion show proceeds to benefit SAM. For more information, www.pleasefixsam.org
Fundraiser	Cure CMD 1st Annual Golf Tournament	Sept 13, '09	Forest Lake, MN	Friends, family and supporters
Fundraiser	New Jersey 1/2 Marathon	May 2, '10	New Jersey	Contact Cecilia Kodoma to sign up as a runner/walker for this event, cecdougk@verizon.net . Fee to join as a Cure CMD runner/walker is \$70.
Medical Conference	CMD Affected Person/Family Conference	Aug 15 & 16, '09	Children's Hospital of Philadelphia	Registration to attend in person or by Webex, remotely, www.curecmd.org/conference
Medical Conference	World Muscle Society	Sept 9 - 12, '09	Geneva, Switzerland	Physicians
Medical Conference	Child Neurology Society	Oct 14 - 17 '09	Louisville, KY	Physicians
Medical Conference	National Society for Genetic Counselors	Nov 13 - 16 '09	Atlanta, GA	Cure CMD will have an exhibit booth. If you live locally in Atlanta and interested in volunteering to staff the booth, contact anne.rutkowski@curecmd.com
Medical Conference	TREAT-NMD/NIH Translational Conference	Nov 17 - 19 '09	Brussels, Belgium	Dr. Anne Rutkowski, Cure CMD Vice Chair will represent Cure CMD and participate in a panel on CMD clinical trial readiness
Conference	CMD Standard of Care Workshop	Nov 14 - 16 '09	Brussels, Belgium	45 International CMD physicians with expertise in diagnostics, neurology, pulmonology, cardiology, gastroenterology, palliative care and orthopedics will meet to review and draft CMD Care Guidelines to be published 2010.
Meeting	Muscular Dystrophy Coordinating Committee	Nov 30, '09	Washington DC	MDCC (Muscular Dystrophy Coordinating Committee) Open to the public, this committee meeting provides oversight on NIH, CDC and DOD funding of muscular dystrophy research. Cure CMD and Parent Project Muscular Dystrophy have teamed up to put together a parent panel presenting perspectives on muscular dystrophy, both DMD and CMD. To attend the MDCC, contact jackie.nelson@curecmd.com