

Fall 2008

helping people with muscular dystrophy

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2152 Upper St. Dennis Road St. Paul, MN 55116 www.gregmarzolfjr.org



Save the Date!!! Saturday, January 24, 2009

'Ciao': Cause To Cook for a Cure presents

'Una Bella Serata' Celebrate with Friends

Come join us in our Cause to Cook for a Cure!! We'll party at Town & Country Club in St. Paul. Look for your invite in the mail or check our web site at www.gregmarzolfjr.org

A Sister Remembers an Exceptional Brother

By Jennifer Marzolf

All my life I was told that my brother Greg was someone exceptional. I was told he was braver and had a stronger will than most people -- and he most certainly did.Yet, to me he was my older brother, my best friend, my bully and my confidant. While those who didn't know him saw him as the boy in the wheelchair, I saw him as normal.

I used to call him my human dictionary while I did my homework because he could spell every word for me, no problem, in one attempt. I also had squirt gun fights with him in the backyard, eventually leading to his



Jenny and Greg Marzolf, 1999

electric wheelchair and him falling in the pool. To me, Greg was the older brother who did what he was supposed to do to a little sister: joke, bully, laugh, teach, and encourage. Greg was the older brother who wouldn't let me get teenage magazines in grade school because they were sending me the wrong message. Greg was also the best friend who I hung out with after school and watched the T.V. shows my parents didn't want me to see. He was the older brother who bullied me, the little sister, and pinned me against the *continued on page 2*

Research update from the U of M's M.D. Center

John W. Day, M.D., Ph.D Director, MD Center, Professor Neurology University of Minnesota

The Paul and Sheila Wellstone Muscular Dystrophy Center was created in 1995, and re-chartered as the Muscular Dystrophy Center ("MDCenter") in 2003. The MD Center at the University of Minnesota continues to expand its work and impact. In the past year, we had many successes in our goal to extinguish muscular dystrophy. Working with the Greg Marzolf Jr. Foundation, we are training new muscle investigators who help us define

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the causes of muscular dystrophy, and, at the same time, enhance treatment and patient care that will reduce the burden of this disease.

Here are some major accomplishments in the 2007-2008 academic year:

• We successfully competed for additional University support, generating a new University-wide initiative --NeuroHealth – Conquering Ataxia, ALS, Parkinson's Disease and MD – that provides the MD Center investigators with ongoing support and a 20,000+ square foot new research laboratory.

• We attracted four prominent new muscular dystrophy investigators

to Minnesota, expanding and enhancing several programs to develop new treatments for MD.

• We have also initiated several new clinical research studies that will evaluate cutting edge therapies for Duchenne and myotonic muscular dystrophies.

• Finally, we have greatly enhanced our clinical program at University and Gillette clinics, incorporating both under

our MDA umbrella to generate one of the premier MD-Centers in the country.

All these accomplishments have intersected with the Gregory Marzolf, Jr. Muscular Dystrophy Training Program – moving individual research programs forward by developing

new muscular dystrophy investigators.

In August of 2008, the MD Center received a grant from the Muscular Dystrophy Association, establishing the University of Minnesota MDCenter as one of the five premier national centers of excellence chosen to create the new "MDA Duchenne Muscular Dystrophy Clinical Research Network." This award demonstrates our MD Center's success on a national stage, which is directly

related to development of the Marzolf Training Program.

The ongoing support from the Greg Marzolf Jr. Foundation is critical to the MD Center, so we can achieve our common goal – <u>to conquer MD for the current generation</u> <u>of patients</u>.

Thank you so much for your generosity in helping us achieve this important goal.

Exceptional Brother - Continued from page 1

wall with his wheelchair after I made fun of him. Greg was and still is in my eyes – completely normal.

I firmly believe that this is the way in which Greg would wish to be viewed, as a person beyond his wheelchair. Because of these traits, to all who knew him, he was truly exceptional. In my eyes, Greg was normal because his wheelchair did not define him and often went unnoticed.

Yet at the same time, everyone around Greg quickly realized that because he was so normal yet lived such a difficult and deeply challenging life, he was extraordinary.

My elder brother Greg Marzolf, Jr. was an advocate for justice. He wished to change the world -not because he was the boy in the

"This award demonstrates

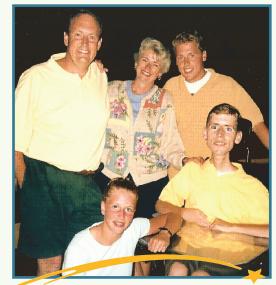
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The Marzolf family, 1999

wheelchair, but because he was an individual who looked beyond his

personal sphere. Greg's desire to educate others on disabilities, prejudice and inequality was driven by the reality that he was not the only one facing such issues.

Today, eight years after Greg left us, his mission and cause carries on. The GMJ Foundation continues to work in Greg's name and for his cause not simply because he was the boy in the wheelchair but because, as many know, he was a truly an exceptional person.

Greg Marzolf Jr. Foundation Newsletter

Fall 2008

2nd Annual Marzolf Graduate Student Symposium held at U of M

The 2nd Annual Marzolf Graduate Student Research Symposium on Muscular Dystrophy was held on Sept. 12, 2008 and was a resounding success. The goals of this symposium were to showcase and foster the efforts of young scientists who are working on Muscular Dystrophy and to recruit talented young investigators to continue their careers at the University of Minnesota. The scientists are:

> Kristen Kallestad - MD/PHD in Neuroscience Kurt Prins, MD/PHD Lisa Borgia, PHD in Muscle Disease Evelyn Houang, Biology Undergraduate Mayank Verma, Biology Undergraduate Allison Kosir, Biology Undergraduate

The symposium highlighted the research of six talented young investigators from the U of M who have received generous support for their muscular dystrophy research from the Greg Marzolf Jr. Foundation. These U of M Graduate and Undergraduate Student Awardees gave brief talks or posters describing their projects. Additionally, three Graduate Students from top muscular dystrophy labs across the country were invited to present their work. Awards were given for the best poster presentations.

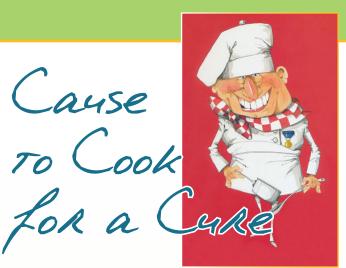
2008 Dark Socks Classic Wrap!

This year's Dark Socks Classic Golf Tournament on June 16 was again a hugh success! Tickets were sold out for the Pontiac Convertible Raffle bringing in \$50,000. In tandem with the golf tournament, the KSTP AM 1500 Online Auction was in full swing, adding a new twist for the Dark Socks Event. Congressman Jim Ramstad donated a tour of the White House West Wing, which the winning bidder received for \$5,000!

As Joe Soucheray stated at the beginning of the Online Auction, "My pal, Gregory, would be pleased that I have moved into the world of technology with this Online Auction."

The Greg Marzolf Jr. Foundation thanks the many sponsors that made this event possible, most notably: **R.F. Moeller** Jeweler, KSTP AMI 500, with Warner Stellian, Waste Management, Citgo, Rollix Vans, White Bear Super Store, and Legends. The total raised was \$132,400.

Another beautiful day was had on Oct. 11 when 400 people walked and wheeled in the MD Stride and Ride. Over \$60,000 was raised!



We are grateful to the many people who have hosted and attended our Cause to Cook home parties in the past three years. And we're ready for more partying! Think about a gathering of any type and make it into a Cause to Cook fundraiser! You can tailgate, potluck, graze and sample a variety of libations.

Contact Mary Michel (chipdecko@aol. com) or visit our web site to learn more about these great parties!

Thanks to our past party hosts and their guests! We have attracted prominent new muscular dystrophy researchers to Minnesota, expanding and enhancing several programs to develop new treatments for MD through our Cause to Cook for a Cure party support!

<u>Hosts</u>	<u>Month</u>
Jack and Nancy Grace	January 2008
Bob and Mary Glineburg	January 2008
Don and Nancy Berdan	November 2007
KC and Elizabeth Kauth	November 2007
Chris and Laura Feile	December 2007
Ben Leer	December 2007
Deb and Ken Smith	December 2007
Jeff and Melanie Goldestsky	October 2006
Kathleen Moriarty	October 2006
Don and Nancy Berdan	October 2006
KC and Elizabeth Kauth	October 2006
Shannon LeClair & Kathy Mullarky	October 2006
Mark and Mary Pincumbe	October 2006
Paula Kelly and Charley Walters	October 2006
Gary and Mamie Fabel	October 2006
Deb and Ken Smith	December 2006

Join us on Jan. 24, 2009 for the Ciao Event! Greg Margolf J FOUNDATION helping people with muscular dystrophy 2152 Upper St. Dennis Road St. Paul, MN 55116 www.gregmarzolfjr.org

Visit us on the Web!

Find updates on Foundation events, research, and opportunities to donate and volunteer! It's all at:

www.gregmarzolfjr.org

Let us hear from you!

Send us your email and we can keep In touch quickly and easily. You can contact us directly at 651-699-3961 or via our web site.



About the Greg Marzolf Jr. Foundation

Founded in 2002 to commemorate the life of Greg Marzolf Jr., our mission is to raise awareness of muscular dystrophy through philanthropic activities and support research for a cure. Foundation activities include:

• The Dark Socks Classic

• Gregory Marzolf Jr. Muscular Dystrophy Training Awards for research assistants at the Institute of Human Genetics at the University of Minnesota

- Cause to Cook for a Cure fundraising parties
- The Stride and Ride event

Contributions to the Greg Marzolf Jr. Foundation are given to the Greater Twin Cities Muscular Dystrophy Association to support research to find a cure for neurological diseases and to the Greg Marzolf Jr. Trainee Program at the Paul and Sheila Wellstone Muscular Dystrophy Center at the University of Minnesota.

For a detailed history of the Foundation please visit www.gregmarzolfjr.org.

Every dollar you provide to the Foundation...

...goes toward eliminating muscular dystrophy. The money raised is central to supporting our mission, which aims to fight MD through research, education, advocacy and service. Together, we share a hope for a tomorrow free of MD.