

# Greg Marzolf Jr. Foundation Community Celebration

Friday, November 15, 2024 5:00PM-7:00PM

The Town & Country Club

See Page 15 for details!

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### Major Progress on Funding a Cure

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# The Power of Partnership

October 2024

GregMarzolfJr.org



# A Letter from Patty Marzolf

Dear Friends:

It is with immense pride and awe that I share that all funds we raise going forward will go directly to the **Greg Marzolf Jr. Muscular Dystrophy Center** at the University of Minnesota.

This name honors my bright son who showed both courage and humor when living with Duchenne Muscular Dystrophy. This name honors a life well lived and cements his legacy. This name also honors all of you. This community accomplished this honor through your tireless and steadfast support. Your contributions directly fund new treatments and clinical studies that give life and hope. I thank you for honoring Greg Jr. and I thank you for believing in our cause.

The re-naming of the MD Center solidifies our partnership with the University of Minnesota and re-ignites our passion to fund a cure for MD. When Gregory was diagnosed, we were told there were no options, no solutions, no hope. But things have changed and this year we've seen tremendous progress:

• In January, the Minnesota Department of Health added Duchenne to the newborn screening panel. Minnesota is just the 3rd state to receive approval. Every child born in Minnesota will now be screened for Duchenne Muscular Dystrophy. This will ensure that those diagnosed with MD will receive critical care and given possible solutions as soon as medically possible.

• In July, Myogenica, a University of Minnesota startup company, announced U.S. Food and Drug Administration approval for an Investigational New Drug (IND) application for MyoPAXon — an induced pluripotent stem cell-derived muscle stem cell product to regenerate skeletal muscle. A pending clinical trial would evaluate the safety, tolerability and engraftment of MyoPAXon in patients with Duchenne Muscular Dystrophy (DMD). If the proposed trial is successful, it has the potential to treat a range of muscular dystrophies, as well as other muscle degenerative conditions.

With progress like this, we have entered a whole new era filled with hope.

When Gregory passed away 24 years ago, he was 20 years old. We crammed as much as we could into our time with Gregory. Traveling across the US and getting involved in church, schools and sports. And yet, on April 13th 2000, we had to say goodbye. Our smart, funny, sarcastic, and strong son's journey with us on earth, ended. He wasn't able to finish college, to move out of our house, or pursue a career. Now, young men with his disease are living into their 30s and 40s. They are able to graduate college, pursue meaningful careers and live independently.

As a mother, there is nothing more meaningful than being able to give families living with MD more time, more experiences, more opportunities and more hope. The pursuit of more, is why we, our family, the Foundation, and our community so relentlessly pursues our mission.

The spirit of Gregory, a young man that was taken from us with Muscular Dystrophy, will now grace the title of the Muscular Dystrophy Center. It will be a reminder that every life is precious and time is of the essence to cure this disease. We need to work harder, support critical research, deliver on our pledge to fund a cure and eradicate Muscular Dystrophy.

As I reflect on this last year, the naming of the Center in Gregory Jr.'s honor and the progress we continue to see, I want to leave you with a poem Gregory wrote:

#### Who Will Remember Me...

If I should die tonight Who will remember me? Will I be forgotten or revered? Will people remember me with thoughts of love or hate? Will my accomplishments make a difference? Will my ideas matter? Will I be remembered as another poor victim that succumbed to a deadly disease or as a person that overcame his disability to achieve his goals? Who will remember me If I should die tonight?

With gratitude,

Patty



# The Lasting Legacy of Greg Marzolf Jr.



Greg Jr. and Greg Sr. at the annual Michel Fishing Trip

This year, the University of Minnesota Muscular Dystrophy Center was named the Greg Marzolf Jr. Muscular Dystrophy Center. The renaming of the Center honors Greg Marzolf Jr. who showed both courage and humor when living with Duchenne Muscular Dystrophy and cements his legacy.

Throughout his 20 years, Greg was an energetic, positive presence in his schools and community. Diagnosed with Duchenne Muscular Dystrophy as a small child, Greg committed himself to improving the lives of people who dealt with adversity and disability on a daily basis.

In 2000, Greg died from the effects of his disease. Greg lived a full life and enriched the lives of others with his spirit and hope. We celebrate his life through the work of the Foundation and, now, through the work of a renowned research center in his name. Remarkable.

"Gregory was the kind of person who had an ability to draw others in and to share his positive outlook."

– Chip Michel

"Although we didn't have the opportunity to meet Greg Jr., the friends and family that were blessed to be in his life keep his spirit alive through their shared stories. His friendships were many and their love ran deep. In 2023, I had the pleasure of meeting Greg's Jr.'s former high school classmate, Robby and his son, as they delivered meals for the GMJF fundraiser. It was touching to see a close friend that cares so deeply about the cause and the family, even 23 years after Greg Jr.'s passing. The love people have for him is truly remarkable!"

– Catina Koenig

"Gregory could give and take a good ribbing! He was very smart and had such a bright future."

- James Moeller

"They couldn't have picked a better name. Greg is the perfect banner man for the University of Minnesota Muscular Dystrophy Center. His moral fiber was above reproach, and his actions embodied the characteristics needed to solve the toughest problems." – Brian Whinnery

With a stronger partnership than ever, the Greg Marzolf Jr. Foundation and now, the Greg Marzolf Jr. Muscular Dystrophy Center at the University of Minnesota, will continue to strive for a cure to Muscular Dystrophy and ensure Greg's legacy lives on.



James Moeller, Greg, and Friends on the Annual Family Trip to Craguns



Greg with high school friends Brian Whinnery and Mike Runyon

### Funding a Cure

This spring, the Greg Marzolf Jr. Foundation gave a gift of \$155,000 to the Greg Marzolf Jr. Muscular Dystrophy Center. This gift supports scholarships for the Annual Greg Marzolf Jr. Undergraduate Research Program and the Kathleen Moriarty Travel Award (which sponsors post-doctoral travel to a conference for continued learning and advancement). This gift also includes support for 5 Scientific Research Projects at the University of Minnesota.

In 2024 The Greg Marzolf Jr. Foundation is honored to support the following innovative projects:

#### Dr. Ashley Martin

Project: "Interrogating DMD-driven cardiomyopathy with the use of FRET-based sarcomere activation biosensor" 2024 Gift Amount: \$20,000

#### Dr. Christina Pacak

Project: "Validation of the D2-mdx Mouse Model as a Platform for Screening Senotherapeutics" 2024 Gift Amount: \$30,000

#### Dr. DeWayne Townsend

Project: "Shedding light on the role of mitrochondria in the progression of cardiomyopathy in Duchenne Muscular Dystrophy." 2024 Gift Amount: \$50,000

#### Dr. Addeli Bez Batti

Angulaski Spies Project: "In vivo stability of therapeutic micro-dystrophin constructs". 2024 Gift Amount: \$30,000

#### Dr. Peter Karachunski

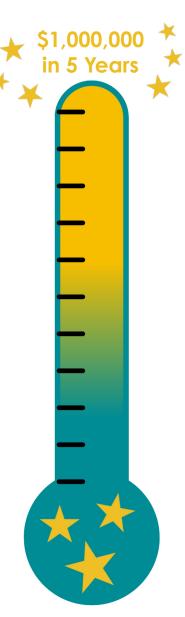
Project: "Clinical research project: long-term outcomes in adult patients with SMA and imaging in DMD" 2024 Gift Amount: \$25,000

### \$1,000,000 in 5 Years

While we celebrate this immense honor of the naming of the Greg Marzolf Jr. Muscular Dystrophy Center at the University of Minnesota, the work of the Greg Marzolf Jr. Foundation is not done. The Greg Marzolf Jr. Foundation stands strong and ready as ever to deliver on the mission of a tomorrow free of MD.

Our goal is to raise **one million dollars in the next five years**, we ask you to join us in this effort and for you to continue your partnership with the Greg Marzolf Jr. Foundation. These next five years will be critical in progress toward a cure, and it is imperative that we do not slowdown, but instead increase funding and support to Muscular Dystrophy research.

Our goal of One Million dollars in five years may seem like a lot of money in a short amount of time but to the families living with Muscular Dystrophy, five years feels like a LIFETIME. The reason we have this aggressive goal is because we have reached the tipping point. The breakthroughs and FDA approvals are at an all-time high. The energy and science is there – but it is funding from non-profit organizations like the Greg Marzolf Jr. Foundation that make the difference in getting to the next big breakthrough. Progress and results do not happen without funding, and the time is now for us to not only continue, but increase our efforts to fund a cure to Muscular Dystrophy.



# April 2024 Gala

What a night at the GMJF Lasting Legacy Gala!

On Saturday, April 13th, 2024, the Greg Marzolf Jr. Foundation hosted its first ever Lasting Legacy Gala at the University of Minnesota McNamara Alumni Center. On the anniversary of Greg's death, friends of the GMJ Foundation gathered to honor Greg's remarkable legacy and celebrate the naming of the Greg Marzolf Jr. Muscular Dystrophy Center at the University of Minnesota.

Thanks to the generosity of our sponsors and donors, we raised over \$200,000 for Muscular Dystrophy research at the University of Minnesota! Guests of the Lasting Legacy Gala enjoyed the silent auction of experiences, the raffle, a delicious D'amico & Sons dinner, and a rousing game of Heads & Tails. The program included the announcement of a \$155,000 gift to 5 scientific and clinical projects for Muscular Dystrophy at the U of MN. As well as the announcement of the goal to raise \$1 Million in the next 5 years for Muscular Dystrophy research here in Minnesota.

Greg Marzolf Jr. Muscular Dystrophy Center Director, Dr. Peter Kang, shared more about the Center and new important breakthroughs.



Patty Marzolf, Greg Marzolf Jr. Foundation President, explained how much has changed since Greg's passing in 2000, and why the mission continues. Patty was also honored with the one and only, Lasting Legacy Award. The award honors her many years of advocacy for Muscular Dystrophy, which led to the incredible honor of the naming of the Greg Marzolf Jr. Muscular Dystrophy Center.

#### Thank you to our generous sponsors who made the Lasting Legacy Gala possible!

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If you didn't attend and would like to make a donation, we appreciate your support! Your donations to the Greg Marzolf Jr. Foundation directly impact the research of the scientists and clinicians at the Greg Marzolf Jr. Muscular Dystrophy Center.



Visit GregMarzolfJr.org or scan the QR code to donate today.

### Major progress in funding a cure for Duchenne Muscular Dystrophy

Progress continues in our mission to fund a cure for Muscular Dystrophy. This July researchers at the University of Minnesota took a pivotal step towards finding a cure for Duchenne Muscular Dystrophy.

Myogenica, a University of Minnesota startup company, announced U.S. Food and Drug Administration approval for an Investigational New Drug (IND) application for MyoPAXon — an induced pluripotent stem cell-derived muscle stem cell product to regenerate skeletal muscle. A pending clinical trial would evaluate the safety, tolerability and engraftment of MyoPAXon in patients with Duchenne Muscular Dystrophy (DMD).

Dr. Peter Kang, a pediatric neuromuscular neurologist and director of The Greg Marzolf Jr. Muscular Dystrophy Center at the University of Minnesota Medical School, would lead the proposed early-stage clinical trial.

"We believe stem cells have enormous potential as a tool for muscle regeneration in Muscular Dystrophy and the timing is perfect to move toward a human clinical trial of this type of therapy in Duchenne Muscular Dystrophy," said Kang.

If the proposed trial is successful, it has the potential to treat a range of muscular dystrophies, as well as other muscle degenerative conditions.

Patty Marzolf, President of The Greg Marzolf Jr. Foundation cheered this news, "This is a tremendous and very significant step in the GMJF's quest for a cure for all living with MD. My heart is filled with gratitude, joy and new found hope for what is ahead."

This development has been made possible by your steadfast support. Dr. Rita Perlingeiro previously expressed the impact of your commitment, "No words can really describe the impact of the Greg Marzolf Jr. Foundation funding to me and to our research over the years. The Greg Marzolf Jr. Foundation was the FIRST to fund this translational project. With seed funds from 2016-2018, we were able to produce enough data to be competitive for larger grants, including awards from the Department of Defense and Duchenne UK. In 2021, we could count again on the Greg Marzolf Jr. Foundation, when our funding was not sufficient to cover all the costs associated with the preclinical work required prior to IND-submission to the FDA."- Dr. Rita Perlingeiro

Thank you again for your continued support in the Greg Marzolf Jr. Foundation, we are grateful for this community and the remarkable work of these researchers.

"We believe stem cells have enormous potential as a tool for muscle regeneration in Muscular Dystrophy and the timing is perfect to move toward a human clinical trial of this type of therapy in Duchenne Muscular Dystrophy." -Dr. Peter Kang

Dr. Perlingeiro and Dr. Kang

# A New Name and a New Beginning

A name is, at its most elemental, a word or string of words that identifies a person, place, or thing. In a deeper sense, a name is a key that unlocks a history and a future. The name that we adopted in January 2024, the Greg Marzolf Jr. Muscular Dystrophy Center, is both a new name and one that is familiar to many of us. Greg Marzolf Jr. was a young man with Duchenne Muscular Dystrophy (DMD) who received his care at the University of Minnesota and was a bright and ambitious college student when he died in 2000.

In the year 2000, there were no approved therapies for DMD, nor was there any substantial activity in human clinical trials. I was still in my child neurology residency in 2000, and remember that virtually all the research on therapies for DMD was on cells and in animal models at that time. In large part due to inspiration from patients such as Greg, many researchers and clinicians here at the University of Minnesota and around the world worked towards the goal of developing new treatments for patients. Fast forward to 2024 and where are we now? There are now 8 therapies approved by the FDA for DMD. It is a new world. And yet, patients with DMD still face uncertain outcomes and there is no definitive cure for DMD. For other muscular dystrophies, there are no FDA-approved therapies at all.

Thanks in large part to successful, sustained fundraising from the Greg Marzolf Jr. Foundation for many years, the University of Minnesota is a pioneer in Muscular Dystrophy research. We have particular strengths in stem cell biology, and as a result, a stem cell-based therapy for DMD that was developed here is now cleared for a human clinical trial by the FDA. Cell therapy is particularly alluring with the promise of true muscle regeneration, and the promise of treating a broad range of muscle diseases in addition to DMD. And now Minnesota is again a pioneer, being one of the first states to adopt universal newborn screening for DMD. The support of the Greg Marzolf Jr. Foundation has enabled us to draw in and support talent from around the world, enabling our faculty, trainees, and students to compete successfully for large grants from the National Institutes of Health (NIH), Muscular Dystrophy Association (MDA), and many other funding agencies.

How does our new name help us find the way to a new future? Our Muscular Dystrophy Center has a long history of innovation dating back to its founding in the 1990s. For many years it proudly carried the names of Paul and Sheila Wellstone, who promoted the importance of Muscular Dystrophy research on a national level. And now, our Muscular Dystrophy Center carries a patient's name, his history, and his hopes – daily reminders of why we do what we do. We work towards the goal that patients like Greg have wanted so much – a cure for Muscular Dystrophy. We appreciate all that you do to bolster our efforts through the Foundation and the Muscular Dystrophy Center, both aptly named after Greg Marzolf Jr.

Peter B. Kang, MD Director, Greg Marzolf Jr. Muscular Dystrophy Center University of Minnesota Medical School

# Greg Marzolf Jr. Muscular Dystrophy Center

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# With Gratitude

The Greg Marzolf Junior Foundation is aware that there are so many important causes to support and that many people have needs today. Which is why we are incredibly grateful for the generous sponsorship of two longtime and beloved families, who have been incredible supporters of this organization.

It is with heartfelt gratitude that we honor the Michel and Moeller families for their consistent partnership in the mission of the Greg Marzolf Jr. Foundation. The steadfast dedication of these sponsors have propelled the GMJF into a new era of giving, and a new hope for those families living with Muscular Dystrophy. We are beyond thankful for their support.

### Donor Spotlight 🛧 The Moeller Family

The Moeller and Marzolf Families have a long history together. Mark Moeller went to high school with Patty Marzolf, Mark played on the same softball team as Greg Sr., and both families attended the same church. Jamey Moeller went to grade school with Gregory. This history and friendship got the Moellers involved with the GMJ Foundation.

Jamey remembers Gregory's sense of humor and his quick wit. Gregory could give and take a good ribbing! He was very smart and had such a bright future. Had he lived long enough to benefit from the advancements that have happened in the past 25 years, he would have been able to finish college, have a career, and live a full life. The Moellers want anyone affected by MD to be able to achieve this dream.



Summer Fun with the Moellers, Marzolfs, and Steadfast "Camp Friends" in 1997



Mark, Carol, and James Moeller

Having the University of Minnesota Muscular Dystrophy Center named after Greg Jr, is beyond Moeller's wildest dreams. When the GMJ Foundation was started it was small, but over the years it grew and culminated in something beyond their expectations. The Moellers hope both Gregs are looking down and smiling about having one of the premier MD research and treatment institutions named after Gregory Marzolf Jr. They are proud of the small part they have played in making this a reality.

The Moellers have been inspired to do more, give more, and work harder because of their involvement with the foundation and the staff at the Greg Marzolf Jr. MD Center. The last part of this journey, finding a cure, is the hardest part. Help is needed to push this across the finish line! Research works and is proven to have improved the quality of life for patients and their families.

The Moellers challenge others to get involved by learning, talking to MD families, and by listening to researchers and administrators at the MD center and discovering their hopes, needs and frustrations. The more money the researchers and scientists have, the faster we will have a cure. The Greg Marzolf Jr. MD Center is a world class institution right here in Minnesota. Funding is needed to support and entice the best doctors and researchers. We need to get the word out and keep the forward momentum going for all those affected by Muscular Dystrophy.

### Donor Spotlight ★ Chip & Mary Michel

Chip and Mary Michel's friendship with Patty and Greg was cemented long before Gregory was diagnosed with MD. It was natural for the Michels to get involved and support the challenges being faced by their good friends.

Chip and Mary remember Gregory as a wonderful young man that brought a positive attitude to everything he was involved with. It had a big impact on them to see his life cut short by Muscular Dystrophy. Society lost out on Gregory's gifts and contributions and those of others whose lives have been cut short by this disease. Change is needed and the Michel's will continue to be a part of it for as long as they are able.

"The University of Minnesota Muscular Dystrophy Center is in our hometown. It is a top-notch institution with a great track record in MD research. It feels good to have donations go to a local institution. This is why it is important to get others involved and to spread the message." – Chip Michel

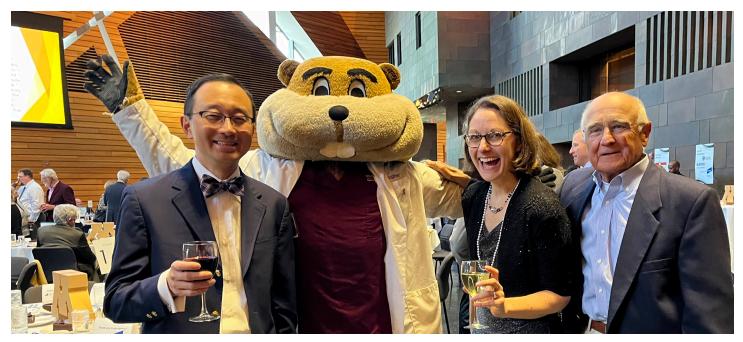
Chip and Mary know there will be no cure without research, and that research costs a lot of money. Over the years, they have given as much as they could afford in support of the GMJ Foundation.



Mary Michel volunteering and hosting lunch for MD Families at the MD Center Family Camp in 2019

The past few years they have been very blessed, which enabled them to be able to increase the amount of their support for a cause that has been so important to them over the years.

The Michels have not just been generous with their financial support, but have put years of "sweat equity" into events – garage sales, golf tournaments, raffles, galas, walks, and beyond. Volunteering time and service on the GMJF Board has been a major part of their lives over the years. Chip and Mary encourage anyone and everyone to get involved in whatever capacity they can. It may be through time, talent, and/or treasure. Every gift, in whatever way given, is valued and necessary to find a cure for Muscular Dystrophy.



Chip Michel with MD Center Director Dr. Peter Kang, and GMJF Awardee Dr. Christy Pacak at the 2024 Lasting Legacy Gala

# **Thank You for Your Steadfast Support**





People don't go to The Baird Koenig Jones group for the basics; they go to them with their concerns and complexities, passions and ambitions, big dreams and bigger decisions. They are a tight team of financial service professionals, who know there's more to life than finance and more to work than money alone. They see the big picture—but not at the expense of the smallest details.

"Passion for any cause starts by feeling connected. As donors and supporters, the most meaningful way to get involved is by attending the amazing events and inviting others to join you. The GMJF is more than just a charitable organization, it's a community of incredible people, and that connection is a gift that keeps on giving!" - Catina Koenia, Managing Director, Baird Koenia Jones Group



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Since its inception, Hays Financial Group has been dedicated to helping organizations and their employees achieve financial wellness. Through personalized fiduciary advisory services and customized plan design, HFG will empower you to make well-informed financial decisions and offer comprehensive retirement benefits to your team.

"Greg and I were classmates together all four years at Cretin-Derham Hall. We met day 1 of freshman year, ate lunch together every day for 4-years and were really good friends. Right now for my wife and I 'time' feels like the scarcest resource but for all of us; time, talent and treasure will vary in abundance throughout our lives. The important thing is to do something... The Greg Marzolf Jr. Muscular Dystrophy Center at the University of Minnesota is on the cusp of greatness and we can all be a part of that through our support of the GMJ Foundation. It's not everyday we can all be a part of something that special but we can today."

- Brain Whinery, President, CPFA, HFG



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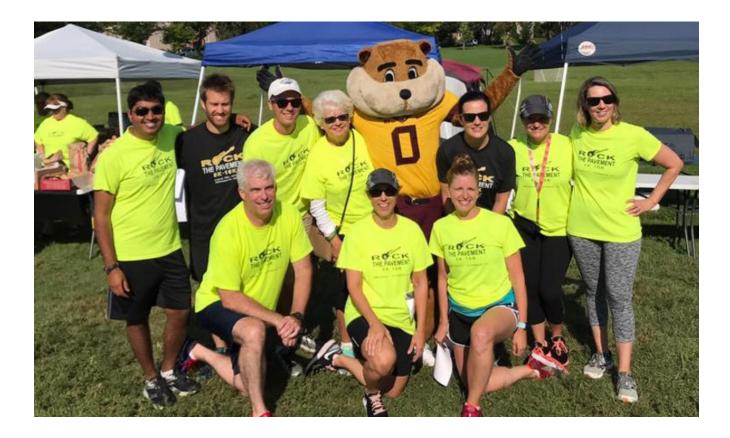
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# **Thank You Board Members & Volunteers**

The naming of the Greg Marzolf Jr. Muscular Dystrophy Center was made possible by the years of service, friendship, donations, and love from the incredible community of the Greg Marzolf Jr. Foundation. Because of the work of **countless volunteers** at various events, the GMJF has continued to ignite and inspire a reason to give. Because of the dedication and intense work of **board members** over the last 23 years, the GMJF has grown from a donation of \$10,000 a year, to \$150,000 a year. Because of you, the **community of donors** and friends who show up ready to give, the naming of the Greg Marzolf Jr. Muscular Dystrophy Center became a reality.





# **Reigniting our Passion to Fund a Cure**

### $\star$ Save These Dates $\star$

### Greg Marzolf Jr. Foundation Community Celebration

Friday, November 15, 2024 ★ 5:00PM-7:00PM

The Town & Country Club ★ 300 N Mississippi River Blvd, St Paul, MN 55104

Join us for appetizers, conversation, and community. At 6:00PM, Greg Marzolf Jr. Foundation President, Patty Marzolf, will provide a brief thank you and update on the GMJF. There has been incredible progress in the research and pursuit of a cure for Muscular Dystrophy. We look forward to this opportunity to share these important milestones with you, as well as an update on where the GMJF is headed in the years to come. There will be a cash bar.

#### Let us know you are coming! Email foundation@gregmarzolfjr.org



### Greg Marzolf Jr. Foundation's

Lasting Legacy Gala

Friday, May 9, 2025

The McNamara Alumni Center at the U of M ★ 200 SE Oak St, Minneapolis, MN 55455

Join us for our annual celebration to recognize the progress this community has made to fund a cure for Muscular Dystrophy. The evening will include a raffle, silent auction, plated dinner, update from The Foundation and a special appeal. We look forward to this time to gather and raise critical funding for MD research at the Greg Marzolf Jr. MD Center at the University of Minnesota.

Formal invitation to follow.

# Not receiving our emails?

Send an email to foundation@gregmarzolfjr.org to be added to our email list.

## Greg Marzolf Jr. Foundation Board 2024

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## Greg Marzolf Jr. Foundation Community Celebration

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The Town & Country Club

See Page 15 for details!

Margolf Jr.

Funding a tomorrow free of Muscular Dystrophy

GMJF

# GregMarzolfJr.org

**Greg Marzolf Jr. Foundation** P.O. Box 16190 St. Paul, MN 55116