UNITEDMSD FOUNDATION
MULTIPLE SULFATASE DEFICIENCY

BEYOND HOPE

INVESTING IN A FUTURE FOR CHILDREN WITH MULTIPLE SULFATASE DEFICIENCY

A CAMPAIGN TO SUPPORT GENE THERAPY CLINICAL TRIALS

Imagine a world where a devastating diagnosis no longer means a death sentence for a child.

At the United MSD Foundation, this vision fuels our every action. We stand alongside families facing the brutal reality of Multiple Sulfatase Deficiency (MSD), a rare and fatal genetic disorder that steals the light from vibrant young lives.

Currently, when families receive this heart-wrenching news, they are met with silence – a void where treatment options should be, leaving them with the sole, agonizing task of providing comfort until their child is lost.

THE CRUSHING REALITY OF MSD

MSD is a cruel thief, progressively robbing children of their abilities: their mobility fades, their vision dims, their cognitive function declines, and ultimately, their lives are tragically cut short. Families are left adrift in a sea of helplessness and isolation, grappling with immense medical, emotional, and financial burdens, often with limited access to specialized knowledge or a supportive community.

The rarity of MSD means research funding is scarce, leaving potential breakthroughs languishing in laboratories, just out of reach for the children who desperately need them.

WHY NOW IS THE TIME

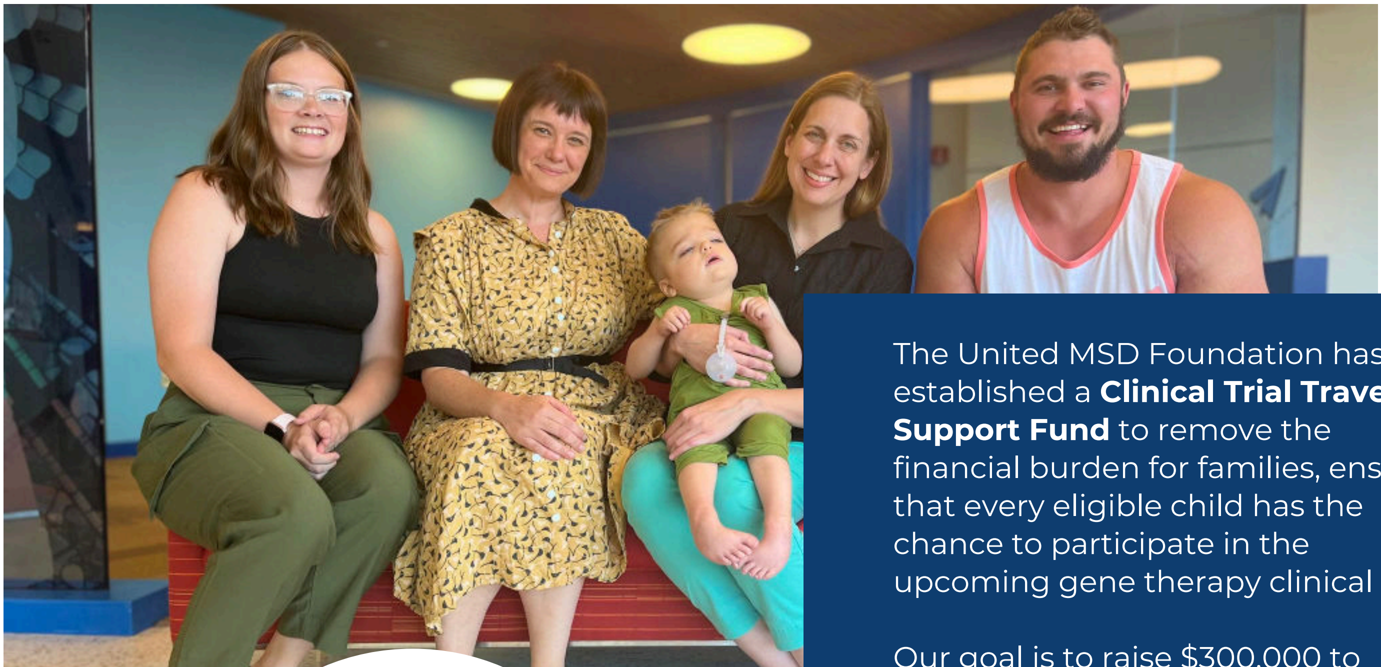
While MSD is rare, the urgency of finding a treatment resonates deeply within the broader community. The profound suffering endured by these children and their families calls upon our shared humanity to offer support and alleviate their burden. The United MSD Foundation stands as a beacon of hope, uniquely addressing the critical gaps in research, support, and awareness that no other organization currently fills.

THE URGENT NEED: REMOVING BARRIERS TO HOPE

We stand on the cusp of a potential breakthrough.

Gene therapy offers a promising avenue for treating MSD, and clinical trials are the crucial next step. However, a significant barrier stands in the way: **travel costs**. Families often live far from trial sites, and the expenses associated with travel, accommodation, and time away from work can be insurmountable, preventing eligible children from accessing this potentially life-saving opportunity.

Our Urgent Request:
Invest in Access, Invest in Hope



The United MSD Foundation has established a **Clinical Trial Travel Support Fund** to remove the financial burden for families, ensuring that every eligible child has the chance to participate in the upcoming gene therapy clinical trials.

Our goal is to raise $300,000 to support 10 clinical trial participants.

Imagine the impact of your sustained generosity...

a child who would have been excluded due to financial constraints receiving a potentially life-altering treatment. A family spared the added burden of financial worry during an already unimaginable crisis. A future where MSD no longer dictates a tragic outcome.

Your philanthropic investment will provide a stable foundation, allowing us to:

- **Predictably support families** as clinical trial timelines unfold.
- **Maximize the impact of the research** by ensuring full participation.
- **Demonstrate the unwavering commitment** of our community to finding a cure.

Join Us: A Call to Action for a Brighter Future

We invite you to become a vital part of this pivotal moment in MSD research. Your multi-year investment in our **Clinical Trial Travel Support Fund** will send a powerful message of hope and provide tangible assistance to families desperately seeking a future for their children.

LEADERSHIP CIRCLE

Commitment:
A minimum total pledge
of $30,000 or more,
payable over three years

PARTNERS IN ACTION

Commitment:
A minimum total pledge
of $15,000 to $29,999,
payable over three years

SUSTAINING SUPPORTERS

Commitment:
A minimum total pledge
of $3,000 to $14,999,
payable over three years

> Your gift to our clinical trial travel fund is more than just a donation; **it's a lifeline**. It's the removal of a barrier, ensuring that financial hardship doesn't silence the hope of a patient seeking a life-altering treatment. It's about the unwavering belief that every eligible child, regardless of their economic circumstances, deserves a chance to participate in research that could redefine their future and the future of all those affected by MSD.
>
> \- Sarah Cortell Vandersypen
> *Executive Director*

Your Partner in Hope

Children diagnosed with MSD face a devastating reality—no cure, no treatment, and a rapidly declining quality of life.

The United MSD Foundation is driving critical research toward a cure and providing essential support to families, including a dedicated Clinical Trial Travel Support Fund to ensure equitable access to a potentially life-saving therapy.

With your sustained investment in our Clinical Trial Travel Support Fund, we can remove barriers to participation, accelerate research, and turn MSD from a fatal disorder into a treatable condition, giving children and families a future filled with hope and the possibility of a longer, healthier life.

Thank you for considering a meaningful multi-year gift to the United MSD Foundation's Clinical Trial Travel Support Fund.

Together, we can turn hope into action and build a brighter future for children with Multiple Sulfatase Deficiency.

SARAH CORTELL VANDERSYPEN, CFRE

Executive Director
United MSD Foundation

LET’S TALK

EMAIL :
svandersypen@curemsd.org

PHONE :
m. 440-832-1261

WEBSITE :
www.CureMSD.org

ADDRESS :
P.O. Box 806, Biloxi, MS 39533

UNITED MSD FOUNDATION

MULTIPLE SULFATASE DEFICIENCY

Beyond Hope: A Campaign to Support Gene Therapy Clinical Trials

Campaign Giving Levels	
Leadership Circle	$30,000 or more
Partners in Action	$15,000 to $29,999
Sustaining Supporters	$3,000 to $14,999

Name *(please print)* ________________________________ **Date** ________________

Signature *(required)* ____

Yes! I/we will support the United MSD Foundation with a gift/pledge of $______________

I/we intend to make this as a multi-year gift payable over: ○ 2 years ○ 3 years

This gift is made ○ In memory of ○ In honor of ______________________________

Payment Options

○ **Check** - Enclosed is my check made payable to the United MSD Foundation
Please return to the United MSD Foundation, P.O. Box 806, Biloxi, MS 39533

○ **Pledge** - Please begin billing me/us for the pledge on (dd/mm/yy)______________
Payment(s) to be made ○ Once ○ Monthly ○ Quarterly ○ Annually

○ **Stock** - I/we will make a gift of stock. (*Please contact me/us to arrange a gift of stock)*

○ **DAF** - I/we will make a gift online through a Donor Advised Fund.

○ **Matching Gift** - My/My spouse's employer has a matching gift program

Donor Name(s)

Donor Name ____
Address____
City, State, Zip ____
Phone ____
Email ____

Donor Recognition

○ In the annual report and other donor recognition materials, my/our name(s) should appear as follows: ________________________________

○ Please do not publish my/our name(s) in printed or digital materials.

Your gift is fully tax-deductible as provided by law.

Questions?
Please call the Executive Director
at (440) 832-1261.