

MSUD FAMILY SUPPORT GROUP (NUTRICIA

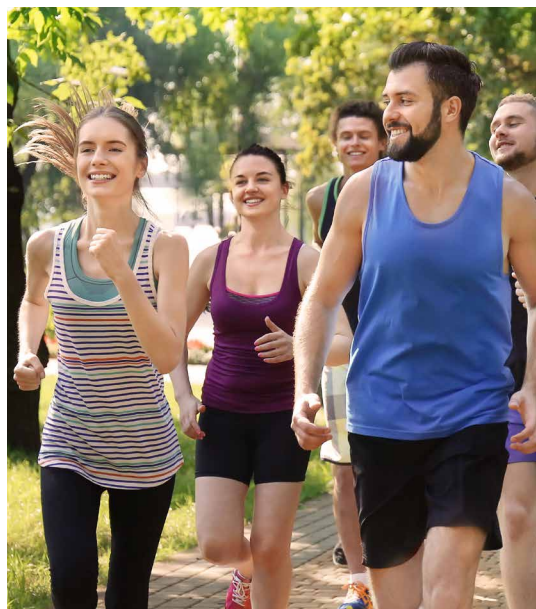
MOVES

WALK • JOG • RUN



Nationally Sponsored by Nutricia North America

Presented by the MSUD Family Support Group



FUNDRAISING TOOLKIT

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WELCOME TO THE TEAM

We're so happy you've joined the team! If you're reading this, you're now part of an incredible group of families, friends, and supporters who are working together to raise awareness and funds for Maple Syrup Urine Disease (MSUD).

Fundraising can feel overwhelming—especially if it's your first time—but don't worry! We created this toolkit to give you the guidance and resources you need to succeed. When one of us succeeds, we all do.

Inside, you'll find everything from fundraising ideas and event checklists to social media templates and more.

You're never alone in this—our entire MSUD community is behind you every step of the way.

Together, we're making progress for those living with MSUD and their families. Thank you for moving with us and for believing in a better future.

Let's get to work!

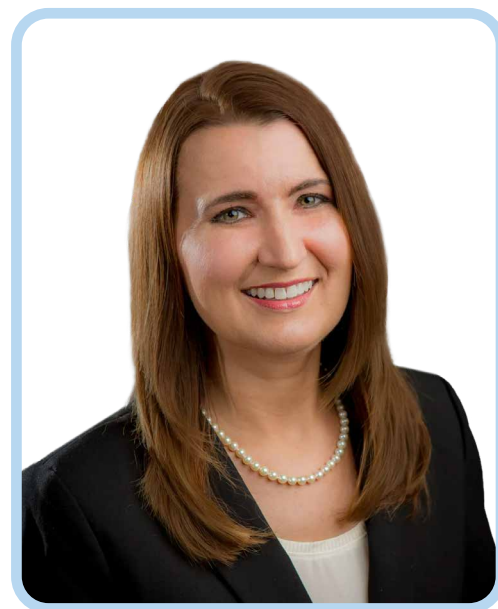
Warmly,



Denise L. Kolivoski, MBA

Executive Director

MSUD Family Support Group



CAMPAIGN OVERVIEW

MSUD Moves is a grassroots-inspired, community-driven campaign that empowers families and supporters to raise funds for MSUD by walking, jogging, or running—while designating their support directly to research initiatives or the 21st MSUD Symposium.

This is not a race—it's a movement.

Whether walking a mile, running in your neighborhood, or dancing with friends, every step celebrates the strength of our community and raises vital funds and awareness. Funds raised may be designated to support either MSUD research or the 21st MSUD Symposium, helping to advance knowledge, connection, and care for those living with MSUD.



FUNDRAISING 101

THE MISSION

The MSUD Family Support Group relies on donations to fulfill its mission of supporting families, advancing research, and raising awareness of Maple Syrup Urine Disease.

Philanthropy is a mutually beneficial relationship. We are providing people an opportunity to feel like they're making a difference by supporting our mission.

Through our fundraising efforts, we provide donors with a chance to make a difference, engage with our community, and help individuals living with MSUD. In return, the MSUD Family Support Group is able to use these generous contributions to continue making an impact in the lives of families across the United States and beyond.



Donors want to feel:

- They are making a difference
- They are part of the MSUD community
- They are helpful and important

Donors want to know:

- What the MSUD Family Support Group accomplished with their gift
- Who their gift(s) help
- Other ways they can get involved

FUNDRAISING 101

MATCHING MISSION TO DONOR VALUES

We want donors to feel inspired to give, but their decision to make a charitable gift is personal. Your personal network will likely be inspired to support the MSUD Family Support Group because of your story and connection to the cause.

The MSUD Family Support Group Do-It-Yourself (DIY) Fundraising movement empowers you to make a difference in your own way—one event, one message, one donation at a time.



Fundraising is...

The **right** person asking
the **right** prospective donor
for the **right** gift
for the **right** program
at the **right** time
in the **right** way.

LOCAL ACTIVITY TOOLKIT

ACTIVITY COMPONENTS

Each family-hosted MSUD Moves activity includes:



Casual Walk-Jog-Run format

(e.g., 1-mile walk, 1-mile jog, 1-mile run — or any accessible variation)



Location

(park, school track, neighborhood, or community space)



GoFundMe Page

By setting up your own GoFundMe page, you can rally friends, family, and community members to join you in making a difference.



MSUD Awareness on Social Media

Share campaign hashtags to raise MSUD awareness online



Personal Storytelling

(by local MSUD families)

LOCAL ACTIVITY TOOLKIT

MSUD MOVES FUNDRAISING CAMPAIGN INSTRUCTIONS

MSUD Moves is a nationwide campaign where participants run, walk, jog, or engage in any physical activity to raise awareness and funds for the MSUD community. Your participation helps support research and the 21st MSUD Symposium, bringing hope and resources to families worldwide. By setting up your own GoFundMe page, you can rally friends, family, and community members to join you in making a difference.

1. Create Your GoFundMe Account

- Visit [GoFundMe.com](https://www.gofundme.com) and click “Start a GoFundMe”.
- If you don’t already have an account, follow the prompts to sign up.

2. Set Your Fundraiser Details

- Include “MSUD Moves” in your fundraiser title (e.g., MSUD Moves – Walking for Research).
- Choose a realistic fundraising goal that motivates your supporters.
- Share why you are participating in MSUD Moves, your connection to the community, and the impact donations will have.

3. Designate Your Fundraiser for the MSUD Family Support Group

- Under “Choose a Nonprofit,” search for MSUD Family Support Group.
- Specify in your description whether your fundraiser supports research or the 21st symposium.

4. Notify the MSUD Family Support Group

- Email Denise at execdirector@msud-support.org to confirm your participation in MSUD Moves.
- You will be provided with the official MSUD Moves logo to include on your fundraiser page and promotional materials.

5. Share Your Fundraiser

- Post your GoFundMe link on social media, email it to friends and family, and encourage others to join or donate.
- Use the hashtag #MSUDMoves to connect with other participants and raise awareness.

Thank you for supporting the MSUD community through your participation in MSUD Moves. Every step, stride, or mile brings us closer to advancing research, funding essential programs, and connecting families. Together, we move for a brighter future.

LOCAL ACTIVITY TOOLKIT

TIMELINE FOR SUCCESS

Use this sample timeline to guide your MSUD Moves activity planning, promotion, and execution. Adjust as needed to match your local needs and schedule.

2 Weeks Before Activity	• Contact the MSUD Family Support Group to confirm your participation • Create a Go Fund Me page using the Step-by-Step instructions to set up your fundraiser • Begin email outreach to family and friends using the friends and family letter template • Start your social media countdown posts • Launch community outreach: clinics, schools, clubs
1 Week Before Activity	• Follow up letter sent to friends and family with calls and emails for support • Prep thank-you emails and continue social media promotion
Activity Day	• Take photos and video • Offer media interviews, if applicable
Post-Activity (Within 1 Week)	• Post a thank-you message on social media and email to supporters • Share your activity success with MSUD Family Support Group (photos, participants, funds raised) • Send thank-you messages to sponsors, donors, and volunteers

LOCAL ACTIVITY TOOLKIT

FRIENDS/FAMILY SUPPORT LETTER

[Your Name]
[Your Address]
[City, State, ZIP Code]
[Email Address] | [Phone Number]
[Date]

Dear Friends and Family,

I'm reaching out to ask for your support for something very close to my heart.

On [Activity Date], I'm organizing an MSUD Moves walk/jog/run in [City]—a local activity that's part of a national campaign led by the MSUD Family Support Group and proudly sponsored by Nutricia North America. This campaign raises awareness and funds for Maple Syrup Urine Disease (MSUD), a rare and life-threatening genetic disorder that affects the body's ability to break down certain proteins.

MSUD may be rare (affecting about 1 in 185,000 infants), but its impact is life-long and deeply personal to me.

[Choose one:]

- I live with MSUD and know firsthand the daily challenges it brings.
- As a [parent/sibling/family member/friend] of someone with MSUD, I've seen the strength it takes to manage this condition every single day.

This activity is more than just a fundraiser—it's a way to bring our community together, raise awareness, and help fund the research and resources that families like mine rely on for support, care, and hope.

This year, the activity will support [select one: the 21st MSUD Symposium or the MSUD Research Fund].

If you choose to support the 21st MSUD Symposium held on June 25–27, 2026 in Cleveland, Ohio, your gift will help cover costs for this critical event, including travel stipends for families, educational sessions with experts, and meals throughout the weekend.

If you select the MSUD Research Fund, your donation will advance vital studies and data collection efforts aimed at improving treatments—and one day, finding a cure.

Here's what your support helps make possible:

- Research into better treatments—and hopefully, one day, a cure
- Resources and education for families facing MSUD
- Advocacy efforts to improve care and access for those affected

If you're able to contribute in any way, please reach out to me directly at [Your Phone Number] or [Your Email]. You can also support online by donating through our GoFundMe page here: [Insert GoFundMe Link].

Thank you for always being in my corner. With your help, we can make real progress for people living with MSUD—and that means the world to me.

With love and appreciation,

[Your Name]
MSUD Moves Local Host
On behalf of the MSUD Family Support Group

LOCAL ACTIVITY TOOLKIT

SOCIAL MEDIA HASHTAG TIPS

When posting on social media, don't forget to use these official campaign hashtags to help amplify your message and connect with the wider MSUD Moves community. Encourage your friends, family, and supporters to share your walk, run, or jog on social media to help raise awareness and amplify your impact. Using campaign hashtags in every post builds momentum and expands support for your efforts.

#MSUDMoves

The official campaign hashtag

#MoveForMSUD

Emphasizes action and purpose

#FundRare

Connects to the broader rare disease fundraising movement.

#NutriciaSupports

Highlights our national sponsor



LOCAL ACTIVITY TOOLKIT

SOCIAL MEDIA POST EXAMPLES AND TIMELINE

1 Week Before Activity	Just one week away! Our family is getting ready for our MSUD Moves activity. We'll be walking to raise awareness for Maple Syrup Urine Disease and to support [MSUD research / the next MSUD Symposium]. We'd love your support — please consider donating or sharing: [Insert Link]
Week of Activity	It's MSUD Moves week! We're taking part in an activity to support the MSUD community and raise awareness for [MSUD research / the MSUD Symposium]. There's no big event — just families like ours walking, jogging, or moving in our own way to make a difference. You can support us here: [Insert Link]
Activity Day	Today's the day! We're walking to raise awareness for MSUD and to support [MSUD research / the MSUD Symposium]. Every step we take honors those living with MSUD and helps move our community forward. Thank you for supporting our effort: [Insert Link] #MSUDMoves #MoveForMSUD #FundRare #NutriciaSupports
	Every step counts. I'm participating in MSUD Moves to support [research / the MSUD Symposium] for those living with Maple Syrup Urine Disease. Please consider donating or sharing my activity: [Insert Link] #MSUDMoves #NutriciaSupports Our family is on the move for MSUD! On [insert date], we're walking to raise awareness, connect with our community, and support [MSUD research / the MSUD Symposium]. Thanks for cheering us on! #MSUDMoves #FundRare #MoveForMSUD
Post-Activity	Thank you! Our MSUD Moves activity is complete, and we're so grateful for your support. Because of you, we helped raise awareness and funds for [MSUD research / the MSUD Symposium]. Every step, every share, and every donation made a difference for families like ours. Stay connected at www.msud-support.org #MSUDMoves #ThankYou #MoveForMSUD #FundRare #NutriciaSupports

LOCAL ACTIVITY TOOLKIT

COMMUNITY OUTREACH

Invite clinics, hospitals, and dietitians to **support your efforts**.

Encourage outreach to individuals, friends, and family members to promote your walk, jog, or run and help increase awareness for MSUD.

Consistent and **frequent** outreach is key!



LOCAL ACTIVITY TOOLKIT

DONATIONS AND WAYS TO GIVE

There are many meaningful ways to support the MSUD Family Support Group and help us advance our mission:

With a Check

Mail your donation to:
MSUD Family Support Group
958 Medinah Terrace
Columbus, Ohio 43235

With a Credit Card

Give securely online at:
www.msud-support.org/donate

With a Company Match

Many companies offer a corporate match for charitable gifts made by their employees. Your gift could be doubled—or even tripled!

With an Estate Gift

Making the gift of a lifetime is simple. You can add the MSUD Family Support Group as a beneficiary in your will or trust.

With a Gift of Stock

A gift of stock or securities can be coordinated through an electronic transfer. Your broker can assist in initiating the process.

With an In-Kind Gift

The MSUD Family Support Group benefits from gifts of tangible property or services. In-kind gifts must be formally accepted to ensure they align with our mission and current needs.



QUESTIONS?

Let's get started together! Whether you're going for a walk to raise awareness, taking part in your own MSUD Moves activity, or just exploring how you can help, we're here to support you every step of the way.

Together, we can make a difference—for families, for research, and for the future of those living with MSUD.

Reach out to:

Denise L. Kolivoski, MBA

Executive Director

MSUD Family Support Group

execdirector@msud-support.org

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