STRATEGIC PLAN

2026-2029

MSUD

FAMILY SUPPORT GROUP

ABOUT MSUD

Maple syrup urine disease (MSUD) is an inherited disorder in which the body is unable to properly process certain protein building blocks properly. The condition gets its name from the distinctive sweet odor of affected infants' urine and is characterized by poor feeding, vomiting, lack of energy (lethargy), and developmental delay. If untreated, MSUD can lead to seizures, coma, and death. MSUD affects an estimated 1 in 185,000 infants worldwide, making it a rare disease.

Currently, there is no cure for MSUD, and treatment options are severely limited, making daily life a significant challenge for individuals and families affected by the disorder.

Living with MSUD requires strict metabolic control, costly medical formulas, and managing the emotional and physical toll of the disease. Families face challenges in accessing care, managing diets, and addressing metabolic crises, highlighting the need for better support and treatment advancements.

Families affected by MSUD encounter a range of life-altering challenges that impact emotional, educational, financial, and advocacy aspects of daily life. Key insights include:

- **Emotional Distress:** Newborn screening is available in every state across the United States. However, even with early diagnosis, parents often experience significant anxiety—not only at the time of diagnosis but throughout their child's life. Neurocognitive deficits, strict dietary management, and the ever-present risk of metabolic crises contribute to ongoing emotional stress and uncertainty.
- **Learning Disabilities:** Many MSUD patients face learning challenges due to late diagnosis or poor metabolic control, often worsened by infections, requiring special remedial efforts.
- **Financial Strain:** Families may struggle with high medical costs, especially when insurance doesn't cover the expensive formulas vital for survival.
- **Advocacy Challenges:** Parents often become advocates for their children, a demanding role made harder without access to adequate medical and psychological support.

MISSION AND VISION

Mission

The MSUD Family Support Group provides support, personal contact, encouragement, knowledge, and hope for those affected by MSUD. The group unites the MSUD families, medical clinicians, and researchers into a community seeking to improve the lives of individuals with MSUD through day to day support, improved treatments, and the search for a potential cure for MSUD.

Vision

To ensure all individuals and families have access to accurate information, quality treatment, and opportunities for improved outcomes, including transplants, to address MSUD.

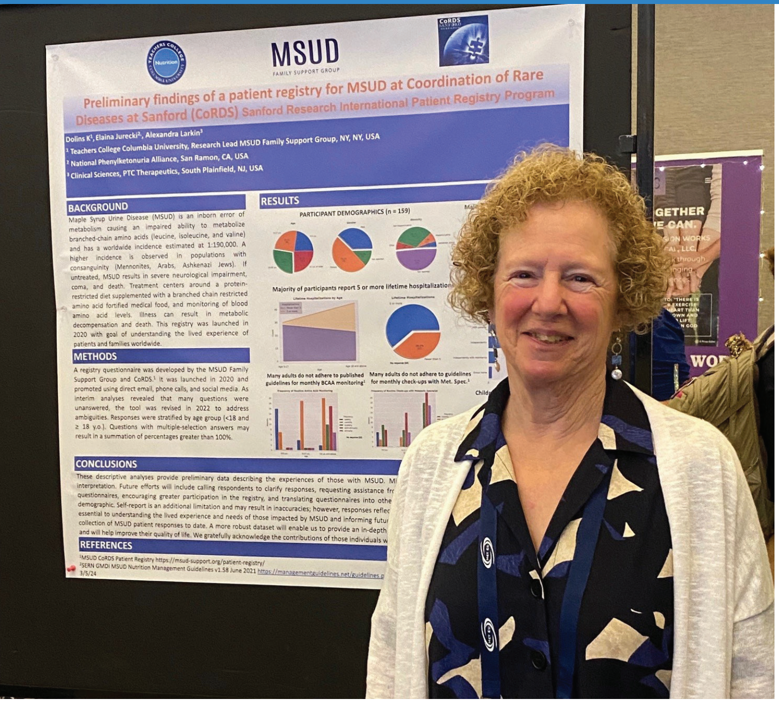
What We Do

- Empower the MSUD Community
- Promote Research
- Conduct Advocacy
- Foster Collaboration
- Champion Equity
- Cultivate Leadership
- Drive Fundraising and Resource Development

Empower the MSUD Community

We aim to empower individuals, families, and professionals in the MSUD community by equipping them with resources, knowledge, and tools to advocate for improved quality of life and care.

What We Do



Promote Research

By supporting ongoing research and education, we aim to improve the lives of those with MSUD through advancements in treatments and potential cures.

Conduct Advocacy

Advocacy ensures that the MSUD community's voice is heard, fostering legislative and regulatory change for expanded care, research, and treatment options. This includes promoting initiatives like the Medical Nutrition Equity Act (MNEA) and enhancing education about transplants as a viable treatment.

Champion Equity

We are committed to fostering diversity, equity, and inclusion while opposing all forms of discrimination. This extends to equitable access to treatment options, including medical foods, formulas, and transplants, regardless of geographic or socioeconomic barriers.

What We Do

Foster Collaboration

Through partnerships with families, researchers, metabolic professionals, and rare disease organizations, we amplify the collective voice of the MSUD community. By working together, we drive advancements in treatment, resources, and awareness.

Cultivate Leadership

We nurture leadership among MSUD advocates, volunteers, and families, equipping them with the skills and opportunities needed to champion the organization's mission and expand its impact globally.

Drive Fundraising and Resource Development

Financial sustainability is critical to supporting the mission and long-term impact of the organization. We aim to diversify revenue streams and strengthen fundraising initiatives to ensure continued support for the MSUD community.

Empower the MSUD Community

STRATEGIC PRIORITIES

Goal One

1

Empower individuals and families to become effective advocates.

- Offer training sessions and webinars to strengthen advocacy initiatives.
- Develop and distribute educational materials, including talking points, for MSUD advocates and ambassadors.
- Encourage strategic partnerships and community building among individuals, families, researchers, and professionals in the MSUD and rare disease community.
- Monitor legislation and policy developments to ensure the community remains informed and engaged.

Promote Research

STRATEGIC PRIORITIES

Goal Two

2

Advance research efforts to improve MSUD treatment and care.

- Encourage participation from the MSUD community in the patient registry.
- Publish findings from the MSUD Patient Registry and promote the use of the patient registry to known researchers in relevant fields.
- Utilize the Scientific Advisory Board and Clinical Advisors to evaluate and share advancements in MSUD research and treatment.
- Host a full-day, in-person Scientific Advisory Board biennial meeting to share advances in research.
- Organize educational sessions and webinars, including the biennial symposium, to share current research and support individuals, families, and professionals in the MSUD community.

Financial Sustainability

STRATEGIC PRIORITIES

Goal Three

Strengthen fundraising efforts and diversify revenue streams.

- Develop and implement a comprehensive fundraising strategy that includes individual giving, corporate sponsorships, and grants.
- Create new opportunities for donor engagement through events, campaigns, and recognition programs.
- Explore innovative revenue streams, such as planned giving, merchandise sales, and partnerships with industry stakeholders.
- Build an endowment fund to ensure long-term financial stability.

3

Organizational Development

STRATEGIC PRIORITIES

Goal Four

Enhance leadership.

- Create a pipeline for the board and committee positions.
- Offer leadership training to enhance knowledge and skills in governance and advocacy.
- Develop a mentorship program, the MSUD Ambassadors, to connect new and experienced volunteers.
- Promote the work of volunteers to celebrate and share their contributions with the MSUD community.

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STRATEGIC PRIORITIES

Empower the MSUD Community	Promote Research	Financial Sustainability	Organizational Development
Goal 1: Empower individuals and families to become effective advocates.	Goal 2: Advance research efforts to improve MSUD treatment and care.	Goal 3: Strengthen fundraising efforts and diversify revenue streams.	Goal 4: Enhance leadership.
Offer training sessions and webinars to strengthen advocacy initiatives. Develop and distribute educational materials, including talking points, for MSUD advocates and ambassadors. Encourage strategic partnerships and community building among individuals, families, researchers, and professionals in the MSUD and rare disease community. Monitor legislation and policy developments to ensure the community remains informed and engaged.	Encourage participation from the MSUD community in the patient registry. Publish findings from the MSUD Patient Registry and promote the use of the patient registry to known researchers in relevant fields. Utilize the Scientific Advisory Board and Clinical Advisors to evaluate and share advancements in MSUD research and treatment. Host a full-day, in-person Scientific Advisory Board biennial meeting to share advances in research. Organize educational sessions and webinars, including the biennial symposium, to share current research and support individuals, families, and professionals in the MSUD community.	Develop and implement a comprehensive fundraising strategy that includes individual giving, corporate sponsorships, and grants. Create new opportunities for donor engagement through events, campaigns, and recognition programs. Explore innovative revenue streams, such as planned giving, merchandise sales, and partnerships with industry stakeholders. Build an endowment fund to ensure long-term financial stability.	Create a pipeline for the board and committee positions. Offer leadership training to enhance knowledge and skills in governance and advocacy. Develop a mentorship program, the MSUD Ambassadors, to connect new and experienced volunteers. Promote the work of volunteers to celebrate and share their contributions with the MSUD community.

Implementation and Review

The MSUD Family Support Group will implement this strategic plan by leveraging its network of leaders, advocates, and professionals. Progress will be reviewed annually to ensure the plan adapts to the evolving needs of the MSUD community, including advances in treatments such as transplants.