



KDM5C ADVOCACY, RESEARCH, EDUCATION, & SUPPORT

Strategic Plan 2023-2025

Approved by the Board of Directors on March 30, 2023

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Letter from the Board Chair:

It is my pleasure to share the KDM5C KARES Foundation's 2023-2025 Strategic Plan. Founded as a non-profit organization in 2022, this inaugural plan outlines our history and builds upon the work we are already doing to promote KDM5C Advocacy, Research, Education and Support across the globe.

For the first several years of her life, my daughter endured a plethora of tests in an effort to explain her intellectual disability, speech challenges, short stature, low muscle tone, and GI issues. While friends and family were very supportive, we felt frustrated and alone. Finally, at age 10, genetic testing revealed her diagnosis – a KDM5C variant. While it was a relief to finally have an explanation, we felt lonelier than ever, considering the extreme rarity of KDM5C-related disorders.

The pediatric geneticist had very limited information, and suggested that I look for other families on social media. After a year with very little success, I created the KDM5C Family Support Group on Facebook. The group now has hundreds of members, representing more than 100 diagnosed individuals worldwide.

After a gathering of a small group of families and researchers in early 2020, it was clear that our community needed more support and research. It was an endeavor that felt overwhelming to take on alone, so I approached three other moms who I knew were passionate about furthering progress for the KDM5C community. After some thoughtful consideration, we formed the KDM5C KARES Foundation, Inc and earned our 501(c)(3) status in May of 2022.

Since our founding and the formation of our Executive Board, we have expanded our Board of Directors to include seven members – six mothers on a mission and the researcher who chairs our Scientific Advisory Board. We have five volunteer committees supporting our goals. We held our first major fundraising event in October 2022 – the Virtual 5k Run, Walk, and Roll. This event raised more than \$60,000. At present, we are a completely volunteer and family-led organization, although we hope to hire staff support in the coming years.

In the coming three years, we seek to make strides and embrace challenges by expanding KDM5C research, building our community and organization in a strategic and sustainable manner, strengthening partnerships, and improving our systems and structures.

KARES is an organization guided by the core values of *hope, innovation, community, and integrity*. Regardless of your connection to KARES, we are all working to advance KDM5C Advocacy, Research, Education and Support. We are committed to using this strategic plan to truly transform our organization over the next three years!

Sincerely,
Amy Robl
KARES Board Chair

Mission: Our mission is to improve the lives of those affected by KDM5C genetic variants through advocacy, research, education, and support for individuals and families.

Vision: We envision a world where patients and families affected by KDM5C genetic variants are able to achieve their highest attainable health in order to thrive in their communities.

Core Values:

- **Hope** – We believe in a positive outlook for the future. We maintain ambitious goals for improved quality of life for those affected by KDM5C variants. We recognize that our challenges and trauma can coexist with joy and hope.
- **Innovation** – We believe in tapping into the best resources to cultivate new skills, opportunities, therapies, and more. We are committed to utilizing technology to improve our organizational structure and research practices, pushing the limits to bring positive impact to our KDM5C community.
- **Community** – We collaborate with KDM5C patients, families, friends, caregivers, clinicians, researchers and partner organizations to build relationships that maximize our impact. We strive for all people to feel a sense of inclusion and belonging in our community.
- **Integrity** – We conduct our work with honesty and transparency. We demonstrate financial stewardship of the resources entrusted to the KARES Foundation. We put relationships first, prioritizing trust and privacy in all interactions with our community.

Our Story

In 2017, when their daughter, Gabby, was 10 years old, The Robl family finally received a diagnosis that explained her symptoms and challenges: a mutation of the KDM5C gene.

Amy Robl searched online for other parents and families affected by this rare syndrome, but couldn't find much support. That's when Amy created the [KDM5C Support Group on Facebook](#), which now has hundreds of members representing more than 100 diagnosed individuals worldwide.

In 2020, a group of families and researchers met up for the first time at the rare disease day conference at Albert Einstein College of Medicine. It was inspiring to see families, clinicians, and scientists come together in support of KDM5C research for the first time. There continues to be strong collaboration amongst these groups and a growing volume of research.

As the Facebook support group continued to grow, several families came together with the idea of creating a Foundation to improve the lives of KDM5C-affected families. The KARES Foundation was born in May of 2022, a nonprofit 501(C)(3) dedicated [KDM5C advocacy, research, education, and support](#) for individuals and families living with KDM5C genetic variants around the globe.

Our Pillars of Work

Advocacy – We advocate for inclusion within our communities. We encourage KARES leadership and families to use their voices to create positive change in rare disease policy and funding.

Research – The KARES Foundation strongly encourages interdisciplinary collaboration and the sharing of resources as a means of accelerating progress in KDM5C research. Research funded by the KARES Foundation is for public use in an effort to educate and promote further discovery.

Education – We aim to empower KDM5C families and caregivers with the tools and resources to navigate the challenges of living with a KDM5C-related disorder. We build the capacity of staff and professional communities (educators, doctors, therapists) through ongoing education and professional development opportunities.

Support – We provide a safe space for exchange and support amongst KDM5C families and caregivers. We partner with other organizations and professionals to support the ever-changing needs of our community.

Key Stakeholders:

As an ultra-rare disease, the KDM5C community is small. We believe it will take the entire KDM5C community to make meaningful progress toward our goals. The KARES Foundation aims to engage all of the following stakeholders in our work:

- KDM5C-affected families and caregivers
 - Newly or recently diagnosed families and friends
 - Existing/known families
 - Patients themselves
- Professional community
 - Clinicians and clinician-researchers
 - Researchers
 - Geneticists
 - Service providers - Allied health professionals (therapists, nutritionists, etc.)
 - Educators
- Donors and partners
 - Current and active funders
 - Prospective funders and partners
 - Other rare disease syndrome-focused organizations and support groups

Accomplishments, Challenges and Opportunities:

The KARES Foundation was founded by a group of KDM5C moms in 2022, and launched with the support of other parents, family members, and key figures from the medical and scientific community. There has been significant progress planning and collaborating with stakeholders to create a framework for success.

Strengths and Accomplishments:

- Formed in May 2022 and quickly developed governance structure and organizational policies, establishing a Board of Directors, Scientific Advisory Board, strategic committees, and volunteer network to support our work.
- Have engaged 480 members in a growing Facebook Support Group.

- Built website and social media infrastructure with cohesive branding guidelines.
- Collaborated with other patient advocacy groups and research communities for mentorship and cross-disease partnership.
- Held a successful virtual 5K event in 2022 with 250 participants in 17 US states raising nearly \$60,000.
- Sent organization representatives to educational conferences and professional development opportunities in patient advocacy, health equity, and more.
- Held a KDM5C Research Update in 2023 bringing together researchers and clinicians from a growing research landscape in multiple countries, states, and academic institutions.
- Partnered with RARE-X to launch a patient-owned data collection program for the KDM5C community to expand and accelerate research.
- Launched the Request for Proposals for the first ever KARES-sponsored KDM5C Research Grant Applications to be funded in 2023.
- Launched a 2023 Virtual Family Education Series to support families on their top requested family support topics (mental health, guardianship, behavior, communication, etc.).
- Held a Strategic Planning meeting in early 2023 and finalized this Strategic Plan.

Weaknesses and Challenges:

- We are a 100% family and volunteer run organization. Families are often stretched due to the needs of caregiving for KDM5C-affected children.
- There is a broad lack of awareness of KDM5C-related disorders, including amongst the medical/scientific community.
- Lack of diversity in our diagnosed population and therefore in organization leadership.
- Challenges in accessing undiagnosed populations and newly diagnosed families or individuals who might want to tap into the KDM5C community.
- The KARES Foundation relies heavily on small donations from individual donors (limited fundraising opportunities).
- Challenges finding the time and staff to source funding via grants and write for these opportunities.

Opportunities:

- There is opportunity for expansion of the KARES Foundation's fundraising sources.
- To grow our budget to be more able to fund research, targeting treatments that improve quality of life for individuals affected by KDM5C genetic variants.
- The opportunity to fund salaries for part or full-time staff member(s) in the future, such as an Executive Director.
- Integrate family support into our programs such as the Family Support Group and Family Education Series, and potentially expanding these offerings to include Sibling Support.
- Continuing to grow the community itself and our partnerships (families, medical professionals, researchers, patient advocacy groups, and industry partners)
- Better engaging all stakeholders in fundraising and development, such as in the Virtual 5K.
- Utilizing the knowledge and experiences of KDM5C families to develop resources for care management.
- Convene an in-person gathering of our community at a future Family & Science Conference.

Our Goals and Objectives

Over the next three years, the KARES Foundation will build on its accomplishments and focus on goals that will position us to achieve our next phase of growth and impact. These goals are interdependent and require robust collaboration across the organization's strategic committees (including the Scientific Advisory Board, Finance Committee, Fundraising Committee, Marketing Committee, and Family and Community Engagement Committee). Throughout all of these areas, the KARES Foundation commits to building a positive organizational culture that fosters respect and appreciation of neurodiversity and individual differences.

The following goals set forth our 2023-2025 plan for success:

Goal 1: *Improve Systems and Structures to Support Our Work*

This goal acknowledges KARES work is expanding rapidly and that our infrastructure needs to grow to support it.

- **Objective 1.1** - Expand staff, intern and volunteer capacity, enhance capacity development, and implement practices that prioritize the well-being of KARES staff and volunteers.
- **Objective 1.2** - Implement project planning and information technology tools to track our goals and streamline our work plans and communication.

Goal 2: *Strengthen Our Community and External Partnerships*

The mission and work of KARES are a big task for one organization. To ensure best practices and long-term sustainability, we will work to strengthen and track collaboration with partners.

- **Objective 2.1** - Strengthen collaboration with existing partners and community members through family education, networking, conferences, and mentoring to/from other patient advocacy groups.
- **Objective 2.2** - Cultivate new partnerships in order to enhance our work so that we may provide existing resources to families rather than recreate them.
- **Objective 2.3** - Map and assess these partnerships in an ongoing way.

Goal 3: *Expand Capabilities for Funding Diversification*

To safeguard the sustainability and potential growth of the KARES Foundation and its programs, we will grow our work through pursuing new opportunities to seek funds.

- **Objective 3.1** - Assess opportunities to seek both one-time and multi-year grant funding from private and public funders.
- **Objective 3.2** - Diversity the KARES Foundation's financial resource base to grow our operations, programming and impact.

Goal 4: *Bolster Collaboration in KDM5C and Cross-Disease Research*

The KARES Foundation aims to support science that will ultimately target treatments for KDM5C genetic variants.

- **Objective 4.1** - Support useful, standardized and secure data collection on KDM5C patients to expand our research network.
- **Objective 4.2** - Develop a Research Grant Program to provide seed grants to interested scientific and medical researchers on a yearly basis.

- **Objective 4.3** - Hold a yearly virtual research symposium to engage research and clinician partners at academic institutions within and outside of the US.
- **Objective 4.4** - Hold one in-person Family and Science Convening during this strategic plan cycle and at least every three years thereafter.

Acknowledgements

We wish to thank the many people who contributed to the development of this strategic plan, including the KARES Board of Directors, researchers, patient families, volunteers, student interns, and more. Your input through research and stakeholder meetings helped us to complete our very first Strategic Planning process!