



UNITED  
MITOCHONDRIAL  
DISEASE  
FOUNDATION.



FY2027-2029 Strategic Plan Overview

# A New Era of Progress: UMDF's Path Forward

United Mitochondrial Disease Foundation

[www.umdf.org](http://www.umdf.org)

# A Defining Moment for the Mitochondrial Disease Community

For decades, families affected by mitochondrial disease have faced limited treatment options, difficult and delayed diagnoses, and uncertainty about the future. Today, our community stands at a historic turning point. The first FDA-approved therapies for mitochondrial diseases – treatments for Barth syndrome and TK2d – became a reality in 2025, marking the beginning of a new era.

But while progress accelerates, the challenges confronting patients remain significant. Most mitochondrial diseases still have no approved therapy. Diagnosis is complex. Access to quality, coordinated care is inconsistent. Families and clinicians alike need leadership, resources, and connection.

The United Mitochondrial Disease Foundation (UMDF) is stepping forward with clarity, urgency, and confidence. Our FY2027–2029 Strategic Plan, overviewed here, outlines the bold actions we will take to accelerate research, strengthen the care ecosystem, foster collaboration, and improve the lives of every person affected by mitochondrial disease.



# A Plan Built by the Community, for the Community

113

Patients and families  
engaged in surveys and  
interviews

9

Patient advisory groups  
surveyed

43

Industry partners engaged  
in surveys and interviews

3

Listening sessions held with  
partners and board, staff  
and community members



UMDF's FY2027-29 strategic plan was shaped by the voices of more than 200 patients, families, clinicians, researchers, partner organizations, and UMDF staff and board members, who shared their experiences, hopes, and priorities. Through interviews, surveys, and listening sessions, stakeholders told us what is needed most: faster diagnosis, better access to care, deeper collaboration, stronger awareness, and increased investment in transformational research.

Those insights became the backbone of this strategic plan. Every pillar reflects what the community asked UMDF to focus on – and what this moment demands. In the pages that follow, you'll find a high level overview of our roadmap for the next three years. Internally, the plans outlined here are paired with detailed objectives and key results, each with a clear owner, to ensure we make meaningful progress on our mission for the good of everyone affected by mitochondrial disease.

# Our Vision

A world free from the challenges of mitochondrial disease.

# Our Mission

We collaborate to support and empower mitochondrial disease patients and families, drive awareness, mobilize advocacy, improve access to diagnosis and quality care, and accelerate breakthroughs in treatments and cures.

## Our Strategic Pillars

The four pillars below define UMDF's areas of greatest focus and innovation over the next three years. These pillars center our work on our mission, and will bring us one step closer to a world free from the challenges of mitochondrial disease.



### **Funding**

Strengthen UMDF's financial foundation and grow revenue to expand transformational research and drive increased impact.

### **Diagnosis & Access**

Expand UMDF programs and initiatives that improve diagnosis and access to quality care for all affected by mitochondrial disease.

### **Collaboration**

Grow UMDF's role as a respected lead convener of the mitochondrial disease community, with a clear model for collaboration and collective impact.

### **Awareness**

Strengthen UMDF's brand while driving greater awareness and understanding of mitochondrial disease and dysfunction.

Pillar 1:

# \$ Funding

Strengthen UMDF's **financial foundation** and **grow revenue** to expand transformational research and drive increased impact.

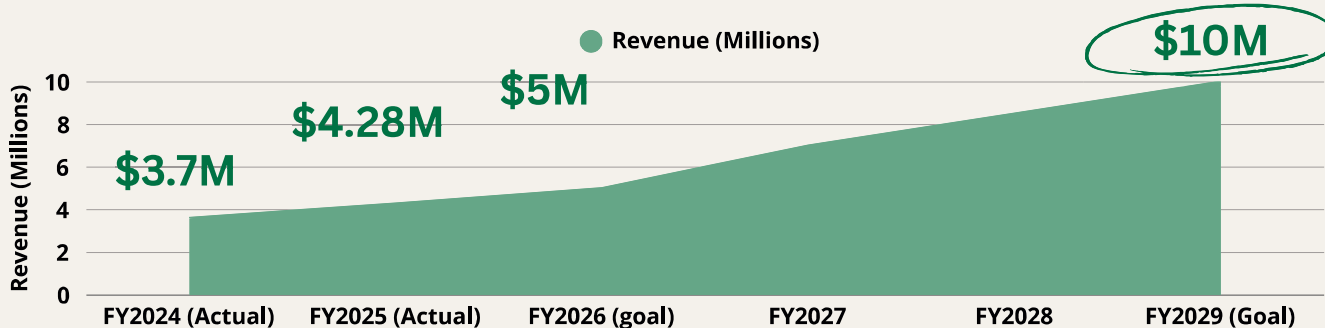
UMDF is poised to lead the next era of progress, but to do so, we must stabilize and then significantly expand our financial resources. Stakeholders told us they want more investment in research, clinical trials, and patient support. Meeting these needs requires strong fiscal management and bold revenue growth.

**Over the next three fiscal years, we will:**

- Strengthen UMDF's financial health with strong nonprofit financial management practices.
- Expand fundraising through national campaigns, events, a leadership giving circle, and more.
- Build multi-year funding partnerships with industry partners and foundations.
- Grow UMDF's annual revenue to \$10M to meet the scale of need.



### An Ambitious \$10M Revenue Growth Goal



## Pillar 2:

# Diagnosis & Access

Expand UMDF programs and initiatives that improve **diagnosis and access to quality care** for all affected by mitochondrial disease.

Patients and families consistently told us that the biggest challenges they face include obtaining a mitochondrial disease diagnosis, getting access to quality care, and navigating a complex medical system. These challenges will only grow as treatments are approved. UMDF will respond by leading the development of ambitious new initiatives focused on diagnosis and access.

### **Over the next three fiscal years, we will:**

- Create a national referral network to connect families and clinicians with expert care.
- Address “diagnostic deserts” through regional pilot programs to increase local capacity.
- Strengthen the mitochondrial medicine workforce through pipeline programs and a new fellowship program for clinicians specializing in mitochondrial disease.
- Launch a centralized Mito Resource Hub to help families find trusted information.
- Support access to emerging therapies, including education, navigation tools, and payer-engagement resources.



## Pillar 3:

# Collaboration

Grow UMDF's role as a respected **lead convener** of the mitochondrial disease community, with a clear model for **collaboration and collective impact.**

The mitochondrial disease space is rich with passionate advocates, single disease organizations, and patient advocacy groups, but the landscape is fragmented. Groups often duplicate efforts and miss opportunities for synergy. Stakeholders overwhelmingly asked UMDF to step forward as a lead convener that can bring the ecosystem together. During this strategic plan, we will answer that call. Our commitment to collaboration extends beyond this pillar and into our mission. Everything we do is driven by the belief that we are stronger together than we are apart.

### Over the next three fiscal years, we will:

- Develop a unified collaboration framework to guide partnerships across research, education, advocacy, and patient support.
- Launch the Unified Mitochondrial Disease Advocacy Council (UMDAC), a groundbreaking coalition aligning the mitochondrial disease community around shared advocacy goals.
- Expand partnerships with academic, clinical, patient, and industry groups.
- Grow our convening power through events and knowledge-exchange platforms.



## Pillar 4:



# Awareness

Strengthen UMDF's **brand** while driving greater **awareness** and understanding of mitochondrial **disease and dysfunction**.

Mitochondrial disease is still widely misunderstood, even in medical settings. Increasing awareness is essential for earlier diagnosis, more funding, stronger research participation, and improved care. Over the next three years, UMDF will invest in growing awareness about mitochondrial disease, and about the work we are doing to support the mitochondrial disease community. At the same time, it is becoming increasingly clear that mitochondrial dysfunction plays a role in other chronic diseases, from Parkinson's to Alzheimer's. During the course of this strategic plan, we will also work to build awareness about this connection, opening up additional funding and opportunities to advance our mission, which will remain focused on primary mitochondrial disease.

### **Over the next three fiscal years, we will:**

- Elevate UMDF's brand visibility through digital channels, media coverage, and expanded content.
- Launch a national mitochondrial disease awareness campaign.
- Partner with organizations focused on other diseases to elevate awareness of mitochondrial dysfunction's role in chronic disease.



A young girl with dark hair in a red shirt and an older man with white hair and glasses in a blue shirt are looking at a document together. The girl is pointing at something on the page, and the man is looking down at it. They appear to be in a meeting or a collaborative work environment. The background is slightly blurred, showing what might be a window or a wall.

# Your support makes this plan possible.

UMDF's next era of progress is within reach – but it will only be possible with strong, collective support. This strategic plan outlines bold steps to accelerate research, improve diagnosis and access, deepen collaboration, and raise national awareness. To deliver on this vision, UMDF aims to grow its annual revenue to **\$10 million** by FY2029, an ambitious goal we cannot reach without your partnership.

## Your support is critical.

Join us in powering this plan, accelerating breakthroughs, and bringing hope to every person affected by mitochondrial disease. Together, we can make the next era of progress a reality.

Contact Jill Guyer, National Director of Development, at [jill.guyer@umdf.org](mailto:jill.guyer@umdf.org) to learn more and begin planning your gift.