



Myotonic Dystrophy Foundation

2026-2029 Strategic Plan

Prepared by Third Plateau
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A Message About Our Future

For everyone affected by myotonic dystrophy, hope is rooted in progress. It comes from every scientific discovery, every family that finds support, every clinician who gains a deeper understanding of the disease, and every advocate who helps raise awareness. That is why this strategic plan gives us tremendous optimism for the future.

We are entering a pivotal moment for the myotonic dystrophy community. Advances in research are creating new opportunities to better understand the disease and develop potential therapies. Awareness of myotonic dystrophy is growing, and collaboration among patients, families, researchers, clinicians, industry partners, and advocates is stronger than ever before. At the same time, significant challenges remain, including delayed diagnosis, gaps in care, limited disease awareness, and the urgent need for effective treatments. This is the right time to align our efforts around a shared vision and a clear path forward.

Our strategic planning process was driven by one simple question: How can we maximize our impact for individuals and families living with myotonic dystrophy over the next three years? Through conversations with stakeholders across the community, we identified where our organization can make the greatest difference and where focused investment will have the strongest impact.

Moving forward, we will prioritize accelerating research and therapeutic development, improving access to education and resources, strengthening support for patients and families, expanding awareness of myotonic dystrophy, and building the partnerships necessary to advance our



mission. We will also continue to invest in the organizational strength and sustainability required to serve the community for years to come.

Because of these priorities, our work will become even more intentional and impactful. We will focus our resources on initiatives that advance promising research, help reduce barriers to care, and connect more individuals and families with the support they need. We will work to ensure that patients and families have a stronger voice in shaping the future of research and care. We will deepen collaboration across the myotonic dystrophy ecosystem to accelerate progress and amplify our collective impact.

Most importantly, this plan positions us to move faster toward the future our community deserves—a future where myotonic dystrophy is diagnosed earlier, managed more effectively, better understood by healthcare providers and the public, and ultimately treated with therapies that improve and extend lives.

This strategic plan is more than a roadmap; it is a commitment to the myotonic dystrophy community. It reflects our determination to meet today's needs while building toward tomorrow's breakthroughs. While the challenges before us are significant, so is the momentum behind this community.

Together, we have an opportunity to transform what is possible for people living with myotonic dystrophy. That opportunity is what gives us hope, and it is what drives us forward.

A handwritten signature in blue ink that reads "Tanya Stevenson".

Tanya Stevenson, EdD, MPH
Chief Executive Officer
Myotonic Dystrophy Foundation

Introduction

Since the conclusion of its previous strategic plan in 2024, the Myotonic Dystrophy Foundation (MDF) has continued to advance its mission to strengthen the DM community through support, care, advocacy, and research that leads us closer to treatments and a cure. Following the completion of its strategic plan, MDF had a successful 2025, including a record-breaking Gala (\$2M+), a record number of research grant submissions, and the highest-attended conference with the largest professional track to date. The year was also spent collecting data from multiple stakeholders, evaluating existing processes and programs, establishing new partnerships, and developing manuscripts and reports for publication.

MDF is currently at a critical inflection point; multiple ongoing clinical trials may lead to treatment opportunities in the coming few years. At the same time, the external landscape presents uncertainties that may impact research funding, healthcare access, and eventual treatment coverage. Looking ahead to the next three years, MDF needs to be ready to respond to emergent changes in the landscape and adapt and scale its work to meet the moment and continue to support the DM community.

To prepare for this exciting and uncertain future, MDF engaged Third Plateau to support the development of its strategic plan. MDF board and staff convened for a two-day strategic planning retreat in January 2026. Third Plateau facilitated the retreat to help board and staff review the current state of the MDF community, envision MDF's ideal future state across the next three years, and scenario plan for contingencies to understand how MDF can prepare for these futures. These discussions and the content generated at the retreat served as the basis for this strategic plan. In the following months, Third Plateau facilitated multiple strategic planning sessions with board members, staff, and other stakeholders to further develop and refine the strategic plan.

Our Purpose

Vision We envision a world with treatments and a cure for myotonic dystrophy.

Mission Community, Care, and a Cure

We support and connect the myotonic dystrophy **community**.

We provide resources and advocate for **care**.

We accelerate research toward treatments and a **cure**.

Our Strategic Focus

To advance our mission and vision over the next three years, we will focus on the following strategic priorities.

1. Continue to evolve MDF's programs to deliver high-quality support for individuals and families affected by DM.

Over the next three years, we will continue to strengthen our ability to support the day-to-day needs of the DM community. Based on emerging community needs, we will continue to build the partnerships and infrastructure that enable us to provide meaningful support to the DM community.

- A. Optimize and prepare current programs and resources, including MDF's flagship international and regional conferences, to be deployed at scale to meet a surge in anticipated demand pending future drug approval.
- B. Strengthen and expand caregiver support to deliver holistic, integrated support across the full caregiving lifecycle, addressing the interconnected, multifaceted burdens caregivers face.

2. Strengthen community readiness for therapeutic breakthroughs by fostering connections and disseminating resources.

Through this work, we will ensure that the DM community is informed, connected, and prepared to navigate and benefit from emerging therapeutic breakthroughs the moment they become available. The strategies below will build upon and leverage the infrastructure of our existing programmatic work.

- A. Continue to provide expanded resources and information to increase community awareness of clinical trials, helping to connect community members to trials when appropriate.
- B. Expand MDF's reach to connect more individuals to programming, resources, and community support by investing in key awareness building efforts and leveraging new data infrastructure.

- C. Build pathways to ensure approved treatments reach as many people as possible by increasing awareness of new treatment options, equipping individuals and healthcare providers with actionable information, working with payers to minimize insurance denials and coverage barriers, and reducing other obstacles that may prevent people from accessing and benefiting from available therapies.

3. Accelerate clinical trial success and treatment development.

MDF will leverage its position and resources to advocate for catalytic advancements across the DM research landscape, such as a global patient engagement platform, clinical endpoint development, and helping to address anticipated shortfalls in DM research funding, while continuing to foster the next generation of DM researchers.

- A. Support the development of a global patient engagement platform to serve as a comprehensive, consolidated platform for access to registry data and patient information to accelerate research, treatments, and a cure.
- B. Continue to facilitate engagement with the FDA, industry, and payors to advocate for clinically relevant endpoints, approvals, and funding.
- C. Continue to support clinical trials and research recruitment and success, including strengthening trial site preparedness.
- D. Continue to support global DM research, including research on care advancement, drug development efforts, and real world evidence (e.g., post-market studies).
- E. Continue to recruit and support the next generation of researchers working on DM.

4. Advance a connected and capable care ecosystem.

To continue to support the care needs of our community and prepare for eventual treatments, we will build, connect, and expand a more coordinated network of care providers and healthcare professionals equipped to confidently diagnose, treat, and support people living with DM. A more robust care ecosystem can in turn drive new DM community members to MDF, where they can receive additional support.

- A. Continue to act as a liaison and interpreter of information across healthcare professionals, community, and industry, turning emerging insights into practical guidance and tools for healthcare professionals.

- B. Build and strengthen relationships with existing healthcare professionals, and identify and reach out to a target set of provider networks who are not yet connected to MDF.
- C. Work to improve diagnostics and shorten diagnostic odyssey.
- D. Support the development of and updates to standards of care for the DM community to support high quality, coordinated DM care.
- E. Strengthen MDF's global presence to improve access to resources and support for the international DM community, including access to resources in their country or region's primary language, while building and deepening relationships with international patient advocacy groups and care providers.

5. Advance research, care, and community impact for DM2.

To advance support for the DM2 community over the next three years, MDF will strategically invest in resources to advance DM2 research, expand access to high-quality care and treatments, and strengthen community-based support for individuals and families.

- A. Strengthen and diversify support for the DM2 community by addressing their distinct and evolving needs.
- B. Continue to prioritize and advance DM2 research.
- C. Leverage MDF's role as a trusted convener to advocate and educate researchers, industry partners, and other stakeholders to advance the development of meaningful clinical endpoints, animal models, and natural history data to accelerate DM2 drug development.

6. Build organizational strength and sustainability to support growing and more complex community needs.

In order to continue to support a rapidly shifting DM ecosystem, MDF must ensure that its staff and organizational resources are prepared to meet emerging needs.

- A. Invest in MDF's staff by fostering strong support systems and right-sizing capacity across the team while leveraging technology and systems to improve efficiency and extend organizational reach.

- B. Maximize current funding streams, including MDF's notable annual gala, to support long-term financial sustainability.
- C. Evaluate the feasibility of alternative funding models.
- D. Continue to strengthen the membership of the Board of Directors and Scientific Advisory Committee.
- E. Develop a communications plan for the next three years, including talking points and messaging for discrete audiences.

Advocacy Agenda

Advocacy is a core part of MDF's work, enabling the organization to further its mission through a multi-pronged advocacy strategy. MDF advances its vision for community, care, and cure through advocacy around the following key areas:

- Federal funding for DM research
- DM drug development/approval
- Disability programs and policies
- Payer coverage, including Medicare/Medicaid, for DM drugs and healthcare

Through continued partnership with rare disease advocacy consultants and lobbyists, MDF will enact an advocacy agenda over the course of this strategic plan. Over the next three years, our advocacy work will focus on:

- Advancing policy and funding to improve quality of life, accelerate research, and support therapeutic development.
- Expanding community readiness by strengthening global connections, increasing awareness, and building volunteer advocacy capacity.
- Accelerating clinical trial success through sustained federal research advocacy, targeted communications, and infrastructure that identifies and closes participation gaps.
- Building a connected care ecosystem by expanding access to genetic testing, screening, diagnostics, and accurate coding to shorten time to diagnosis and improve care pathways.
- Driving focused progress in DM2 by convening stakeholders, defining barriers, and mobilizing funding to accelerate DM2-specific research and therapeutic development.

Conclusion

Throughout this strategic planning process, we reflected on progress made across the past four years toward our prior priorities and mission, reviewed data gathered over 2025, considered potential scenarios for the coming years, and ensured that staff are supported and equipped to execute on the priorities laid out in this plan.

As we look towards an exciting, yet uncertain future, we are confident that the strategies generated in this planning process will enable us to move forward with confidence, alignment, and clarity as we continue to support our community, the broader care ecosystem, and efforts to develop a cure.