

About the Myotonic Dystrophy Foundation

Who We Are

The Myotonic Dystrophy Foundation (MDF) is the world's largest patient organization focused solely on myotonic dystrophy (DM). Our mission, "Care and a Cure," is to enhance the quality of life of people living with DM, and advance research focused on finding treatments and a cure.

What We Do

Support & Education

MDF provides emotional support, education, and resources to affected individuals and their families, and conducts outreach to raise awareness about DM in the medical community and the general population. Programs include:

- [MDF Toolkit](#), a comprehensive packet of information and resources for newly-diagnosed families and their doctors;
- [MDF Warmline](#), staffed phone support for individuals needing information about resources and advice on living with DM;
- www.myotonic.org, a comprehensive website with information, resources, and a digital academy with over 250 hours of videos and webinars on an array of topics;
- [MDF Annual Conference](#), an opportunity for members of the DM community to learn about daily living strategies and products, updates on research and advocacy, and more;
- [Webinars](#) and other assistance and education programs;
- [TeamMDF](#), a grassroots volunteer corps focusing on support groups, fundraisers, outreach to medical professionals and government officials, and other resources and programs, which acts as an organized community face and voice for DM issues.

Research

MDF is committed to helping advance research and therapies. Efforts include:

- Supporting up-and-coming postdoctoral fellowships to expand the research base;
- Launching and managing the **Myotonic Dystrophy Family Registry**. More information can be found at www.myotonicregistry.org;
- Investing in target identification and drug screening;
- Supporting a robust clinical research network to increase the efficiency of testing new drug candidates;
- Determining the true prevalence of the DM mutation in the population and documenting the socio-economic burden of the disease.

Advocacy

MDF advocates for legislation, research, and infrastructure initiatives that will advance our understanding of myotonic dystrophy, accelerate drug development, and improve diagnosis and care. We strive to raise visibility of myotonic dystrophy and people living with DM with key stakeholders in Congress, federal and state agencies, medical professionals, and the media.