

OUR IMPACT REPORT

2020



MDF FACEBOOK POSTS &
PRIVATE GROUPS RECEIVED

> 8,500 LIKES,
COMMENTS & SHARES



200 hours of in-person
& virtual support
group meetings



DOWNLOADS OF THE MDF TOOLKIT
& OTHER ONLINE RESOURCES

Our mission, “Care and a Cure,” is to enhance the quality of life of people living with myotonic dystrophy (DM) and accelerate research focused on finding treatments and a cure.

The Myotonic Dystrophy Foundation (MDF) is the world's largest DM-focused patient advocacy organization. Our programs include funding critical research, providing comprehensive resources and support to people living with the disease, and advocating with government agencies to enhance the drug development pipeline, increase research funding and improve patient services.

CARE IMPACT

- **More than 15,000 DM patients and family members** worldwide are served by our support programs and resources every year
- MDF hosts the **largest annual DM-focused conference in the world**, delivering education and support programs, convening stakeholders and connecting research and industry professionals and community members
- We have improved care for affected individuals by **publishing clinical care recommendations** with an international network of medical experts
- MDF spearheaded a multi-pronged effort with the U.S. Social Security Administration to **improve access to disability benefits** for people living with myotonic dystrophy
- Our **support group network, Warmline and Phone Buddies programs** connect and support MDF community members around the world

CURE IMPACT

- Over the last 5 years, MDF invested more than **\$5 million in a drug development acceleration** effort including 15 major initiatives designed to attract more industry investment, lower barriers to therapy development, and expand the amount of data available to drive discovery
- MDF's efforts have attracted more than **40 companies** into DM drug development with the anticipation of new therapies entering clinical trials in 2021
- We have expanded the DM **clinical trial infrastructure** projects by funding the DM Clinical Research Network (DMCRN) which now includes **16 global research centers**
- More than **30 DM research fellows** have been funded leading to over **70 new peer-reviewed publications** now advancing DM academic knowledge and research
- MDF maintains one of the **largest DM patient registries in the world** to ensure to collect data needed for better disease understanding and ensure that the community is organized and trial-ready
- MDF's **advocacy for additional DM funding** at the National Institutes of Health, the Centers for Disease Control and the Department of Defense, has led to **\$5.47 million** in new government funding since 2018

YOUR DONATIONS AT WORK

Approximately 80 cents of every dollar donated goes straight to funding research and providing resources to families living with DM.

