



**Our mission is to enhance the quality of life of people living with myotonic dystrophy (DM) and advance research focused on treatments and a cure.**

Myotonic is the world's largest DM-focused patient advocacy organization. Our programs include funding critical research, providing comprehensive resources and support to affected individuals, and advocating with government agencies to enhance the drug development pipeline, increase research funding and improve patient services.

# OUR IMPACT REPORT

2018 - 2019

**THE MYOTONIC COMMUNITY  
SPANS 78 COUNTRIES**



**MORE THAN 500**  
Warmline calls & emails  
from people living with  
DM, caregivers, medical  
professionals & others

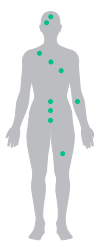


MYOTONIC FACEBOOK  
POSTS & STORIES RECEIVED

**>12,500 LIKES,**  
COMMENTS & SHARES



**28,000+**  
VISITORS  
explored the online  
Myotonic Body Systems Tool



**200** hours of in-person  
& virtual support  
group meetings



DOWNLOADS OF THE MYOTONIC  
TOOLKIT & OTHER  
ONLINE RESOURCES

## CARE IMPACT

- **More than 15,000 DM individuals and family members** worldwide are served by our support programs and resources every year
- Myotonic 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
- Myotonic 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 Myotonic community members around the world

## CURE IMPACT

- In 2015, Myotonic launched a **\$5 million, 3-year 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
- Myotonic'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** 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
- Myotonic maintains one of the **largest DM patient registries in the world** and is working with other registries throughout the US and abroad to collect and harmonize data needed for better disease understanding and ensure that the community is organized and trial-ready
- Myotonic'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

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

