



## Care and a Cure

# CARE PROGRAMS REPORT

2017 - 2018



THE MDF COMMUNITY SPANS  
62 COUNTRIES



**MORE THAN 500**

Warmline calls & emails  
from people living with  
DM, caregivers, medical  
professionals & others

MDF FACEBOOK POSTS &  
PRIVATE GROUPS RECEIVED

**>38,000 LIKES,**  
COMMENTS & SHARES



**55,000+**  
**VISITORS**

explored the online  
MDF Body Systems Tool

**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 treatments and a cure.

When it comes to Care, MDF delivers a comprehensive array of resources that includes toolkits, guidelines, conferences and events, a comprehensive website, a live Warmline, support groups and much more. MDF's goal is to anticipate and fulfill the Care needs of families living with DM.

## NEW MDF CARE INITIATIVES

### CLINICAL CARE RECOMMENDATIONS

MDF recruited an international team of over 66 clinical experts to develop best-in-class clinical care recommendations for professionals serving adults with myotonic dystrophy type 1 (DM1). Care recommendations are also available for childhood myotonic dystrophy patients and people living with myotonic dystrophy type 2 (DM2). Recommendations for specialists in cardiac, respiratory care, and speech and language pathology will be available soon.

### MDF EMPLOYMENT ACCESS PROGRAM

MDF is launching an access-to-work program in 2019 that will connect job placement experts and appropriate state and federal agencies to assist MDF community members in securing meaningful employment in work environments that accommodate the DM-related limitations they may face. Watch for the new toolkit that will help our community navigate the complex job landscape.

### GOING TO SCHOOL WITH MYOTONIC DYSTROPHY: A GUIDE TO UNDERSTANDING SPECIAL EDUCATION AND IDEA

As children ages 1-21 with congenital and childhood-onset myotonic dystrophy transition through stages of life, guidelines can help parents communicate with education and medical professionals to ensure high-quality and appropriate services and support for their children into young adulthood. MDF collaborated with an MDF community panel and experts in early intervention, literacy, assessment, system accountability, accessibility, employment, social/emotional learning, and disability and health on this comprehensive guide.

### MDF DM DAYS

MDF is joining forces with DM clinical care centers in the U.S. to offer local resource summits. These special one-day free events will bring together clinicians, researchers and MDF community members, and will feature patient-centered programming, breakout sessions, as well as interactive Ask-The-Experts sessions.



# MDF CARE TOOLS & RESOURCES

## BODY SYSTEMS TOOL

One of MDF's most popular resources for individuals and families affected by myotonic dystrophy, this interactive online tool helps users understand the complexities of this multi-systemic genetic disorder that can affect all age groups.

## MDF TOOLKIT

To help families and healthcare providers, MDF created its cornerstone resource, the MDF Toolkit. Developed and updated by the MDF Scientific Advisory Committee, the toolkit includes valuable information for affected individuals and their families, as well as resources for medical professionals.

## SOCIAL SECURITY BENEFITS TOOLKIT

MDF published a step-by-step guidebook to help individuals and families understand the process of applying for disability benefits available through the U.S. Social Security Administration (SSA). The toolkit assists individuals in navigating the application process for Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) benefits.

## ANESTHESIA GUIDELINES

Anesthesia and opioids create special, potentially life-threatening risks for myotonic dystrophy patients. Serious complications are most common in post-anesthesia when risk of aspiration and other complications increase. MDF created life-saving guidelines for anesthesiologists and other healthcare providers treating DM patients.

## FIND A DOCTOR PROGRAM

MDF developed this online search tool to connect members of the MDF community to a variety of medical professionals who understand DM and have experience in treating DM patients. This constantly expanding, community-generated list features clinicians based in countries around the globe.

## FINANCIAL RESOURCES TOOLKIT

When an individual or family is faced with a progressive condition like myotonic dystrophy, additional financial expenses and loss of steady income might accompany the disease. This toolkit compiles national resources available to DM families across the U.S. State-based guides are currently under development.

## DIGITAL ACADEMY

The MDF website offers more than 100 hours of inspirational and informative webinars, videos, educational resources and family stories that cover topics ranging from disease understanding to symptom management.

## MDF ANNUAL CONFERENCE

The MDF Annual Conference gathers hundreds of families, clinicians, researchers, industry representatives and caregivers working to improve the lives of people living with DM. Highlights include information sessions, resource fairs, networking opportunities, research updates and industry presentations on drug development efforts.

## MDF WARMLINE

MDF offers professionally-staffed phone support for over 250 family members and medical professionals who call each year for resources, support and referrals.

## MDF SUPPORT GROUPS

MDF supports dozens of in-person and virtual meetings taking place in MDF communities around the world. The meetings bring community members together to share their experiences, create supportive friendships and reduce the isolation that often accompanies this disease.

## MDF JUVENILE-ONSET ADULT PROGRAM

The MDF Juvenile-onset Adult (JOA) program is a new program created to meet the unique needs of the JOA population. This comprehensive support program includes offerings specifically for the JOA community; a private Facebook group, monthly Facebook chats, monthly group phone support, a caregiver toolkit, an updated MDF Annual Conference track, and camp.

MDF's sole Care focus is to protect and improve the quality of life of the international community of people and families living with myotonic dystrophy.

To access professional and patient resources or find out how you can help support Care and a Cure, visit [www.myotonic.org](http://www.myotonic.org) or call 415-800-7777.

