



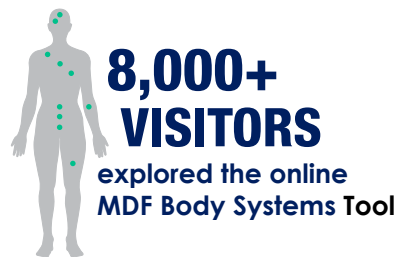
CARE PROGRAMS REPORT

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.

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

When it comes to Care, the Myotonic Dystrophy Foundation (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.

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 [children living with myotonic dystrophy type 1 \(CDM\)](#) as well as for [adults living with myotonic dystrophy type 2 \(DM2\)](#). In addition, MDF has also developed recommendations for specialists in [cardiac](#), [respiratory care](#), and [speech and language pathology](#). MDF provides topic specific guidelines on [physical therapy](#), [COVID-19](#), and [anesthesia](#). These resources can be accessed digitally at www.myotonic.org/toolkits-publications.

MDF EMPLOYMENT ACCESS PROGRAM

MDF launched an access-to-work program in 2020 that connects 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. Read the new [MDF Employment Access Toolkit](#) for help navigating the complex job landscape.

BUILDING BETTER QUALITY OF LIFE

MDF has developed a series of guidelines focused on personal care and daily activities for people living with DM. In collaboration with professionals specializing in myotonic dystrophy, MDF has created reference guidelines on [exercise](#) and [nutrition](#), a community sourced [cook book](#), [health insurance](#), and a reference for [occupational therapists](#).

ADAPTING TO A NEW NORMAL

In spite of the [COVID-19 Pandemic](#), MDF connected more clinicians, researchers and MDF community members across the globe than ever before. To support the DM community MDF pivoted to a socially distanced program and developed [DM specific respiratory guidelines](#), a [vaccine FAQ](#), and a brand new [webinar series](#). MDF continues to build on these programs with the [Ask-the-Expert](#) and [Meet the DM Drug Developer](#) webinar series.

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](#) as well as a [quick reference version](#) for anesthesiologists and other healthcare providers treating people living with DM.

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. as well as [State-based guidelines](#) focused on local resources.

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.

To access professional and patient resources for myotonic dystrophy or find out how you can help support Care and a Cure, visit www.myotonic.org or call 415.800.7777.