



CARE PROGRAMS REPORT

2018 - 2019



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

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'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, Myotonic delivers a comprehensive array of resources that includes toolkits, guidelines, conferences and events, a comprehensive website, a live Warmline, support groups and much more. Myotonic aims to anticipate and fulfill the Care needs of families living with DM.

MYOTONIC CARE INITIATIVES

CLINICAL CARE RECOMMENDATIONS

Myotonic 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 and people living with myotonic dystrophy type 2 (DM2), as well as for specialists in cardiac and respiratory care.

MYOTONIC EMPLOYMENT ACCESS PROGRAM

Myotonic is launching an access-to-work program in 2020 that will connect job placement experts and appropriate state and federal agencies to assist Myotonic 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. Myotonic collaborated with a Myotonic community panel and experts in early intervention, literacy, assessment, system accountability, accessibility, employment, social/emotional learning, and disability and health on this comprehensive guide.

MYOTONIC DM DAYS

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

MYOTONIC CARE TOOLS & RESOURCES

BODY SYSTEMS TOOL

One of Myotonic'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.

MYOTONIC TOOLKIT

To help families and healthcare providers, Myotonic created its cornerstone resource, the Myotonic Toolkit. Developed and updated by the Myotonic 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

Myotonic 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 patients living with myotonic dystrophy. Serious complications are most common in post-anesthesia when risk of aspiration and other complications increase. Myotonic created life-saving guidelines for anesthesiologists and other healthcare providers treating DM patients.

FIND A DOCTOR PROGRAM

Myotonic developed this online search tool to connect members of the Myotonic 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. Individual state-specific guides are currently under development.

DIGITAL ACADEMY

The Myotonic 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.

MYOTONIC ANNUAL CONFERENCE

The Myotonic 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.

MYOTONIC WARMLINE

Myotonic offers professionally-staffed phone support for over 500 family members and medical professionals who call each year for resources, support and referrals.

MYOTONIC SUPPORT GROUPS

Myotonic supports dozens of in-person and virtual meetings taking place in DM 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.

MYOTONIC JUVENILE-ONSET ADULT PROGRAM

The Myotonic Juvenile-onset Adult (JOA) program is a 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, a caregiver toolkit, a special Myotonic Annual Conference track, and summer camp.

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