

Resources

Written by Admin At PatientCrossroads

Wednesday, 06 February 2013 01:14 - Last Updated Wednesday, 21 October 2015 16:44

Find a host of resources to support you and your family members living with DM. Access information on how to better manage symptoms, patient advocacy groups, online support resources, and more.

[Managing DM](#) . Myotonic dystrophy symptoms tend to worsen gradually over several decades. While no treatment exists that slows the progression of myotonic dystrophy, management of its symptoms can greatly improve quality of life. Taking steps early to prevent or treat problems as they come up can help avert complications.

[Myotonic Dystrophy Foundation Toolkit](#) , produced by the Myotonic Dystrophy Foundation. MDF has created an easy-to-use Toolkit with the guidance of the MDF medical and scientific advisory committee. The Toolkit includes valuable information for affected individuals and their families, detailed information and resources for medical professionals, **Myotonic Dystrophy: The Facts** , by Prof. Peter Harper, a wallet-sized medical alert card, a medical history sheet and much more.

[Financial Resources for People Living with DM](#) offers a compilation of financial resources available on a federal/national level for people living with myotonic dystrophy in the United States. The information was compiled by Dr. Leslie Krongold, a member of the extended MDF team, a DM support group leader and a DM community member. Click [here](#) to go directly to the document, or click [here](#) to download the information as a PDF.

[Anesthesia Guidelines](#). Regardless of the form of DM or the severity of DM symptoms experienced, individuals can have severe and life-threatening reactions to anesthesia and should be monitored carefully whenever anesthesia is administered.

[Myotonic Dystrophy Foundation Warmline](#) . Professionally staffed phone and email support for people living with myotonic dystrophy, their caregivers, medical professionals and others interested in support, guidance, advice and resources for myotonic dystrophy.

Resources

Written by Admin At PatientCrossroads

Wednesday, 06 February 2013 01:14 - Last Updated Wednesday, 21 October 2015 16:44

[PubMed](#) . PubMed is a searchable database of published scientific research articles maintained by the National Library of Medicine. This site is designed for researchers and clinicians and contains journal articles about research in myotonic dystrophy. View their online tutorials on the use of the site. Visitors can search terms such as myotonic dystrophy, Steinert's disease, proximal myotonic myopathy, and PROMM to find articles about research into myotonic dystrophy.

[ClinicalTrials.gov](#) . ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted in the United States and around the world. The website is maintained by the National Library of Medicine. You can search for studies by topic and find out more information about a study's purpose, who may participate, locations and phone numbers for more details.

[Aging Well with Muscular Dystrophy: Dealing with Pain](#)

[National DM & FSHD Registry](#) . This registry is housed at the University of Rochester and is a separate registry from MDFR. The information collected from this registry is used to develop critically important natural history, disease progression and other myotonic dystrophy data to promote long-term understanding and discovery.

PATIENT ADVOCACY GROUPS:

[Myotonic Dystrophy Foundation](#)

[Treat-NMD](#)

[Muscular Dystrophy Association](#)

Resources

Written by Admin At PatientCrossroads

Wednesday, 06 February 2013 01:14 - Last Updated Wednesday, 21 October 2015 16:44

ONLINE SUPPORT RESOURCES

[Myotonic Dystrophy Support Group](#)

[Myotonic Dystrophy Foundation Community Forum](#)