

## FOR IMMEDIATE RELEASE

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### International Myotonic Dystrophy Awareness Day Declared for September 15, 2021

February 28, 2021, Worldwide: In honour of Rare Disease Day 2021, a global alliance of myotonic dystrophy-focused organisations have, for the first time, united to announce the declaration of **International Myotonic Dystrophy Awareness Day** to be observed each September 15<sup>th</sup>.

Raising awareness of myotonic dystrophy (DM) is critical as it is a rare, multi-systemic, progressive, inherited disease that affects successive family generations but is often misdiagnosed and poorly supported. Myotonic dystrophy is the most common form of adult muscular dystrophy and considered the most variable of all known conditions, yet there is currently no cure and there are no approved treatments.

Often quoted as affecting 1 in 8,000 people in the general population, [a recent genetic study has shown the disease to be far more common at 1 in 2,100](#), and some regions may be as high as 1 in 550. *There are well over a million people living with DM globally, yet thousands of people do not know they have the disease and are in need of care.*

Caused by an inherited genetic anomaly, individuals with DM experience varied and complex symptoms, from locked muscles (myotonia), to heart, breathing, digestive, hormonal, and cognitive difficulties. It is common for older family members to be

diagnosed following the birth of particularly affected child and, despite the availability of simple genetic tests, misdiagnoses persist for decades.

The declaration of International Myotonic Dystrophy Day is a collaboration of dozens of myotonic dystrophy groups and organisations from around the globe – each dedicated to helping raise awareness of the condition in their local geographies on September 15, 2021 and beyond.

“By coordinating the communication of these different organisations, the voice of the DM community will be amplified and magnified, providing a broader and more comprehensive awareness across the globe,” reflected Midori Senoo, Managing Director of the [Myotonic Dystrophy Patients' Group of Japan](#) (DM-family).

“International Myotonic Dystrophy Awareness Day aims to make this condition more widely known by garnering the attention of the wider general public, healthcare providers, policy makers, regulators, education providers, biopharmaceutical organisations, researchers, and anyone with an interest in changing the future of myotonic dystrophy. It is an opportunity to share knowledge and help improve care. This will complement the annual July Family Day event whilst focusing global attention on DM each September.” said Emma-Jayne Ashley, Founding Trustee of [Cure DM in the UK](#).

This is an exciting time for the DM community with multi-national recruitment of a Phase III clinical trial recently announced for the congenital form of the disease and significant new investment into research and technologies focused on identifying treatments. With over [40 companies focused on myotonic dystrophy](#), the field is constantly learning and there is hope for improved quality of life, reduced disability, and increased life expectancy for individuals living with this disease within the next few years. New technologies also hold great promise for individuals with other muscular dystrophies and for conditions with a similar genetic base, such as Fragile X syndrome and Huntington’s disease. But there is more work to be done.

“We must continue to raise the profile of myotonic dystrophy to grow the attention of drug developers, clinical care teams, insurance companies, and government agencies so the devastating generational impact of this disease is evident and more

resources are amassed to improve diagnosis and quality of life, provide appropriate and early clinical care, and find effective treatments. The international effort now dedicated to raising awareness and changing the path of this disease instills confidence that we will influence major advancements,” said Dr. Tanya Stevenson, CEO of the [Myotonic Dystrophy Foundation in the US](#).

The organisations below invite all members of the global DM community to participate in International Myotonic Dystrophy Awareness Day on September 15th by talking about their experiences with friends and family, writing letters or meeting with lawmakers, advocating for DM research funding and provision of care, sharing DM [clinical care guidelines](#) with healthcare providers, raising funds for research, and other activities that will help foster greater understanding about the disease.

Learn more about the international organisations working together to raise awareness, learn how to join the movement, and find DM resources, here: [www.myotonic.org/international-dm-day](http://www.myotonic.org/international-dm-day). More information will be posted throughout the year.

**[Global Alliance Organisations Continued On Next Page](#)**

# International Myotonic Dystrophy Awareness Day

## 15<sup>th</sup> September

Listed alphabetically by country.



MDA Australia (Australia)



Association Belge contre les Maladies  
neuro-Musculaires (Belgium)



The Neuromuscular Disease  
Network for Canada (Canada)



Muskelsvindfonden  
(Denmark)



Euro-DyMA (Europe)



AFM-Téléthon (France)



Deutschen Gesellschaft für  
Muskelkranke e.V. (Germany)



Muscular Dystrophy Association  
HELLAS (Greece)



FMM - Fondazione Malattie  
Miotoniche (Italy)



Myotonic Dystrophy Patients'  
Group of Japan (Japan)



Stichting MD Nederland  
(Netherlands)



Spierziekten Nederland  
(Netherlands)



ASRIMM

Association Suisse Romande Intervenant  
contre les Maladies neuro-Musculaires  
(Switzerland)



Cure DM Myotonic Dystrophy  
UK (United Kingdom)



Myotonic Dystrophy  
SUPPORT GROUP  
Myotonic Dystrophy Support  
Group (United Kingdom)



Muscular Dystrophy UK  
(United Kingdom)



UK Myotonic Dystrophy Patient  
Registry (United Kingdom)



Muscular Dystrophy  
Association USA (USA)



Myotonic Dystrophy  
Foundation (USA)



Myotonic Dystrophy Family  
Registry (USA)



International Myotonic Dystrophy  
Consortium (Worldwide)

To join the global alliance, visit <https://www.myotonic.org/international-dm-day>