PRESS RELEASE

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INTERNATIONAL
Myotonic
Dystrophy
Awareness Day
SEPTEMBER 15

Global Alliance of 60+ Organizations Unites for Rare Disease Day to Advance Care, Research, and Access for Myotonic Dystrophy

February 28, 2026, Worldwide – In recognition of **Rare Disease Day 2026**, the Global Alliance for Myotonic Dystrophy Awareness proudly stands together as over 60 organizations worldwide raising awareness of myotonic dystrophy (DM) and advocating for improved care, research, and access for individuals and families affected by this complex rare disease.

Established in 2021, the Global Alliance brings together patient advocacy organizations, clinicians, researchers, and industry partners united by a shared commitment to improving outcomes for the global myotonic dystrophy community through collaboration, education, and advocacy.

Myotonic dystrophy is a progressive, inherited neuromuscular disease that affects multiple body systems, including muscle function, the heart, lungs, gastrointestinal system, endocrine function, and cognition. It is the most common form of adult-onset muscular dystrophy, yet it remains widely underdiagnosed and misunderstood. Many individuals experience long delays in diagnosis and limited access to specialized care, highlighting the urgent need for coordinated global action.

To address these challenges, the Global Alliance has aligned around three shared areas of focus:

1. Improving clinical education and awareness

Members of the Global Alliance work to help healthcare providers better recognize and manage myotonic dystrophy by educating physicians, nurses, therapists, and other providers. Increased awareness among clinical care teams can reduce delays in diagnosis and improve the quality and coordination of care for people living with myotonic dystrophy.

“Improving clinician education is critical to achieving faster diagnosis and improved care of people with myotonic dystrophy,” said Dr. John W. Day, Director, Neuromuscular Division and Clinics, Stanford University. “Assuring that all healthcare providers are well trained in how to access reliable, up-to-date, disease-specific information about myotonic dystrophy, directly results in better recognition, more timely diagnosis, and improved patient outcome.”

2. Preparing and supporting individuals for clinical research and trials

With a growing pipeline of promising research and potential therapies, clinical trial readiness has become increasingly important. The Global Alliance supports efforts to provide clear, accessible information about research and clinical trials, so individuals living with myotonic dystrophy understand what to expect and feel supported throughout the research process.

“Patient registries are a cornerstone of clinical trial readiness,” said Ms. Helen Walker, UK Myotonic Dystrophy Patient Registry Project Manager. “They help connect individuals to research opportunities, support trial planning, and ensure the voices of people living with myotonic dystrophy are represented. Registries play a vital role in accelerating research while empowering patients to participate with confidence.”

3. Supporting access to care and treatment coverage

The Global Alliance also works to improve access to essential care and treatment by engaging policymakers, insurers, and healthcare systems. This includes advocating for coverage of diagnostic testing, specialist care, medical equipment, supportive therapies, and future disease-modifying treatments.

“Improving outcomes for people living with myotonic dystrophy requires more than scientific progress, it demands equitable and immediate access to emerging knowledge, treatments, and therapies,” said Dr. Andy Rohrwasser, Chief Scientific Officer at the Myotonic Dystrophy Foundation. “All patients must be able to obtain timely diagnoses, receive specialized multidisciplinary care, and benefit from emerging therapies as soon as they become available. Through collaboration with clinicians, policymakers, and global partners, we reduce barriers and ensure that advances in research translate into meaningful impact for the entire DM community.”

Together, these efforts reflect the continued growth and maturity of the global myotonic dystrophy ecosystem. In recent years, advances in research, increased collaboration, and stronger patient engagement have created renewed momentum and optimism for the future of myotonic dystrophy care and treatment.

The Global Alliance also encourages the community to look ahead to **International Myotonic Dystrophy Awareness Day on September 15**. Planning is already underway for monument light-ups, proclamations, and local awareness activities around the world. Communities are encouraged to begin outreach efforts now to help amplify awareness and participation.

Through collective action on Rare Disease Day and beyond, the Global Alliance for Myotonic Dystrophy Awareness remains committed to driving progress, fostering collaboration, and improving the lives of people living with myotonic dystrophy worldwide.

For more information and to get involved, visit:
https://www.myotonic.org/international-dm-day

The Global Alliance for Myotonic Dystrophy Awareness

INTERNATIONAL
Myotonic Dystrophy
Awareness Day
SEPTEMBER 15

To learn more and apply to join the Global Alliance, please visit www.myotonic.org/international-dm-day

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ASMNM

MUSCULAR DYSTROPHY AUSTRALIA

ABMM ASBL Téléthon.be

NMD4C

MDC MUSCULAR DYSTROPHY CANADA
DMC DYSTROPHIE MUSCULAIRE CANADA

MUSKELSVINDFONDEN plads til forskelle!

EURO-DYMA

AFMTÉLÉTHON INNOVER POUR GUÉRIR

DGM Deutsche Gesellschaft für Muskelkranke e.V.

MDA ΕΛΛΑΣ
ΣΩΜΑΤΕΙΟ ΦΡΟΝΤΙΔΑΣ ΑΤΟΜΩΝ ΜΕ ΝΕΥΡΟΜΥΙΚΕΣ ΠΑΘΗΣΕΙΣ

CENTRO CLINICO Nemo

fm fm

DM family

Maastricht UMC+

MD NEDERLAND

SPIERZIEKTEN NEDERLAND

THE UNIVERSITY OF AUCKLAND NEW ZEALAND

F B

ARTHEx biotech

ciber CENTRO DE INVESTIGACIÓN BIOMÉDICA EN RED

DM1-Hub

IGTP Germans Trias i Pujol Research Institute

INCLIVA | VLC Instituto de Investigación Sanitaria

VNIVERSITAT DE VALÈNCIA Translational Genomics Group

ASRIMM

LUPIN NEUROSCIENCES

NOVARTIS

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Cure DM Research ♥ Support ♥ Awareness

Myotonic Dystrophy SUPPORT GROUP

Muscular Dystrophy UK Fighting muscle-wasting conditions

St George's University Hospitals NHS Foundation Trust
Outstanding care every time

TREAT-NMD Neuromuscular Network

UK Myotonic Dystrophy Patient Registry
Newcastle University
John Walton Muscular Dystrophy Research Centre

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HOUSTON Methodist LEADING MEDICINE

Juvena THERAPEUTICS Decoding Secreted Proteins

K-STATE

SCHOOL OF MEDICINE DEPARTMENT OF NEUROLOGY

The Jackson Laboratory Leading the search for tomorrow's cures

MDA Muscular Dystrophy Association

Myotonic Dystrophy FOUNDATION

Myotonic Dystrophy Family Registry

Connecting people with researchers

Paul D. Wellstone Muscular Dystrophy Research Centers

PepGen

Stanford MEDICINE

UF Center for NeuroGenetics College of Medicine UNIVERSITY of FLORIDA

NeuroGenetics Student Organization at the University of Florida

THE RNA INSTITUTE COLLEGE OF ARTS & SCIENCES UNIVERSITY AT ALBANY

UNIVERSITY OF IOWA HEALTH CARE

HEALTH UNIVERSITY OF UTAH

VERTEX

VCU School of Medicine

Wake Forest School of Medicine

IDMC15 International Myotonic Dystrophy Consortium Meeting - 15 Saguenay.Québec.Canada