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US Contact Name: Tanya Stevenson
US Contact Email: Tanya.Stevenson@myotonic.org

UK Contact Name: Emma-Jayne Ashley
UK Contact Email: curedm@outlook.com

Spain Contact Name: Javier Baigorri
Spain Contact Email: info@adm1es.com

Global Alliance Recognizes Sixth International Myotonic Dystrophy Awareness Day

More than 60 organizations unite to strengthen awareness, registries, research, and access to care for people living with myotonic dystrophy (DM).

15 September 2026, Worldwide: The Global Alliance for Myotonic Dystrophy Awareness (Global Alliance) proudly celebrates the sixth annual International Myotonic Dystrophy Awareness Day. More than 60 organizations from around the world are uniting to raise awareness, advance research, and improve care and quality of life for people living with myotonic dystrophy (DM) and their families.

Building on six years of international collaboration, the Global Alliance remains committed to three shared areas of focus: improving education and awareness about DM among healthcare professionals; preparing and supporting people living with DM to take part in clinical research and trials; and advancing access to comprehensive care and future treatments.

Myotonic dystrophy is a complex, inherited, and progressive disease with symptoms that can begin at any age. DM is the most common form of adult-onset muscular dystrophy and affects many body systems, including muscle function, the heart, lungs, endocrine system, gastrointestinal system, and cognition. Although DM may affect as many as 1 in 2,100 people, myotonic dystrophy remains under-recognized, and diagnosis is often delayed for years after symptoms first appear. Greater awareness can support earlier diagnosis, better care, and future treatment opportunities for the DM community.

As the global myotonic dystrophy community continues to grow stronger, international collaboration has become one of the greatest drivers of progress.

Strengthening patient registries around the world is a key part of this work. High-quality registries help researchers understand the natural history of DM, identify potential participants for clinical studies, and ensure the experiences of people living with DM are reflected in the development of future therapies. “The progress we've made over the past several years demonstrates what can be achieved when organizations around the world work towards a common goal,” said Dr. Gisela Nogales, Principal Investigator of DM1-Hub in Spain. “By sharing knowledge, collaborating across borders, and building robust patient registries, we are laying the foundation for breakthrough research, improved clinical care, and ultimately better outcomes for people living with myotonic dystrophy.”

The momentum surrounding myotonic dystrophy research has never been greater. Around the world, researchers, clinicians, industry partners, and patient organizations are working together to better understand the disease and evaluate potential therapies. With an increasing number of clinical studies and investigational programs underway, there is growing optimism that today's research will lead to tomorrow's treatments.

“Commenting on recent scientific advice received from FDA, Health Canada, and MHRA on how to move forward with another clinical study marks an exciting milestone not only for AMO, but hopefully for the entire myotonic dystrophy community,” said Dr. Mike Snape, CEO of AMO Pharma. “Every new trial represents another opportunity to deepen our understanding of myotonic dystrophy and move potential therapies closer to the people who need them. Continued collaboration among researchers, clinicians, patient organizations, and individuals living with myotonic dystrophy will be essential to maintaining this momentum.”

Improving daily life for people living with myotonic dystrophy and their families also remains central to the Global Alliance's mission. Access to knowledgeable healthcare professionals, reliable information, support services, and community connections can make a meaningful difference throughout diagnosis and care.

“Living with a rare condition can feel isolating, but no family should have to navigate myotonic dystrophy alone,” said Alan Breathnach, CEO of Muscular Dystrophy Ireland. “Awareness creates understanding, understanding leads to earlier diagnosis and better care, and together we can build stronger support networks that empower individuals and families at every stage of their journey.”

The Global Alliance encourages everyone to take part in International Myotonic Dystrophy Awareness Day on 15 September by wearing green, telling their stories, sharing educational resources, connecting with elected officials, requesting that local landmarks be illuminated in green, and raising awareness in their communities. Every conversation, shared resource, and act of advocacy brings us closer to a future where people living with myotonic dystrophy receive timely diagnosis, comprehensive care, and effective treatments.

Together, we are changing the future of myotonic dystrophy.

About the Global Alliance for Myotonic Dystrophy Awareness

Established in 2021, the Global Alliance for Myotonic Dystrophy Awareness now includes more than 60 international nonprofit and charitable organizations, academic and research institutions, biotechnology and pharmaceutical companies, patient advocacy groups, and others working together to raise awareness of myotonic dystrophy around the world.

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