

PRESS RELEASE

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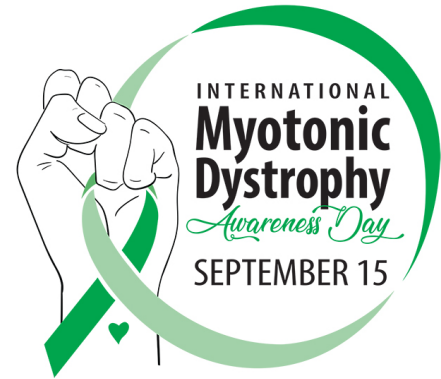
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FOR IMMEDIATE RELEASE

Myotonic Dystrophy Advocates Join Forces: 57+ Global Alliance Organisations Unite to Raise Awareness on Rare Disease Day 2024

February 9, 2024, Worldwide: In honor of Rare Disease Month 2024, the [Global Alliance for Myotonic Dystrophy Awareness](#), for the 4th year running, proudly stands together to celebrate the remarkable strength and resilience of the myotonic dystrophy (DM) community around the globe. With over 57 organisations focused on advancing the understanding of and care for this rare genetic disorder, the Global Alliance continues to be a beacon of hope for people living with myotonic dystrophy, their families, and healthcare professionals around the globe.

The Global Alliance for Myotonic Dystrophy Awareness invites individuals, organisations, and policymakers around the world to join us in raising awareness of myotonic dystrophy and advocating for improved care and research for those living with the disease.

Myotonic dystrophy (DM) is a rare and [complex disease](#) affecting muscle strength and wasting, respiratory systems, heart function, cognitive abilities, and more. DM is a progressive, inherited disease that affects successive generations and is often misdiagnosed and poorly supported. [With as many as 1 in 2,100 individuals at risk of developing the disease or passing it on to the next generation](#), myotonic dystrophy is the most common form of adult-onset muscular dystrophy. Despite its prevalence and complexity, there are currently no disease-modifying treatments or cures available for this debilitating condition.

While myotonic dystrophy affects people all around the world, possibly including people in your local community, it remains a relatively unknown disorder. By

joining forces to raise awareness, the Global Alliance aims to shed light on the challenges faced by those living with myotonic dystrophy and to increase awareness and understanding of the disease on all fronts.

“This year promises to be exhilarating for the DM community with six [MDF Regional Conferences in the US](#), the [14th International Myotonic Dystrophy Consortium meeting \(IDMC\) in the Netherlands](#) for DM researchers and clinicians, and incredible advancements to the [DM Drug Development Pipeline](#),” said Emily Romney, MPA, Community Education Manager at the [Myotonic Dystrophy Foundation](#). “We look forward to furthering the Global Alliance’s shared goals, as we combine forces to elevate education, awareness, and support for myotonic dystrophy, marking a significant stride toward a brighter future for individuals living with DM and their families.”

As part of the Global Alliance’s commitment to achieving positive change for individuals and families affected by DM, its members will continue to direct their energies toward two primary areas of focus in 2024:

1. Awareness and education among clinical care teams,
2. Clinical trial readiness for participants.

The first area of focus is raising awareness and education among clinical care teams. This will involve working with medical professionals to increase their understanding of DM, [including its symptoms, diagnosis, and available treatments](#). By doing so, the Global Alliance hopes to improve the quality of care that individuals with DM receive, [reduce the time to diagnosis](#), and ultimately improve their quality of life.

“In our pursuit for effective treatments and lasting solutions, we recognize the importance of collaborating with clinicians and researchers who are already involved with DM, and reaching out to those who may not be as familiar.” said Emma-Jayne Ashley, Founding Trustee at [CureDM](#). “By working together we strive to transform the landscape of myotonic dystrophy, offering hope, supporting adequate clinical care, and improving quality of life for the DM community.”

The second area of focus will be clinical trial readiness for participants. With no existing cure for DM, [clinical trials](#) are crucial to the development of new treatments and therapies. However, recruiting participants for clinical trials can be challenging, and the Global Alliance will work to improve access to information

about trials and support for those who wish to participate. The Global Alliance will also work to ensure that clinical trials are designed to be inclusive, accessible, and accommodating for all individuals with DM.

“DM awareness is ever more relevant as clinical trials are now seriously ramping up, both in the number of trials as well the number of patients that are being invited to join. There is the importance of patient recruitment for these trials, but at least as important is communicating to the wider community that the outlook for DM has fundamentally changed in only the past few years.” said Jorg van Gent from [MD Nederland](#). "The message is this: DM is a devastating disease, and now more than ever before we can work towards improving all the lives affected by one of the most prevalent rare diseases.”

The Global Alliance encourages and invites all members of the DM community to actively participate in [Rare Disease Day on February 29th](#), [DM Families Day on July 29th](#), and [International Myotonic Dystrophy Awareness Day on September 15th](#). These important days present an opportunity for individuals and organisations to come together and raise awareness of myotonic dystrophy through various activities. These may include sharing personal experiences with friends and family, writing letters to, or meeting with, [policy makers to advocate for DM research funding and provision of care](#), sharing [DM clinical care guidelines](#) with healthcare providers, organizing fundraising events, lighting up monuments and landmarks in green, and more!

Through these efforts, the Global Alliance for Myotonic Dystrophy Awareness hopes to foster wider recognition and a greater understanding of the disease and to ultimately improve the lives of those affected by it.

Together, we are changing the future of myotonic dystrophy.

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Established in 2021, the Global Alliance for Myotonic Dystrophy Awareness now includes over 57 international nonprofit organisations, academic and research institutions, biotechnology and pharmaceutical companies, patient advocacy groups, and others working together to raise myotonic dystrophy awareness. Discover DM resources and learn how you can join the movement at: <https://www.myotonic.org/international-dm-day>

The Global Alliance for Myotonic Dystrophy Awareness



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To join the Global Alliance for DM Awareness, visit <https://www.myotonic.org/international-dm-day>.