

PRESS RELEASE

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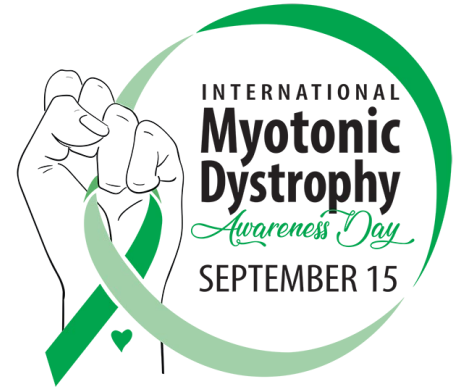
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FOR IMMEDIATE RELEASE

Global Alliance of 60+ Myotonic Dystrophy Organisations Celebrate the Fourth Annual International Myotonic Dystrophy Awareness Day

15 September 2024, Worldwide: On the 15th of September 2024, the [Global Alliance for Myotonic Dystrophy Awareness](#) unites over 60+ organisations from around the globe to mark the fourth annual International Myotonic Dystrophy Awareness Day. This day is dedicated to raising awareness about myotonic dystrophy (DM), a complex and often misunderstood genetic disease that affects thousands of individuals and families worldwide.

This Awareness Day, the Global Alliance for Myotonic Dystrophy Awareness invites individuals, organisations, and policymakers around the world to raise awareness of myotonic dystrophy. To contribute to local efforts, you may consider donating to one of the 60+ members of the Global Alliance from over 16 countries across 4 continents at: www.myotonic.org/international-dm-day

Myotonic dystrophy is a progressive, inherited [disease](#) that affects muscle strength, respiratory systems, heart function, cognitive abilities, and more. Because the disease is so complex, myotonic dystrophy is often misdiagnosed and poorly supported. By uniting efforts to raise awareness, the Global Alliance seeks to shed light on the challenges faced by those living with myotonic dystrophy and to enhance understanding of the disease worldwide.

Michael Walker, the Chair of the Board of Trustees of the [Myotonic Dystrophy Support Group based in the UK](#), who has dedicated over 20 years to the cause, emphasises the importance of this day, "Every year, International Myotonic Dystrophy Awareness Day provides us with a powerful platform to amplify the voices of those living with myotonic dystrophy. It is a chance to educate the health professionals, especially those in Primary Care, the local Members of Parliament, and the public, about the urgent need for better care, research, support, and understanding of the condition. Our collective efforts are vital in improving the lives of individuals and their families affected by this challenging condition."

With no current cure or disease-modifying treatments available, raising awareness and fostering research are crucial steps toward improving the lives of those impacted by this condition.

"As someone who sees the impact of myotonic dystrophy both in the research lab and in the lives of affected individuals, I am deeply committed to advancing our understanding of this disease," said myotonic dystrophy doctoral researcher Juan Arboleda, President of the [NeuroGenetics Student Organization at the University of Florida](#). "International Myotonic Dystrophy Awareness Day is a reminder that the scientific community must continue to push for breakthroughs in treatment and care, while also fostering hope for those living with DM."

The Global Alliance for Myotonic Dystrophy Awareness recognises the importance of uniting under a common goal of therapies and ultimately, a cure. Catherine Stace, CEO of [Muscular Dystrophy Australia](#), highlights the global reach of the Alliance, "In Australia and beyond, we are united in our mission to bring myotonic dystrophy out of the shadows. By working together with our global partners, we are not only raising awareness but also driving meaningful change in how this condition is perceived and managed. The strength of our community lies in our ability to support one another and advocate for a future where no one has to face myotonic dystrophy alone."

The Global Alliance for Myotonic Dystrophy Awareness invites everyone—individuals, families, healthcare professionals, companies, hospitals/clinics, research labs and advocates—to participate in this year’s International Myotonic Dystrophy Awareness Day on the 15th of September. Through your participation, you will shed light on the challenges faced by those with DM and promote a greater understanding of the disease.

Together, we can change the future of myotonic dystrophy.

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Established in 2021, the Global Alliance for Myotonic Dystrophy Awareness now includes over 60 international nonprofit organisations, academic and research institutions, biotechnology and pharmaceutical companies, patient advocacy groups, and others working together to raise myotonic dystrophy awareness. Discover myotonic dystrophy resources and learn how you can join the movement at: www.myotonic.org/international-dm-day

The Global Alliance for Myotonic Dystrophy Awareness

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

