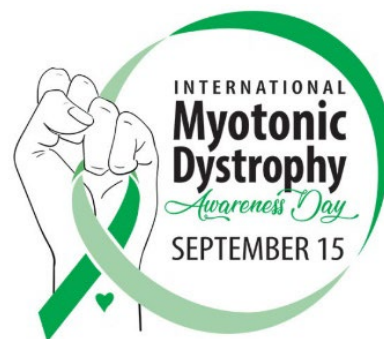


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Global Alliance of 60+ Myotonic Dystrophy Organizations Recognizes 5th Annual International Myotonic Dystrophy Awareness Day, September 15, 2025

September 15, 2025, Worldwide – The [Global Alliance for Myotonic Dystrophy Awareness](#) (Global Alliance) proudly marks the fifth annual International Myotonic Dystrophy Awareness Day, bringing together over 60 organizations from 17 countries across five continents in a unified effort to raise awareness, promote research, and advocate for improved care for individuals and families affected by [myotonic dystrophy](#).

As the most common form of adult-onset muscular dystrophy, myotonic dystrophy is a complex, inherited, and progressive disorder that affects multiple body systems including muscle, respiratory, cardiac, gastrointestinal, and cognitive function. Despite its prevalence, affecting as many as 1 in 2,100 people, myotonic dystrophy remains underdiagnosed and widely misunderstood. Raising global awareness is essential not only for increasing understanding, but also for empowering individuals and driving meaningful change.

"This Awareness Day is a powerful reminder that no matter where we are in the world, we are united by a shared mission: to uplift individuals and families living with myotonic dystrophy," said Dr. Andrea Swenson from the [University of Iowa Health Care Medical Center](#). "By working together across borders, languages, and healthcare systems, we can accelerate progress and create lasting change for the global myotonic dystrophy community."

With no treatment currently available, ensuring that individuals living with myotonic dystrophy are informed, supported, and prepared to participate in research and [clinical trials](#) is critical to the success of these trials and to future treatment breakthroughs. This has become a key focus for the Global Alliance, especially as the number of promising investigational therapies [continues to grow](#).

"Clinical trial readiness is about more than just enrolling participants, it's about making sure individuals are aware of their options, understand what to expect, and feel confident stepping into the research process," said Dr. Araya Puwanant from [Wake Forest University School of Medicine](#). "It's an incredibly exciting time in the myotonic dystrophy community, with more potential therapies on the horizon than ever before. We want to make sure the community is prepared to step up, take part in, and ultimately advance trials and studies."

International Myotonic Dystrophy Awareness Day also shines a light on the importance of sustained and collaborative research efforts. Progress in understanding the genetic, molecular,

and clinical complexities of myotonic dystrophy has accelerated in recent years, thanks to the contributions of researchers, patient registries, and international partnerships.

“Research is the foundation of every breakthrough. From identifying disease mechanisms to exploring potential interventions, the work being done in labs and clinics around the world brings us closer to treatments every day,” said Dr. Anne Bruijnes from [Maastricht University Medical Center+](#). “The commitment of our research community, alongside the voices of those living with myotonic dystrophy, is driving this movement forward.”

The progress being made in myotonic dystrophy research and therapeutic development and testing is a testament to what can be achieved through global collaboration and sustained commitment. As we reflect on how far we’ve come, the Global Alliance also looks ahead, inviting everyone to be part of the movement for change. The Global Alliance encourages supporters to take action by sharing stories on social media, lighting up landmarks in green, engaging policymakers, and distributing educational materials within their local communities.

For more information and to get involved, visit:
<https://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/international-dm-day

