



## **Myotonic Dystrophy Foundation Applauds U.S. Senator Tim Kaine for Leading Resolution Designating September 15<sup>th</sup> International Myotonic Dystrophy Awareness Day**

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**August 4, 2021. Worldwide:** The Myotonic Dystrophy Foundation (MDF) applauds U.S. Senator Tim Kaine (D-VA) for introducing the first ever U.S. Senate resolution designating September 15<sup>th</sup> as International Myotonic Dystrophy Awareness Day. Raising awareness of myotonic dystrophy is critical as it is a rare, multi-systemic, progressive, inherited disease that affects successive family generations but is often misdiagnosed and poorly supported. Affecting as many as 1 in 2,100 individuals, myotonic dystrophy is the most common form of adult muscular dystrophy and considered the most variable of all known conditions, yet there is currently no cure and there are no approved treatments.

“Despite its prevalence, myotonic dystrophy remains one of the least researched and funded genetic disorders. Senator Kaine’s resolution will help to highlight the devastating generational impact of this disease, focus global attention on accelerating drug discovery, and work to advance healthcare for our community,” said Dr. Tanya Stevenson, CEO of the Myotonic Dystrophy Foundation in the US. “We are grateful for Senator Kaine’s leadership in our international efforts to reduce time to diagnosis, improve quality of life, provide appropriate and early clinical care, and find effective treatments for individuals and families living with myotonic dystrophy.”

Virginia-based researchers are among the global leaders working to better understand myotonic dystrophy and discover new treatments and a cure. Much of this work is being led by researchers at Virginia Commonwealth University (VCU) and supported by local Virginia MDF advocates.

“VCU is leading international research efforts to better understand the causes of myotonic dystrophy type 1, which we estimate impacts 975,000 to 3 million people globally,” said Nicholas Johnson, M.D., Associate Professor and Vice Chair of Research in the Department of Neurology at VCU School of Medicine. “Senator Kaine’s resolution is an important step in our global campaign to build myotonic dystrophy awareness, which we hope will lead to an increase in resources to advance research that will benefit the myotonic dystrophy community as well as individuals living with related repeat expansion disorders like ALS and Huntington’s disease.”

“As the father of two sons who were diagnosed with myotonic dystrophy in 2006, we know firsthand how limited awareness of the disease makes it harder to get a diagnosis and find proper medical care,” said Todd Stone, former MDF Board Member from Richmond, Virginia. “We are thankful for Senator Kaine’s work to help advance research and improve the quality of life of



individuals with myotonic dystrophy. His work on this front first began when he met my sons soon after their myotonic dystrophy diagnosis and then served on the Myotonic Dystrophy Foundation Board of Directors. His continued leadership in the Senate to change the future of this disease is inspiring.”

David Brand, an MDF advocate from Virginia Beach said, “It took almost a year for my three-year old granddaughter to receive a diagnosis of the congenital form of myotonic dystrophy after an unexpected two-month stay in the hospital. Thankfully she is receiving good care following her diagnosis but her doctors can only treat her symptoms as there are no FDA approved treatments for myotonic dystrophy and government research is limited. Senator Kaine’s efforts give me hope that my granddaughter and thousands of other kids, and adults, with this rare genetic disorder will have a brighter future.”

Caused by an inherited genetic anomaly, individuals with myotonic dystrophy experience varied and complex symptoms, from locked muscles (myotonia), to heart, breathing, digestive, hormonal, and cognitive difficulties. It is not uncommon for older family members to only be tested following the birth of a particularly affected child, and despite the availability of simple genetic tests, misdiagnoses can persist for decades.

Myotonic dystrophy does not always look the same. The different body systems affected, the severity of symptoms, and the age of onset of those symptoms varies greatly between individuals, even within the same family. Many of these individuals live with debilitating symptoms yet in the majority of situations, they never receive adequate or proactive medical care which could dramatically improve their quality of life. More research is desperately needed to change this reality.

The U.S. myotonic dystrophy Senate Resolution is part of a global movement that includes over 40 international organizations involved in myotonic dystrophy. All are united in raising awareness of the condition in their local geographies on September 15, 2021 and beyond. Learn more about the Global Alliance working together to raise awareness, how to join the movement, and where you can find myotonic dystrophy focused resources and clinical care guidelines: [www.myotonic.org/international-dm-day](http://www.myotonic.org/international-dm-day).

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The Myotonic Dystrophy Foundation (MDF) was founded in 2007 by families seeking answers and support. The MDF mission, "Care and a Cure," is to enhance the quality of life of people living with myotonic dystrophy and accelerate research focused on finding treatments and a cure. Through direct services, research, education, and advocacy, MDF empowers the myotonic dystrophy community, improves access to effective healthcare, and eliminates barriers to drug development. MDF is the leading global advocate helping individuals and families navigate the myotonic dystrophy disease process, and is often the first resource contacted by newly-diagnosed patients, their families, their social workers, and their physicians around the world. To learn more visit: [www.myotonic.org](http://www.myotonic.org)