

117TH CONGRESS
2D SESSION

S. RES. 772

Recognizing the seriousness of myotonic dystrophy and expressing support for the designation of September 15, 2022, as “International Myotonic Dystrophy Awareness Day”.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 19, 2022

Mr. KAINE (for himself, Ms. LUMMIS, Ms. KLOBUCHAR, and Ms. SMITH) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

SEPTEMBER 29, 2022

Committee discharged; considered and agreed to

RESOLUTION

Recognizing the seriousness of myotonic dystrophy and expressing support for the designation of September 15, 2022, as “International Myotonic Dystrophy Awareness Day”.

Whereas myotonic dystrophy is a rare, multi-systemic, inherited disease that affects approximately 1 in 2,100 individuals and more than 150,000 individuals in the United States;

Whereas 1 in 8,000 individuals are living with myotonic dystrophy globally, yet thousands of individuals do not know they have the disease and are in need of care;

Whereas myotonic dystrophy is the most common form of adult-onset muscular dystrophy, and the symptoms of the disease become more severe with each generation;

Whereas the disease is caused by a mutation in the DMPK gene, resulting in myotonic dystrophy type 1, or the CNBP gene, resulting in myotonic dystrophy type 2;

Whereas those mutations prevent those genes from functioning properly, impacting multiple body systems;

Whereas those mutations are autosomal dominant mutations, in which one copy of the altered gene is sufficient to cause the disorder, and affected individuals have a 50 percent chance of passing on the mutated gene to their children;

Whereas, through this inherited genetic anomaly, individuals with myotonic dystrophy experience varied and complex symptoms, ranging from skeletal muscle problems, early cataracts, and excessive daytime sleepiness to heart, breathing, digestive, hormonal, speech, swallowing, diabetic, immune, vision, and cognitive difficulties;

Whereas myotonic dystrophy is a highly variable and complicated disorder, and the younger an individual is when symptoms first appear, the more severe symptoms are likely to be;

Whereas misdiagnoses have persisted for decades, and delays in diagnosing myotonic dystrophy are common;

Whereas there are currently no treatments approved by the Food and Drug Administration for myotonic dystrophy;

Whereas the Myotonic Dystrophy Foundation was founded in 2007 with a mission to enhance the quality of life of individuals living with myotonic dystrophy and accelerate research focused on finding treatments and a cure;

Whereas, in 2014, Congress enacted the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2014 (Public Law 113–166; 128 Stat. 1879), which advanced muscular dystrophy research and public health surveillance activities, including for myotonic dystrophy;

Whereas, in September 2017, recognizing the seriousness of the disease and the especially disabling impact of myotonic dystrophy on individuals with congenital myotonic dystrophy, the Social Security Administration added congenital myotonic dystrophy to the Compassionate Allowance Program, which allows individuals to quickly qualify for disability benefits, including health insurance coverage;

Whereas, in 2018, Congress added myotonic dystrophy to the list of eligible conditions for research funding under the Peer Reviewed Medical Research Program of the Department of Defense, which resulted in more than \$6,000,000 in new research awards; and

Whereas a more robust scientific investment in myotonic dystrophy research will improve health outcomes, reduce disability, and increase life expectancy for individuals living with myotonic dystrophy, and holds great promise for helping individuals with similar genetic diseases: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) expresses support for the designation of
3 September 15, 2022, as “International Myotonic
4 Dystrophy Awareness Day”;

1 (2) recognizes the seriousness of myotonic dys-
2 trophy; and

3 (3) supports the goals and ideals of Inter-
4 national Myotonic Dystrophy Awareness Day, which
5 include—

6 (A) committing to promoting and advanc-
7 ing the health, well-being, and inherent dignity
8 of all children and adults with myotonic dys-
9 trophy;

10 (B) supporting the advancement of sci-
11 entific and medical myotonic dystrophy re-
12 search;

13 (C) fostering biopharmaceutical innovation
14 that will lead to Food and Drug Administra-
15 tion-approved treatments and eventually a cure
16 for myotonic dystrophy;

17 (D) advancing programs and policies that
18 assist individuals living with myotonic dys-
19 trophy and the caregivers of such individuals;
20 and

21 (E) encouraging awareness and education
22 of myotonic dystrophy for patients, caregivers,
23 clinicians, and researchers.

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