117TH CONGRESS
1ST SESSION

S. RES. 336

Designating September 15, 2021, as ''International Myotonic Dystrophy Awareness Day'' and supporting the goals and ideals of International Myotonic Dystrophy Awareness Day.

IN THE SENATE OF THE UNITED STATES

AUGUST 4, 2021

Mr. KAINE (for himself and Ms. KLOBUCHAR) submitted the following resolution; which was referred to the Committee on the Judiciary

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RESOLUTION

Designating September 15, 2021, as ''International Myotonic Dystrophy Awareness Day'' and supporting the goals and ideals of International Myotonic Dystrophy Awareness Day.

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

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

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

Whereas the disease is caused by mutations in the DMPK gene and the CNBP gene, resulting in myotonic dystrophy type 1 and myotonic dystrophy type 2, respectively;

Whereas those mutations prevent the DMPK gene and the CNBP gene from functioning properly, impacting multiple body systems;

Whereas the genetic mutations are autosomal dominant mutations, where a single 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, including skeletal muscle problems, excessive daytime sleepiness, early cataracts and heart, breathing, digestive, hormonal, speech, swallowing, diabetic, immune, vision, and cognitive difficulties;

Whereas myotonic dystrophy is a highly variable and complicated disorder in which the younger an individual is when symptoms first appear, the more severe symptoms are likely to be, with progressively more severe symptoms occurring after the earlier symptoms are experienced;

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

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

Whereas, in 2007, the Myotonic Dystrophy Foundation was founded with a mission to enhance the quality of life of

people living with myotonic dystrophy and to accelerate research focused on finding treatments and a cure;

Whereas, in 2014, Congress reauthorized the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2014 (Public Law 113–166; 42 U.S.C. 201), which increased muscular dystrophy research funding and public health surveillance activities, including for myotonic dystrophy;

Whereas, in September 2017, recognizing the seriousness of myotonic dystrophy 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 Allowances program that 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;

Whereas funding for myotonic dystrophy research supported by the National Institutes of Health remained flat between 2010 and 2020 with the agency awarding $24,000,000 in research grants in fiscal year 2020; and

Whereas increased Federal funding for 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

Resolved, That the Senate—

(1) designates September 15, 2021, as ''International Myotonic Dystrophy Awareness Day''; and

(2) supports the goals and ideals of International Myotonic Dystrophy Awareness Day, including—

(A) committing to promoting and advancing the health, well-being, and inherent dignity of all children and adults with myotonic dystrophy;

(B) supporting the advancement of scientific and medical myotonic dystrophy research at the National Institutes of Health and as part of the Peer Reviewed Medical Research Program of the Department of Defense;

(C) fostering biopharmaceutical innovation that will lead to treatments approved by the Food and Drug Administration and eventually a cure for myotonic dystrophy;

(D) advancing programs and policies that assist individuals disabled by myotonic dystrophy and the caregivers of those individuals; and

(E) encouraging awareness and education of myotonic dystrophy among patients, caregivers, clinicians, and researchers.

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