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(Original Signature of Member)

118TH CONGRESS
2D SESSION

H. RES. _____

Expressing support for the designation of June 20, 2024, as ''World FSHD Day''.

IN THE HOUSE OF REPRESENTATIVES

Mrs. DINGELL submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Expressing support for the designation of June 20, 2024, as ''World FSHD Day''.

Whereas facioscapulohumeral muscular dystrophy (FSHD) is a genetic neuromuscular disease (NMD) that leads to the weakening of skeletal muscles;

Whereas FSHD's name comes from the typical pattern of muscle weakness at onset, beginning with the face (facio), shoulder girdle (scapulo), and upper arms (humeral);

Whereas FSHD Type 1 is the more common form of FSHD, accounting for approximately 95 percent of FSHD cases; results from deletions in the D4Z4 region on chromosome 4; and leads to abnormal expression of the DUX4 gene;

Whereas approximately 5 percent of FSHD cases, known as FSHD Type 2, are linked to mutations on a gene called SMCHD1, located on chromosome 18;

Whereas there are still many FSHD cases of unknown genetic cause;

Whereas FSHD is an inherited condition that can affect many family members across generations;

Whereas FSHD is genetically transmissible in an autosomal dominant fashion, meaning that an affected parent has a 50 percent chance of passing the genetic defect on to each child;

Whereas 30 percent of new FSHD patients have no prior family history of the disease and are affected as a result of congenital spontaneous genetic mutation;

Whereas FSHD exists worldwide, affects both sexes equally, and has no particular racial, geographic, or ethnic distribution;

Whereas an estimated 1 in 8,000 individuals, or 41,487 Americans, are living with FSHD;

Whereas FSHD symptoms can develop at any age and can differ in the initial pattern of muscle weakness;

Whereas weakness in abdominal muscles is common and can lead to lordosis, an exaggerated curve in the lower spine;

Whereas the loss of upper body mobility is a debilitating symptom of FSHD that significantly impacts patients' ability to perform daily tasks necessary to care for themselves;

Whereas lower leg weakness often occurs and can lead to a condition called foot drop, where the foot stays down after pushing off when walking;

Whereas FSHD can reduce patients' ability to work and earn a living;

Whereas asymmetrical muscle loss is a hallmark symptom of FSHD with an unknown cause, and most patients observe that one arm, shoulder blade, or lower leg is weakened while the other remains stronger;

Whereas about 20 percent of FSHD patients will become dependent on a wheelchair or scooter;

Whereas patients with FSHD may develop progressive weakness of the respiratory muscles or scoliosis, which can cause fatal respiratory insufficiency;

Whereas more than 70 percent of FSHD patients experience debilitating pain and fatigue, which can severely limit daily activities;

Whereas the loss of facial expression and mobility, as well as others' lack of understanding of FSHD, is emotionally distressing and can cause FSHD patients to withdraw socially;

Whereas individuals with FSHD, like those with other rare disorders, experience challenges in obtaining a diagnosis, with the average time to receive an accurate FSHD diagnosis being 9 years;

Whereas genetic testing is needed to definitively diagnose FSHD, and further investments in genetic testing are required to ensure access to testing for all Americans;

Whereas, to date, the Food and Drug Administration (FDA) has yet to approve any treatments for FSHD;

Whereas, as a result of the Orphan Drug Act, there have been important advances in research on and treatment

for rare diseases, including efforts to develop treatments for FSHD;

Whereas Congress and the FDA have affirmed the importance of incorporating patient perspectives throughout the drug review process through implementation of the 21st Century Cures Act, the HEART Act, and FDA guidance;

Whereas the FDA's Patient-Focused Drug Development program is a critical resource that allows patients and caregivers to educate the FDA and other stakeholders on their lived experiences;

Whereas there is a critical need for research and development to advance treatments for FSHD;

Whereas the FSHD Society, a nonprofit organization established in 1991, is dedicated to increasing, engaging, and empowering stakeholders and aggressively leveraging and expanding resources, with the goal of developing treatments for FSHD by 2025 and eventually a cure;

Whereas on June 29, 2020, the FSHD community held its first-ever externally led patient-focused drug development meeting; and

Whereas FSHD patient advocacy organizations, research funding nonprofits, biopharmaceutical industry partners, and other key stakeholders sponsor World FSHD Day in the United States to increase public awareness and generate additional support for FSHD: Now, therefore, be it

Resolved, That the House of Representatives—

(1) supports the designation of June 20, 2024, as ''World FSHD Day''; and

(2) recognizes the importance of—

(A) improving awareness of and education about facioscapulohumeral muscular dystrophy (in this resolution referred to as ''FSHD'');

(B) encouraging accurate and early diagnosis of FSHD through genetic screening;

(C) supporting and funding future biomedical and scientific research to improve physical functioning and quality of life for individuals living with FSHD;

(D) developing new treatments, diagnostics, and cures for FSHD; and

(E) advancing programs and policies that support individuals living with FSHD and their caregivers.