FSHD Awareness Day Resolution Language - DRAFT

118th Congress
H. Resolution XX - Expressing support for the designation of June 20 each year as "World Facioscapulohumeral muscular dystrophy (FSHD) Day"

Designating June 20, 2024 as "World FSHD Day."

In the House of Representatives of the United States

XX Representatives….

RESOLUTION
Designating June 20, 2024 as "World FSHD Day"

Whereas Facioscapulohumeral muscular dystrophy, or 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 weakness at onset: 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, resulting from deletions of D4Z4 units on chromosome 4 and leading to abnormal expression in muscle of the DUX4 gene;[1]

Whereas the remaining 5 percent of FSHD cases are known as FSHD Type 2, which are linked to mutations on a gene called SMCHD1, on chromosome 18;[2]

Whereas there are still ~2% of FSHD cases of unknown genetic cause;

Whereas FSHD is a genetic condition that is inherited and can affect many family members across generations. FSHD is genetically transmissible in an autosomal dominant fashion, meaning an affected parent has a 50 percent chance of passing the genetic defect on to each child;

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

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

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[1] https://www.omim.org/entry/158900
[2] https://www.omim.org/entry/158901

Whereas an estimated 1 in 8,000 individuals, or 41,487 Americans are living with FSHD;[3]

Whereas FSHD symptoms can develop at any age, from infancy through advanced age and can differ in the typical initial pattern of muscle weakness;

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

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

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

Whereas patients with FSHD may become respiratory insufficient if they have progressive weakness of respiratory muscles and/or a scoliosis, which can be fatal;

Whereas over 70 percent of FDSH 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 many other rare disorders, experience challenges with obtaining a diagnosis with the average time to receive an accurate FSHD diagnosis being 9 years;

Whereas genetic testing is needed to definitely diagnosis FSHD and further investments in genetic testing are required to ensure accessibility for all Americans;

Whereas, to date, there is no FDA-approved treatment 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 development efforts in FSHD;

Whereas Congress and the Food and Drug Administration (FDA) have affirmed the importance of incorporating the patient perspective 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 for patients and caregivers to educate FDA and other stakeholders on their lived experiences;

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[3] https://pubmed.ncbi.nlm.nih.gov/25122204/

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

Whereas the FSHD Society, a non profit organization established in 1991 to accelerate research leading to treatments by 2025 and eventually a cure, is dedicated to increasing, engaging, and empowering stakeholders and aggressively leveraging and expanding resources to find a cure for FSHD;

Whereas on June 29, 2020, the FSHD Society convened the Voice of the Patient Forum, the FSHD community's first ever externally led patient-focused drug development (EL-PFDD) meeting;

Whereas the FSHD Society and [INSERT SUPPORTIVE ORGANIZATION(S)] sponsor "World FSHD Day" in the United States to increase public awareness and generate additional support for FSHD;

Whereas "World FSHD Day" is expected to be observed in the United States for years to come, providing hope and information for patients, caregivers, and families around the country:

Resolved, That the House of Representatives—

(1) supports the designation of June 20, 2024 as "World FSHD Day"; and
(2) recognizes the importance of, with respect to FSHD -

(a) Improving awareness and education of FSHD;
(b) Encouraging accurate and early diagnosis through genetic screening;
(c) Supporting and funding future biomedical and scientific research to alleviate challenges related to upper body mobility;
(d) Developing new treatments, diagnostics, and cures; and
(e) Advancing programs and policies that support individuals living with FSHD and their caregivers.