



SR0176

LRB104 08264 MST 18314 r

1 SENATE RESOLUTION

2 WHEREAS, Facioscapulohumeral muscular dystrophy, or FSHD,
3 is a genetic neuromuscular disease that leads to the weakening
4 of skeletal muscles; and

5 WHEREAS, FSHD gets its name from the muscles affected in
6 the face (facio), shoulder girdle (scapulo), and upper arms
7 (humeral); and

8 WHEREAS, Individuals with FSHD, like those with other rare
9 disorders, often experience challenges in obtaining a timely
10 diagnosis, which takes an average of nine years for this
11 condition; and

12 WHEREAS, An estimated 1 in 8,000 individuals, or 40,000
13 Americans, are living with FSHD; and

14 WHEREAS, FSHD symptoms can develop at any age, from
15 infancy through adulthood, and can differ in the pattern and
16 severity of muscle weakness; and

17 WHEREAS, Approximately 20 percent of individuals with FSHD
18 will become dependent on a wheelchair or scooter; and

19 WHEREAS, Patients with FSHD can develop respiratory

1 insufficiency, which can be fatal, especially in surgical or
2 trauma settings; and

3 WHEREAS, The majority of individuals with FSHD experience
4 chronic pain and fatigue, which may severely limit daily
5 activities; and

6 WHEREAS, The loss of upper body mobility is a debilitating
7 symptom of the disease that can significantly impact the
8 ability to perform daily tasks; and

9 WHEREAS, There is a critical need for continued research
10 and development of new treatments for FSHD; therefore, be it

11 RESOLVED, BY THE SENATE OF THE ONE HUNDRED FOURTH GENERAL
12 ASSEMBLY OF THE STATE OF ILLINOIS, that we declare June 20,
13 2025 as FSHD Awareness Day in the State of Illinois.