



HR0922

LRB104 22030 MST 38091 r

1 HOUSE 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 HOUSE OF REPRESENTATIVES OF THE ONE  
12 HUNDRED FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
13 we declare June 20, 2026 as FSHD Awareness Day in the State of  
14 Illinois.