

By: Kuempel

H.R. No. 443

R E S O L U T I O N

1 WHEREAS, There are nearly 10,000 known diseases and
2 conditions that are considered rare by medical authorities in the
3 United States, and each year, thousands of Texans are among those
4 whose lives are changed by these diseases; and

5 WHEREAS, A rare disease is defined as one that affects fewer
6 than 200,000 people, but even though a specific disease may afflict
7 only a small number of sufferers, such conditions, as a group,
8 affect almost 30 million Americans, or nearly one in 10 people in
9 our nation; and

10 WHEREAS, Many rare diseases are serious and debilitating,
11 with a significant impact on the lives of those affected and their
12 families, and approximately 95 percent of rare diseases have no
13 FDA-approved treatment; and

14 WHEREAS, The National Economic Burden of Rare Disease Study
15 in the United States estimated that the overall economic burden of
16 rare diseases in 2019 exceeded \$966 billion; and

17 WHEREAS, Individuals and families who face a rare disease
18 often experience a sense of isolation, difficulty in getting an
19 accurate and timely diagnosis, few treatment options, and problems
20 in receiving reimbursement for treatment; moreover, those who are
21 diagnosed with a lesser known disorder often find that they must
22 bear the lion's share of the responsibility for raising awareness
23 as well as for raising funds for research toward a possible
24 treatment or cure; and

1 WHEREAS, Thousands of patients, family members, friends,
2 co-workers, medical professionals, researchers, government
3 officials, and companies developing treatments are pleased to join
4 together with patient advocacy organizations like The National
5 Organization for Rare Disorders (NORD), EveryLife Foundation for
6 Rare Diseases, and the Texas Rare Alliance as part of a nationwide
7 observance of Rare Disease Day to advocate for continued research
8 and access to diagnosis and treatment; now, therefore, be it

9 RESOLVED, That the House of Representatives of the 88th Texas
10 Legislature hereby recognize February 28, 2023, as Rare Disease Day
11 and encourage all Texans to learn more about this matter of serious
12 concern.