

1 HJR149
2 190682-2
3 By Representatives Weaver, Williams (P), McCutcheon, Ball,
4 Hall, Sanderford, Daniels and Whorton (R)
5 RFD: Rules
6 First Read: 06-FEB-18

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8 RECOGNIZING FEBRUARY 28, 2018, AS RARE DISEASE DAY
9 IN ALABAMA.

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11 WHEREAS, there are approximately 7,000 diseases and
12 conditions considered rare, each affecting fewer than 200,000
13 Americans in the United States according to the National
14 Institutes of Health (NIH); and

15 WHEREAS, while each of these diseases may affect
16 small numbers of people, rare disease as a group affects
17 almost 30 million people in the United States; and

18 WHEREAS, eighty percent of rare diseases are genetic
19 in origin, and it is estimated that about 50 percent of all
20 rare diseases affect children; and

21 WHEREAS, while fewer than 500 orphan drugs and
22 biologic medical products have been approved for the treatment
23 of rare diseases by the Food and Drug Administration (FDA), 95
24 percent of the millions of Americans with rare diseases still
25 have no approved treatment specific to their disease; and

1 WHEREAS, rare diseases can become chronic,
2 progressive, disabling, and life-threatening conditions,
3 significantly impacting the lives of those affected; and

4 WHEREAS, relatively common symptoms can hide
5 underlying rare diseases, leading to misdiagnosis and delayed
6 treatment; individuals and families affected by rare diseases
7 often face challenges, such as diagnosis delay, difficulty
8 finding a medical expert, a sense of isolation and
9 psychological burden, few treatment options, lack of support
10 services, and problems related to accessing treatment or
11 ancillary services; and

12 WHEREAS, many patients and families affected by less
13 widely known rare diseases, bear a large share of the burden
14 regarding critical issues, such as finding adequate treatment
15 and raising funds for research, education, and awareness to
16 support the search for those treatments; and

17 WHEREAS, almost 500,000 residents of Alabama are
18 among those affected by rare diseases since nearly 1 in 10
19 Americans in the United States have a rare disease; and

20 WHEREAS, it is important for Alabamians and all
21 Americans to support those affected by rare diseases and to
22 promote the awareness of the needs of rare disease patients
23 and the acceptance of their diagnoses; and

24 WHEREAS, rare diseases affect almost 30 million
25 individuals in the United States and almost 500,000 just in
26 Alabama. Each disease can severely impact a patient not only
27 with physical disabilities, but also in many cases with

1 intellectual disabilities, and for some premature death. In
2 addition, the disease affects the patient and family as a
3 whole mentally, emotionally, and financially. Many rare
4 diseases are genetic or present as birth defects providing for
5 a lifelong diagnosis. Examples of rare diseases present among
6 Alabamians, include Multiple Sclerosis, Cerebral Palsy, ALS
7 (Lou Gehrig's Disease), Duchenne Muscular Dystrophy, Juvenile
8 Rheumatoid Arthritis, and pediatric cancers. Individually, a
9 rare disease is rare; with it only affecting less than 200,000
10 individuals. However, when rare diseases are looked at
11 collectively as a community, rare is no longer rare; and
12 millions are affected, which gives rise to the need for a
13 comprehensive public health approach, to build awareness, to
14 educate, and to improve the care and health of those affected
15 by a rare disease; and

16 WHEREAS, on the last day of the month of February,
17 patients, caregivers, and their families, medical
18 professionals, researchers, government officials, companies
19 developing treatments for rare diseases, and others in the
20 State of Alabama join together to focus attention on rare
21 diseases as a public health issue and participate in the
22 observance of Rare Disease Day; now therefore,

23 BE IT RESOLVED BY THE LEGISLATURE OF ALABAMA, BOTH
24 HOUSES THEREOF CONCURRING, That we recognize February 28,
25 2018, and the last day in February in each succeeding year, as
26 Rare Disease Day in Alabama.

1 BE IT FURTHER RESOLVED, That February 2018 and every
2 February in each succeeding year be recognized as Rare Disease
3 Awareness month.

4 BE IT FURTHER RESOLVED, That this resolution be
5 provided for presentation as an expression of our sentiment in
6 this regard.