

1 HJR149
2 190682-3
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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2 ENROLLED, House Joint Resolution,
3 RECOGNIZING FEBRUARY 28, 2018, AS RARE DISEASE DAY
4 IN ALABAMA.

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

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

13 WHEREAS, eighty percent of rare diseases are genetic
14 in origin, and it is estimated that about 50 percent of all
15 rare diseases affect children; and

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

21 WHEREAS, rare diseases can become chronic,
22 progressive, disabling, and life-threatening conditions,
23 significantly impacting the lives of those affected; and

24 WHEREAS, relatively common symptoms can hide
25 underlying rare diseases, leading to misdiagnosis and delayed

1 treatment; individuals and families affected by rare diseases
2 often face challenges, such as diagnosis delay, difficulty
3 finding a medical expert, a sense of isolation and
4 psychological burden, few treatment options, lack of support
5 services, and problems related to accessing treatment or
6 ancillary services; and

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

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

15 WHEREAS, it is important for Alabamians and all
16 Americans to support those affected by rare diseases and to
17 promote the awareness of the needs of rare disease patients
18 and the acceptance of their diagnoses; and

19 WHEREAS, rare diseases affect almost 30 million
20 individuals in the United States and almost 500,000 just in
21 Alabama. Each disease can severely impact a patient not only
22 with physical disabilities, but also in many cases with
23 intellectual disabilities, and for some premature death. In
24 addition, the disease affects the patient and family as a
25 whole mentally, emotionally, and financially. Many rare

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

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

20 BE IT RESOLVED BY THE LEGISLATURE OF ALABAMA, BOTH
21 HOUSES THEREOF CONCURRING, That we recognize February 28,
22 2018, and the last day in February in each succeeding year, as
23 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.

