**A** **HOUSE RESOLUTION**

TO DECLARE FEBRUARY 28, 2021, AS “RARE DISEASE DAY” IN THE STATE OF SOUTH CAROLINA IN ORDER TO RAISE AWARENESS FOR THE NEED OF RESEARCH, TREATMENT, AND MEDICAL AVAILABILITY FOR THOSE WHO SUFFER FROM RARE DISEASES.

Whereas, according to the National Institutes of Health (NIH), there are nearly seven thousand diseases and conditions in the United States considered rare, each disease affecting fewer than two hundred thousand Americans; and

Whereas, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost thirty million Americans; and

Whereas, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

Whereas, while more than eight hundred drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), millions of Americans still have rare diseases for which there is no approved treatment; and

Whereas, individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services; and

Whereas, while the public is familiar with some rare diseases such as “Lou Gehrig’s disease” and is sympathetic to those affected, many patients and families affected by less widely known rare diseases bear a large share of the burden of funding research and raising public awareness to support the search for treatments; and

Whereas, thousands of residents of South Carolina are among those affected by rare diseases since nearly one in ten Americans have rare diseases; and

Whereas, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2021; and

Whereas, in the State of South Carolina, patients, medical professionals, researchers, government officials, and companies developing orphan products to treat people with rare diseases, and others will participate in that observance. Now, therefore,

Be it resolved by the House of Representatives:

That the members of the South Carolina House of Representatives, by this resolution, declare February 28, 2021, as “Rare Disease Day” in the State of South Carolina in order to raise awareness for the need of research, treatment, and medical availability for those who suffer from rare diseases.

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