

2016 First Extraordinary Session

HOUSE RESOLUTION NO. 13

BY REPRESENTATIVE ZERINGUE

A RESOLUTION

To recognize Monday, February 29, 2016, as Rare Disease Day in the state of Louisiana.

WHEREAS, according to the National Institutes of Health, there are nearly 7,000 diseases and conditions that are considered rare in the United States; and

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

WHEREAS, many rare diseases are serious and debilitating and significantly impact the lives of those affected; and

WHEREAS, while more than four hundred fifty drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration, 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 in finding a medical expert, and lack of access to treatments or ancillary services; and

WHEREAS, many patients and families affected by rare diseases bear the burden of funding research and raising public awareness to support the search for treatments; and

WHEREAS, thousands of residents in the state of Louisiana are among those affected by rare diseases since nearly one in ten Americans have a rare disease; and

WHEREAS, Monday, February 29, 2016, has been designated by the National Organization for Rare Disorders (NORD) for a nationwide observance of Rare Disease Day; and

WHEREAS, thousands of patients, caregivers, medical professionals, researchers, companies that develop orphan products to treat people with rare diseases, and others in the state of Louisiana will participate in the nationwide observance.

THEREFORE, BE IT RESOLVED that the House of Representatives of the Legislature of Louisiana does hereby recognize Monday, February 29, 2016, as Rare Disease Day in the state of Louisiana and does hereby encourage all Louisiana citizens to learn more about rare diseases and what can be done to support individuals with rare diseases and their families.

BE IT FURTHER RESOLVED that a suitable copy of this Resolution be transmitted to Melody Ferrufino.

---

SPEAKER OF THE HOUSE OF REPRESENTATIVES