

A CONCURRENT RESOLUTION designating February 29, 2016, as Rare Disease Day in Kentucky.

WHEREAS, there are over 6,800 rare diseases afflicting nearly thirty million people in the United States and thousands of Kentuckians; and

WHEREAS, children with rare genetic diseases account for more than half of the population affected by rare diseases in the United States; and

WHEREAS, many rare diseases are serious, life-threatening, and lack an effective treatment; and

WHEREAS, rare diseases and conditions include epidermolysis bullosa, progeria, sickle cell anemia, Tay-Sachs, cystic fibrosis, many childhood cancers, and fibrodysplasia ossificans progressiva; and

WHEREAS, people with rare diseases experience challenges that include difficulty in obtaining an accurate diagnosis, limited treatment options, and difficulty finding physicians or treatment centers with expertise in their diseases; and

WHEREAS, great strides have been made in research and treatment for rare diseases as a result of the federal Orphan Drug Act and amendments made to that Act; and

WHEREAS, both the United States Food and Drug Administration and the National Institutes of Health have established special offices to advocate for rare disease research and treatments; and

WHEREAS, the National Organization for Rare Disorders, an organization established in 1983 to provide services to, and advocate on behalf of, patients with rare diseases, was a primary force behind the enactment of the Orphan Drug Act and remains a critical public voice for people with rare diseases; and

WHEREAS, the National Organization for Rare Disorders sponsors Rare Disease Day in the United States to increase public awareness of rare diseases; and

WHEREAS, Rare Disease Day has become a global event occurring annually on the last day of February; and

WHEREAS, this body joins millions around the world in observing Rare Disease Day and recognizes the 2016 world focus on continuing to find ways to work together to provide the different kinds of care that people living with a rare disease need;

NOW, THEREFORE,

Be it resolved by the Senate of the General Assembly of the Commonwealth of Kentucky, the House of Representatives concurring therein:

➔Section 1. The Senate and the House of Representatives designate February 29, 2016, as Rare Disease Day across the Commonwealth of Kentucky.