

HOUSE JOINT RESOLUTION 147

By Calfee

A RESOLUTION to designate February 28, 2019, as "Rare Disease Day" in Tennessee.

WHEREAS, in an effort to raise awareness in the United States about rare diseases, Rare Disease Day, observed on February 28, 2011, has been designated as the occasion to engage a national audience in an attempt to raise the public's cognizance about issues surrounding rare diseases; and

WHEREAS, there are nearly 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 Americans; and

WHEREAS, while each of these diseases may affect a small number 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 nearly 330 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between eleven and fourteen million people, according to the Food and Drug Administration, there are still well over fifteen million Americans with rare diseases who have no treatment specific to their disease; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

WHEREAS, some rare diseases, such as Lou Gehrig's disease and Huntington's disease, are relatively well known; many others are not known at all by the public, so patients

and their families must bear a large share of the burden of raising public awareness and funds for research; and

WHEREAS, Prader-Willi syndrome (PWS) is the most common known genetic cause of life-threatening obesity in children; although the cause is complex, PWS results from an abnormality on the 15th chromosome; and

WHEREAS, PWS occurs in males and females equally and in all races; prevalence estimates have ranged from 1:8,000 to 1:25,000, with the most likely figure being 1:15,000; and

WHEREAS, the National Organization for Rare Disorders (NORD) organizes an annual nationwide observance of Rare Disease Day on February 28, and on this day, patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases join together to focus attention on rare diseases as a public health issue; and

WHEREAS, successes of the annual Rare Disease Day USA include governors in forty states issuing proclamations to recognize the important issue; the rarediseaseday.us website being launched; more than 350 groups signing on as Rare Disease Day Partners; and patient stories appearing on ABC News, blogs, editorials, newspapers, and many other websites to address the travailing issue; and

WHEREAS, thousands of residents of our great State are among those affected by rare diseases, as nearly one in ten Americans has a rare disease; now, therefore,

BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES OF THE ONE HUNDRED ELEVENTH GENERAL ASSEMBLY OF THE STATE OF TENNESSEE, THE SENATE CONCURRING, that February 28, 2019, is hereby designated as "Rare Disease Day" in Tennessee. This body encourages all Tennesseans to educate themselves about the reality of rare diseases across our State and nation.

BE IT FURTHER RESOLVED, that an appropriate copy of this resolution be prepared for presentation with this final clause omitted from such copy.