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By:  Kuempel H.R. No. 443

R E S O L U T I O N

WHEREAS, There are nearly 10,000 known diseases and conditions that are considered rare by medical authorities in the United States, and each year, thousands of Texans are among those whose lives are changed by these diseases; and

WHEREAS, A rare disease is defined as one that affects fewer than 200,000 people, but even though a specific disease may afflict only a small number of sufferers, such conditions, as a group, affect almost 30 million Americans, or nearly one in 10 people in our nation; and

WHEREAS, Many rare diseases are serious and debilitating, with a significant impact on the lives of those affected and their families, and approximately 95 percent of rare diseases have no FDA-approved treatment; and

WHEREAS, The National Economic Burden of Rare Disease Study in the United States estimated that the overall economic burden of rare diseases in 2019 exceeded $966 billion; and

WHEREAS, Individuals and families who face a rare disease often experience a sense of isolation, difficulty in getting an accurate and timely diagnosis, few treatment options, and problems in receiving reimbursement for treatment; moreover, those who are diagnosed with a lesser known disorder often find that they must bear the lion's share of the responsibility for raising awareness as well as for raising funds for research toward a possible treatment or cure; and

WHEREAS, Thousands of patients, family members, friends, co-workers, medical professionals, researchers, government officials, and companies developing treatments are pleased to join together with patient advocacy organizations like The National Organization for Rare Disorders (NORD), EveryLife Foundation for Rare Diseases, and the Texas Rare Alliance as part of a nationwide observance of Rare Disease Day to advocate for continued research and access to diagnosis and treatment; now, therefore, be it

RESOLVED, That the House of Representatives of the 88th Texas Legislature hereby recognize February 28, 2023, as Rare Disease Day and encourage all Texans to learn more about this matter of serious concern.