A RESOLUTION

Designating October 5, 2020, as "Peroxisomal Disorder Awareness Day" in Pennsylvania.

WHEREAS, Peroxisomal biogenesis disorder – Zellweger spectrum disorder (PBD-ZSD) and related single enzyme deficiencies are progressive, genetic disorders impacting peroxisomes found in every cell of the body that are necessary for cell function, brain development and the formation of myelin; and

WHEREAS, Disorders that impact peroxisomes cause damage to the kidneys and liver, and the endocrine, hepatic gastrointestinal and neurological organ systems; and

WHEREAS, PBD-ZSD and related single enzyme deficiencies have a devastating impact on the health and finances of individuals of all ages, and equally affect individuals of all races, genders, nationalities, geographic locations and income levels; and

WHEREAS, Individuals diagnosed with PBD-ZSD and related single enzyme deficiencies inherit the disease in an autosomal
recessive inheritance pattern; and
WHEREAS, There are very few treatments and still no cure for PBD-ZSD and related single enzyme deficiencies, which impact an estimated 1 in 50,000 live births annually; and
WHEREAS, All patients seeking care for PBD-ZSD and related single enzyme deficiencies suffer from a variety of health issues, causing a severe strain on resources and on the delivery of health care in the United States; and
WHEREAS, Individuals diagnosed with PBD-ZSD and related single enzyme deficiencies are instilled with fear of an unknown future with a life-threatening genetic disease and apprehension over possible discrimination, including the risk of losing their health and life insurance, their jobs and their chances of promotion; and
WHEREAS, Friends, loved ones, spouses and caregivers of patients seeking care for PBD-ZSD and related single enzyme deficiencies must shoulder the physical, emotional and financial burdens of the disease; and
WHEREAS, Individuals who have chronic, life-threatening diseases like PBD-ZSD and related single enzyme deficiencies and their caregivers have a predisposition to depression because of their anxiety over pain, suffering and premature death; and
WHEREAS, Peroxisomal disorder awareness and education are important to raise public awareness and understanding of PBD-ZSD and related single enzyme deficiencies; therefore be it RESOLVED, That the House of Representatives designate October 5, 2020, as "Peroxisomal Disorder Awareness Day" in Pennsylvania.