

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 548 Session of 2019

INTRODUCED BY HEFFLEY, HENNESSEY, KORTZ, KINSEY, LONGIETTI, RYAN, FREEMAN, DIGIROLAMO, PYLE, YOUNGBLOOD, READSHAW, SCHLEGEL CULVER, BOBACK, HILL-EVANS, BROWN, SCHMITT, CALTAGIRONE, MURT AND GILLEN, OCTOBER 11, 2019

REFERRED TO COMMITTEE ON HEALTH, OCTOBER 11, 2019

A RESOLUTION

1 Designating October 5, 2019, as "Peroxisomal Disorder Awareness
2 Day" in Pennsylvania.

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

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

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

16 WHEREAS, Individuals diagnosed with PBD-ZSD and related ◀

1 single enzyme deficiencies inherit the disease in an autosomal
2 recessive inheritance pattern; and

3 WHEREAS, There are very few treatments and still no cure for
4 PBD-ZSD and related single enzyme deficiencies, which impact an ◀
5 estimated 1 in 50,000 live births annually; and

6 WHEREAS, All patients seeking care for PBD-ZSD and related ◀
7 single enzyme deficiencies suffer from a variety of health
8 issues, causing a severe strain on resources and on the delivery
9 of health care in the United States; and

10 WHEREAS, Individuals diagnosed with PBD-ZSD and related ◀
11 single enzyme deficiencies are instilled with fear of an unknown
12 future with a life-threatening genetic disease and apprehension
13 over possible discrimination, including the risk of losing their
14 health and life insurance, their jobs and their chances of
15 promotion; and

16 WHEREAS, Friends, loved ones, spouses and caregivers of
17 patients seeking care for PBD-ZSD and related single enzyme ◀
18 deficiencies must shoulder the physical, emotional and financial
19 burdens of the disease; and

20 WHEREAS, Individuals who have chronic, life-threatening
21 diseases like PBD-ZSD and related single enzyme deficiencies and ◀
22 their caregivers have a predisposition to depression because of
23 their anxiety over pain, suffering and premature death; and

24 WHEREAS, Peroxisomal disorder awareness and education are
25 important to raise public awareness and understanding of PBD-ZSD ◀
26 and related single enzyme deficiencies; therefore be it

27 RESOLVED, That the House of Representatives designate October
28 5, 2019, as "Peroxisomal Disorder Awareness Day" in
29 Pennsylvania.