
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 AND MURT, 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 syndrome
4 spectrum (PBD, ZSS) and related single enzyme deficiencies are
5 progressive, genetic disorders impacting the peroxisomes found
6 in eukaryotic cells that are necessary for cell function, brain
7 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, ZSS 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, ZSS and related
17 single enzyme deficiencies inherit the disease in an autosomal

1 recessive inheritance pattern; and

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

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

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

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

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

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

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