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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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SENATE RESOLUTION

No. 246 Session of  
2019

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INTRODUCED BY YUDICHAK, FONTANA, BROWNE, DINNIMAN, J. WARD,  
BREWSTER, PHILLIPS-HILL, TARTAGLIONE, HUGHES, AUMENT AND  
SCHWANK, OCTOBER 21, 2019

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INTRODUCED AND ADOPTED, OCTOBER 21, 2019

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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 which are necessary for cell function, brain  
7 development and the formation of myelin; and

8 WHEREAS, Disorders which impact peroxisomes cause damage to  
9 the kidneys and liver and to 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 Senate designate October 5, 2019, as  
27 "Peroxisomal Disorder Awareness Day" in Pennsylvania.