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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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HOUSE RESOLUTION

No. 1008 Session of  
2020

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INTRODUCED BY HEFFLEY, BURNS, HENNESSEY, RYAN, MURT, LONGIETTI,  
KINSEY, MILLARD, READSHAW AND SONNEY, SEPTEMBER 25, 2020

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INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,  
SEPTEMBER 25, 2020

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A RESOLUTION

1 Designating October 5, 2020, 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  
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-ZSD 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-ZSD 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-ZSD 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-ZSD 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-ZSD and related single enzyme deficiencies and  
21 their caregivers have a predisposition to depression because of  
22 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-ZSD  
25 and related single enzyme deficiencies; therefore be it

26 RESOLVED, That the House of Representatives designate October  
27 5, 2020, as "Peroxisomal Disorder Awareness Day" in  
28 Pennsylvania.