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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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SENATE RESOLUTION

No. 366 Session of  
2020

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INTRODUCED BY YUDICHAK, LANGERHOLC, BARTOLOTTA, SCAVELLO,  
KILLION, PHILLIPS-HILL, J. WARD, MENSCH, STEFANO AND PITTMAN,  
SEPTEMBER 18, 2020

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REFERRED TO RULES AND EXECUTIVE NOMINATIONS, SEPTEMBER 18, 2020

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A RESOLUTION

1 Recognizing October 5, 2020, as "National Peroxisomal Disorder  
2 Awareness Day" in Pennsylvania.

3 WHEREAS, Raising public awareness and understanding of  
4 peroxisomal biogenesis disorder-Zellweger spectrum disorder  
5 (PBD-ZSD) and related single enzyme deficiencies is needed  
6 because they are rare, terminal and genetic diseases impacting  
7 children; and

8 WHEREAS, Helping to foster understanding of the impact of PBD  
9 and ZSD and related single enzyme deficiencies has a positive  
10 impact on patients and their families; and

11 WHEREAS, PBD-ZSD and related single enzyme deficiencies are  
12 progressive, genetic disorders impacting the peroxisomes causing  
13 damage to the kidneys, liver, endocrine, hepatic,  
14 gastrointestinal and neurological organ systems; and

15 WHEREAS, These disorders have a devastating impact on the  
16 health and finances of people of all ages, and equally affects  
17 people of all races, genders, nationalities, geographic

1 locations and income levels; and

2 WHEREAS, People diagnosed with PBD-ZSD and related single  
3 enzyme deficiencies inherit the disease in an autosomal  
4 recessive inheritance pattern; and

5 WHEREAS, There are very few treatments and still no cure for  
6 PBD-ZSD and the related disorders which impact an estimated 1 in  
7 50,000 live births annually; and

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

12 WHEREAS, PBD-ZSD and related single enzyme deficiencies  
13 instills in patients and their caregivers a fear of an unknown  
14 future with a life-threatening genetic disease and apprehension  
15 over possible discrimination, including the risk of losing their  
16 health and life insurance, their job and chances for promotions;  
17 and

18 WHEREAS, Countless friends, loved ones, spouses and  
19 caregivers of patients with PBD-ZSD and related single enzyme  
20 deficiencies must shoulder the physical, emotional and financial  
21 burdens that PBD-ZSD and related single enzyme deficiencies  
22 cause; and

23 WHEREAS, The severity of the symptoms of PBD-ZSD and related  
24 single enzyme deficiencies and the limited public awareness of  
25 these diseases cause many patients and their caregivers to live  
26 in denial and forego regular visits to their physicians or avoid  
27 following good health management which would help avoid more  
28 severe complications; and

29 WHEREAS, People who have chronic, life-threatening diseases  
30 like PBD-ZSD and related single enzyme deficiencies and their

1 caregivers have a predisposition to depression because of their  
2 anxiety over pain, suffering and premature death; and

3 WHEREAS, The Global Foundation for Peroxisomal Disorders is  
4 dedicated to conducting research to find treatments and a cure,  
5 fostering public awareness and understanding and educating  
6 patients and their families about the disease to improve their  
7 treatment and care; and

8 WHEREAS, Further, the Global Foundation for Peroxisomal  
9 Disorders provides support, including sponsoring "National  
10 Peroxisomal Disorder Awareness Day," also known annually as  
11 "Pause for PBD," to raise funds for research, education,  
12 advocacy and awareness; and

13 WHEREAS, This year, the Global Foundation for Peroxisomal  
14 Disorders is partnering with sister organizations in Canada, the  
15 United Kingdom and other countries to increase international  
16 awareness of PBD-ZSD and related single enzyme deficiencies;  
17 therefore be it

18 RESOLVED, That the Senate recognize October 5, 2020, as  
19 "National Peroxisomal Disorder Awareness Day" in Pennsylvania,  
20 to raise awareness and understanding of peroxisomal disorders in  
21 the Zellweger spectrum and the related single enzyme  
22 deficiencies.