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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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HOUSE RESOLUTION

No. 408 Session of  
2013

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INTRODUCED BY STERN, CALTAGIRONE, COHEN, MIRABITO, LONGIETTI,  
DIGIROLAMO, MILLARD, YOUNGBLOOD, HENNESSEY, HEFFLEY, QUINN,  
MAJOR, BAKER, READSHAW, V. BROWN, PICKETT, SONNEY,  
SCHLOSSBERG, BOBACK, MACKENZIE, KNOWLES, GODSHALL, O'BRIEN,  
ROCK, KORTZ, HARHART, GIBBONS, ROSS, FREEMAN, CLYMER,  
BENNINGHOFF, HESS, GRELL, C. HARRIS, R. MILLER, GINGRICH,  
DENLINGER, FLECK, PETRI, GILLEN, WHITE, MOUL, OBERLANDER,  
DeLUCA, BROOKS, MAHONEY, GOODMAN, TOOHL, D. COSTA, MILNE AND  
MURT, JULY 10, 2013

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INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,  
JULY 10, 2013

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A RESOLUTION

1 Recognizing the month of August 2013 as "Adrenoleukodystrophy  
2 Awareness Month" in Pennsylvania and encouraging research on  
3 adrenoleukodystrophy to be conducted.

4 WHEREAS, Adrenoleukodystrophy (ALD) is an X-linked genetic  
5 disorder that affects the adrenal glands and is characterized by  
6 progressive brain and central nervous system deterioration; and

7 WHEREAS, ALD affects mostly males, but some women who are  
8 carriers can have milder forms of the disease; and

9 WHEREAS, There are three distinct types of ALD; and

10 WHEREAS, The first type of ALD, childhood cerebral ALD,  
11 affects boys between four and ten years of age and affects one  
12 in every 17,900 boys worldwide; and

13 WHEREAS, With childhood cerebral ALD, boys develop normally  
14 until the onset of symptoms occur, which typically rival those

1 of attention deficit disorder before serious neurological  
2 involvement becomes apparent at which time the symptoms progress  
3 rapidly and lead to a vegetative state within two years and  
4 eventually death; and

5 WHEREAS, The second type of ALD, adrenomyeloneuropathy (AMN),  
6 affects otherwise healthy adult males between 20 and 40 years of  
7 age; and

8 WHEREAS, AMN affects the spinal cord and leads to symptoms  
9 similar to multiple sclerosis which worsen over a period of  
10 decades; and

11 WHEREAS, Thirty-five percent of men affected by AMN develop  
12 cerebral symptoms similar to childhood cerebral ALD which lead  
13 to death in just a few short years; and

14 WHEREAS, The third type of ALD, Addison's disease, affects  
15 all age groups and can be life threatening; and

16 WHEREAS, With Addison's disease, adrenal glands produce too  
17 little cortisol as well as insufficient levels of aldosterone;  
18 and

19 WHEREAS, ALD is more widespread than amyotrophic lateral  
20 sclerosis (ALS), often referred to as "Lou Gehrig's disease";  
21 and

22 WHEREAS, Treatment with adrenal hormones can be lifesaving;  
23 and

24 WHEREAS, Symptomatic and supportive treatments for ALD  
25 include physical therapy, psychological support and special  
26 education; and

27 WHEREAS, Two additional treatments, Lorenzo's oil and bone  
28 marrow transplantation, appear to be most effective in early  
29 stages of the disease but are not effective in later stages of  
30 the disease; and

1       WHEREAS, Genetic counseling is recommended for prospective  
2 parents with a family history of ALD; and

3       WHEREAS, Prenatal diagnosis of ALD is also available; and

4       WHEREAS, Increasing awareness and understanding of ALD and  
5 promoting research on the disease will help children and adults  
6 with ALD be identified as early as possible when there is the  
7 best hope of a beneficial treatment; therefore be it

8       RESOLVED, That the House of Representatives recognize August  
9 2013 as "Adrenoleukodystrophy Awareness Month" in Pennsylvania  
10 and encourage research on adrenoleukodystrophy to be conducted.