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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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HOUSE RESOLUTION

No. 1014 Session of  
2018

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INTRODUCED BY CRUZ, YOUNGBLOOD, DIGIROLAMO, DONATUCCI, KINSEY,  
WATSON, HENNESSEY, NEILSON, PASHINSKI, TOOHL, WARD,  
BIZZARRO, BURNS, VAZQUEZ, HILL-EVANS, LONGIETTI, READSHAW,  
D. COSTA, MURT, DRISCOLL, M. QUINN, MILLARD, MARSICO,  
BRADFORD, SCHWEYER, CALTAGIRONE, GILLEN AND FARRY,  
JULY 18, 2018

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INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,  
JULY 18, 2018

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A RESOLUTION

1 Designating the month of September 2018 as "Leukodystrophy  
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Leukodystrophy is a rare and terminal disease  
4 presenting itself in multiple manifestations that attack the  
5 central nervous system, severely impacting physical abilities,  
6 mental capacity and quality of life; and

7 WHEREAS, The group of rare disorders known as  
8 leukodystrophies destroy the central nervous system by  
9 disrupting the growth and maintenance of myelin, a sheath that  
10 insulates nerve cells and destroys white matter in the brain;  
11 and

12 WHEREAS, Leukodystrophies are progressive, meaning that they  
13 tend to get worse throughout the life of the patient; and

14 WHEREAS, There are more than 40 known variations and even  
15 more unidentified forms of leukodystrophy that exist; and

1       WHEREAS, When all variations of leukodystrophy are grouped  
2 together, it is as prevalent as cystic fibrosis; and

3       WHEREAS, Infants born with leukodystrophy appear normal at  
4 birth, with symptoms appearing during infancy or childhood; and

5       WHEREAS, There is no cure for leukodystrophy, but treatment  
6 may include medications, physical, occupational and speech  
7 therapies and nutritional, educational and recreational  
8 programs; and

9       WHEREAS, Additional treatment options such as bone marrow  
10 transplantation are emerging due to continued research and  
11 medical advances; and

12       WHEREAS, Organizations, including the United Leukodystrophy  
13 Foundation, Hunter's Hope Foundation, The Myelin Project, the  
14 MLD Foundation and the Adrenoleukodystrophy Foundation have  
15 dedicated their work to public education, disease research and  
16 patient treatment; and

17       WHEREAS, Act 148 of 2014 requires hospitals in this  
18 Commonwealth to screen newborns for Krabbe disease, a  
19 leukodystrophy; and

20       WHEREAS, X-linked adrenoleukodystrophy (X-ALD) was added to  
21 the Federal Recommended Uniform Screening Panel in 2016; and

22       WHEREAS, Hospitals in this Commonwealth began screening all  
23 newborns for X-ALD in April 2017; and

24       WHEREAS, It is imperative that parents learn about  
25 leukodystrophy and understand the importance of screening and  
26 early detection of Krabbe disease, X-ALD and other  
27 leukodystrophies; therefore be it

28       RESOLVED, That the House of Representatives designate the  
29 month of September 2018 as "Leukodystrophy Awareness Month" in  
30 Pennsylvania; and be it further

1       RESOLVED, That the Commonwealth officially recognize the  
2 importance of leukodystrophy awareness and encourage parents and  
3 future parents to educate themselves on these diseases and take  
4 the necessary steps to ensure the health of their children.