
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 453 Session of
2017

INTRODUCED BY CRUZ, DIGIROLAMO, BAKER, KINSEY, SCHLOSSBERG,
RYAN, TOOHL, SONNEY, DUSH, MURT, ROZZI, LONGIETTI, READSHAW,
CALTAGIRONE, KORTZ, V. BROWN, WATSON, MILLARD, D. COSTA,
BOBACK, GABLER, SCHWEYER, BIZZARRO, FARRY, GILLEN AND
MARSICO, AUGUST 24, 2017

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
AUGUST 24, 2017

A RESOLUTION

1 Designating the month of September 2017 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

16 WHEREAS, When all variations of leukodystrophy are grouped

1 together, it is as prevalent as cystic fibrosis; and

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

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

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

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

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

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

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

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

27 RESOLVED, That the House of Representatives designate the
28 month of September 2017 as "Leukodystrophy Awareness Month" in
29 Pennsylvania; and be it further

30 RESOLVED, That the Commonwealth officially recognize the

- 1 importance of leukodystrophy awareness and encourage parents and
- 2 future parents to educate themselves on these diseases and take
- 3 the necessary steps to ensure the health of their children.