
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 478 Session of
2015

INTRODUCED BY CRUZ, YOUNGBLOOD, DONATUCCI, BISHOP, V. BROWN,
THOMAS, HENNESSEY, SONNEY, DUSH, J. HARRIS, DiGIROLAMO,
KIRKLAND, McNEILL, DRISCOLL, BIZZARRO, SCHLOSSBERG,
CALTAGIRONE, LONGIETTI, ROZZI, KINSEY, VEREB, WHEELAND,
D. COSTA, COHEN, MURT, MILLARD, PASHINSKI, WATSON, EVERETT,
MARSICO, READSHAW, GROVE, SCHWEYER, MAJOR, MAHONEY, GINGRICH
AND ROSS, SEPTEMBER 18, 2015

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
SEPTEMBER 18, 2015

A RESOLUTION

1 Designating the month of September 2015 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 over 40 known variations and even more
15 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 for most leukodystrophies includes medications, physical,
7 occupation and speech therapies, and nutritional, educational
8 and recreational programs; and

9 WHEREAS, Additional treatments for some leukodystrophies,
10 such as bone marrow transplantation, are emerging due to
11 continued research and medical advances; and

12 WHEREAS, Organizations, including, but not limited to, the
13 United Leukodystrophy Foundation, Hunter's Hope Foundation, the
14 Myelin Project, the MLD Foundation and the Adrenoleukodystrophy
15 Foundation have dedicated their work to public education,
16 disease research and 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, It is imperative that parents learn about
21 leukodystrophy and understand the importance of screening for
22 and detecting Krabbe disease and other leukodystrophies early;
23 therefore be it

24 RESOLVED, That the House of Representatives designate the
25 month of September 2015 as "Leukodystrophy Awareness Month" in
26 Pennsylvania; and be it further

27 RESOLVED, That the Commonwealth officially recognize the
28 importance of Leukodystrophy awareness and encourage parents and
29 future parents to educate themselves on these diseases and take
30 the necessary steps to ensure the health of their children.