
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 994 Session of
2015

INTRODUCED BY CRUZ, YOUNGBLOOD, KINSEY, DIGIROLAMO, BAKER,
KIRKLAND, TOOHIL, COHEN, ROSS, HENNESSEY, WATSON,
SCHLOSSBERG, CALTAGIRONE, VEREB, WARD, NEILSON, MILLARD,
J. HARRIS, LONGIETTI, MURT, MAJOR, MARSICO, PAYNE, EVERETT,
GINGRICH AND READSHAW, SEPTEMBER 15, 2016

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
SEPTEMBER 15, 2016

A RESOLUTION

1 Designating the month of September 2016 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 for most leukodystrophies includes medications, physical,
6 occupation and speech therapies and nutritional, educational and
7 recreational programs; and

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

11 WHEREAS, Organizations, including, but not limited to, the
12 United Leukodystrophy Foundation, Hunter's Hope Foundation, the
13 Myelin Project, the MLD Foundation and the Adrenoleukodystrophy
14 Foundation have dedicated their work to public education,
15 disease research and 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 recently
20 added to the Federal Recommended Uniform Screening Panel (RUSP);
21 and

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

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

28 RESOLVED, That the House of Representatives designate the
29 month of September 2016 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.