

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

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

3 WHEREAS, There is no cure for leukodystrophy but treatment
4 for most leukodystrophies includes medications, physical,
5 occupation and speech therapies and nutritional, educational and
6 recreational programs; and

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

10 WHEREAS, Organizations, including, but not limited to, the
11 United Leukodystrophy Foundation, Hunter's Hope Foundation, the
12 Myelin Project, the MLD Foundation and the Adrenoleukodystrophy
13 Foundation have dedicated their work to public education,
14 disease research and patient treatment; and

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

18 WHEREAS, X-linked Adrenoleukodystrophy (X-ALD) was recently
19 added to the Federal Recommended Uniform Screening Panel (RUSP);
20 and

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

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

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

LEGISLATIVE REFERENCE BUREAU

RESOLUTION

INTRODUCED _____, 20 _____

BY _____, **District NO.** _____

BY _____, **District NO.** _____

BY _____, **District NO.** _____

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See next page for additional co-sponsors.

| | |
|---------------------------------|----------|
| Referred to Committee on | |
| Date _____ | 20 _____ |
| Reported _____ | 20 _____ |
| As Committed-Amended | |
| Recommendation | |
| _____ | |
| By Hon. _____ | |