

A RESOLUTION

1 Designating the month of September 2019 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 destroys 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 50 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 may include medications, physical, occupational and speech
5 therapies and nutritional, educational and recreational
6 programs; and

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

10 WHEREAS, Organizations, including the United Leukodystrophy
11 Foundation, Hunter's Hope Foundation, The Myelin Project, the
12 MLD Foundation and the Adrenoleukodystrophy Foundation have
13 dedicated their work to public education, disease research and
14 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 added to
19 the Federal Recommended Uniform Screening Panel in 2016; and

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

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

26 RESOLVED, That the House of Representatives designate the
27 month of September 2019 as "Leukodystrophy Awareness Month" in
28 Pennsylvania; and be it further

29 RESOLVED, That the Commonwealth officially recognize the
30 importance of leukodystrophy awareness and encourage parents and

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

LEGISLATIVE REFERENCE BUREAU

RESOLUTION

INTRODUCED _____, 20 _____

BY _____, District NO. _____

See next page for additional co-sponsors.

Referred to Committee on

Date _____ 20 _____

Reported _____ 20 _____

As Committed-Amended

Recommendation

By Hon. _____