
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 1011 Session of
2020

INTRODUCED BY CRUZ, YOUNGBLOOD, BOBACK, SCHLOSSBERG, KINSEY,
HOWARD, GALLOWAY, DRISCOLL, BURNS, BROWN, SAYLOR, MILLARD,
LONGIETTI, HEFFLEY, MALAGARI, FARRY AND DEASY,
SEPTEMBER 25, 2020

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
SEPTEMBER 25, 2020

A RESOLUTION

1 Designating the month of September 2020 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, with symptoms that
13 worsen throughout the life of the patient; and

14 WHEREAS, There are more than 50 identified leukodystrophies,
15 yet nearly half of patients with leukodystrophy remain
16 unclassified; and

1 WHEREAS, As research advances, scientists will continue to
2 discover and classify new variations in this family of diseases;
3 and

4 WHEREAS, Alone, each leukodystrophy may be considered rare,
5 but as a group these diseases affect approximately 1 in 7,000
6 individuals; and

7 WHEREAS, Infants born with leukodystrophy appear normal at
8 birth, yet, symptoms may appear during infancy or childhood; and

9 WHEREAS, Although there is no cure for leukodystrophy,
10 treatment may include medications, physical, occupational and
11 speech therapies and nutritional, educational and recreational
12 programs; and

13 WHEREAS, Additional treatment options such as bone marrow
14 transplantation are emerging due to continued research and
15 medical advances; and

16 WHEREAS, Organizations, including the United Leukodystrophy
17 Foundation, Hunter's Hope Foundation, The Myelin Project, the
18 MLD Foundation and the Adrenoleukodystrophy Foundation have
19 dedicated their work to public education, disease research and
20 patient treatment; and

21 WHEREAS, Act 148 of 2014 requires hospitals in this
22 Commonwealth to screen newborns for Krabbe disease, a
23 leukodystrophy; and

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

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

28 WHEREAS, It is imperative that parents learn about
29 leukodystrophy and understand the importance of screening and
30 early detection of Krabbe disease, X-ALD and other

1 leukodystrophies; therefore be it

2 RESOLVED, That the House of Representatives designate the
3 month of September 2020 as "Leukodystrophy Awareness Month" in
4 Pennsylvania; and be it further

5 RESOLVED, That the Commonwealth officially recognize the
6 importance of leukodystrophy awareness and encourage current and
7 future parents to educate themselves on these diseases and take
8 the necessary steps to ensure the health of their children.