
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 1013 Session of
2020

INTRODUCED BY CRUZ, YOUNGBLOOD, SCHLOSSBERG, BOBACK, HOWARD,
GALLOWAY, DRISCOLL, BURNS, McNEILL, BROWN, SAYLOR, MILLARD,
LONGIETTI, HEFFLEY, MADDEN, MALAGARI, READSHAW, KINSEY,
SCHLEGEL CULVER AND FARRY, SEPTEMBER 25, 2020

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

A RESOLUTION

1 Designating the month of September 2020 as "Krabbe Disease
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Globoid cell leukodystrophy, commonly known as
4 Krabbe disease, is an inherited degenerative disorder of the
5 central and peripheral nervous systems; and

6 WHEREAS, Krabbe disease is one of a group of genetic
7 disorders called leukodystrophies; and

8 WHEREAS, The disease most often affects infants, with onset
9 before six months of age, but can occur in adolescence or
10 adulthood; and

11 WHEREAS, Symptoms include irritability, unexplained fever,
12 limb stiffness, seizures, feeding difficulties, vomiting,
13 slowing of mental and motor development, muscle weakness,
14 spasticity, deafness and blindness; and

15 WHEREAS, Infantile Krabbe disease affects 1 in 100,000
16 infants in the United States; and

1 WHEREAS, There is no cure for Krabbe disease, but treatment
2 has been successful when it has begun before the appearance of
3 overt symptoms and when the disease has been diagnosed early;
4 and

5 WHEREAS, Act 148 of 2014 requires hospitals in this
6 Commonwealth to screen newborns for Krabbe disease and five
7 other lysosomal storage disorders; and

8 WHEREAS, Early detection through newborn screening is crucial
9 for affected children to receive potentially lifesaving
10 treatment which is effective if administered before a child is
11 symptomatic; and

12 WHEREAS, It is imperative that parents understand the
13 importance of Krabbe disease screening and early detection;
14 therefore be it

15 RESOLVED, That the House of Representatives designate the
16 month of September 2020 as "Krabbe Disease Awareness Month" in
17 Pennsylvania; and be it further

18 RESOLVED, That the Commonwealth officially recognize the
19 importance of screening for this disease and encourage parents
20 and future parents to educate themselves on this disease and
21 take the necessary steps to ensure the health of their children.