## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## HOUSE RESOLUTION

No. 993

Session of 2015

INTRODUCED BY CRUZ, YOUNGBLOOD, KINSEY, DIGIROLAMO, BAKER, ROSS, COHEN, HENNESSEY, ROZZI, WATSON, SCHLOSSBERG, CALTAGIRONE, VEREB, BOBACK, SAYLOR, KIRKLAND, TOOHIL, WARD, KIM, NEILSON, MILLARD, LONGIETTI, COOK-ARTIS, MURT, MAJOR, MARSICO, GOODMAN, PAYNE, EVERETT, GINGRICH AND READSHAW, SEPTEMBER 15, 2016

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

## A RESOLUTION

- Designating the month of September 2016 as "Krabbe Disease 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 the 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 and
- 13 slowing of mental and motor development, muscle weakness,
- 14 spasticity, deafness and blindness; and
- 15 WHEREAS, There is no cure for Krabbe disease but treatment

- 1 has been successful when it has begun before the appearance of
- 2 overt symptoms and when the disease has been diagnosed early;
- 3 and
- WHEREAS, Act 148 of 2014 requires hospitals in this
- 5 Commonwealth to screen newborns for Krabbe disease and five
- 6 other Lysosomal Storage Disorders; and
- WHEREAS, It is imperative that parents understand the
- 8 importance of screening for and detecting Krabbe disease early;
- 9 therefore be it
- 10 RESOLVED, That the House of Representatives designate the
- 11 month of September 2016 as "Krabbe Disease Awareness Month" in
- 12 Pennsylvania; and be it further
- 13 RESOLVED, That the Commonwealth officially recognize the
- 14 importance of screening for this disease, and encourage parents
- 15 and future parents to educate themselves on this disease, and
- 16 take the necessary steps to ensure the health of their children.