A RESOLUTION

1 Designating the month of September 2020 as "Krabbe Disease Awareness Month" in Pennsylvania.
2 WHEREAS, Globoid cell leukodystrophy, commonly known as Krabbe disease, is an inherited degenerative disorder of the central and peripheral nervous systems; and
3 WHEREAS, Krabbe disease is one of a group of genetic disorders called leukodystrophies; and
4 WHEREAS, The disease most often affects infants, with onset before six months of age, but can occur in adolescence or adulthood; and
5 WHEREAS, Symptoms include irritability, unexplained fever, limb stiffness, seizures, feeding difficulties, vomiting, slowing of mental and motor development, muscle weakness, spasticity, deafness and blindness; and
6 WHEREAS, Infantile Krabbe disease affects 1 in 100,000 infants in the United States; and
WHEREAS, There is no cure for Krabbe disease, but treatment has been successful when it has begun before the appearance of overt symptoms and when the disease has been diagnosed early; and

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

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

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

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

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