## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## HOUSE RESOLUTION

No. 146

Session of 2015

INTRODUCED BY CRUZ, YOUNGBLOOD, DIGIROLAMO, DAVIS, BROWNLEE, SCHLOSSBERG, THOMAS, HARHART, HAHN, WATSON, SANTARSIERO, KINSEY, GABLER, DRISCOLL, MILLARD, KORTZ, MURT, BISHOP, CUTLER, CALTAGIRONE, KIM, BAKER, J. HARRIS, O'BRIEN, DONATUCCI, READSHAW, BOBACK, FARINA, GRELL, ROSS, WHEELAND, GOODMAN, McCARTER AND GILLEN, MARCH 4, 2015

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, MARCH 4, 2015

## A RESOLUTION

- 1 Expressing condolences upon the passing of Hannah Rose Ginion of 2 Levittown and honoring her life and the contributions she
- made to strengthen the laws of this Commonwealth.
- 4 WHEREAS, Hannah Rose Ginion, lovingly known as "Hannah Bear,"
- 5 passed away December 28, 2014, a few weeks shy of her second
- 6 birthday; and
- 7 WHEREAS, Hannah was born January 15, 2013, a healthy baby
- 8 girl weighing 8 pounds, 11 ounces, to parents Justin Ginion and
- 9 Victoria Pizzullo of Levittown; and
- 10 WHEREAS, At first, Hannah was meeting and exceeding all of
- 11 her milestones, but at four months of age, Hannah suddenly and
- 12 inexplicably began regressing; and
- 13 WHEREAS, On June 17, 2013, five-month-old Hannah was
- 14 diagnosed with Krabbe disease at Children's Hospital of
- 15 Philadelphia; and
- 16 WHEREAS, Krabbe disease is a rare, inherited degenerative

- 1 disorder of the central and peripheral nervous systems; and
- 2 WHEREAS, Infants born with Krabbe disease appear normal at
- 3 birth; and
- 4 WHEREAS, Symptoms of Krabbe disease begin between three and
- 5 six months of age and include irritability, unexplained fever,
- 6 limb stiffness, seizures, feeding difficulties, vomiting and
- 7 slowing of mental and motor development; and
- 8 WHEREAS, Other symptoms include muscle weakness, spasticity,
- 9 deafness and blindness; and
- 10 WHEREAS, There is no cure for Krabbe disease but studies show
- 11 that early treatment may delay its onset when detection occurs
- 12 before symptoms begin; and
- 13 WHEREAS, Hannah's parents, Justin and Vicki, began advocating
- 14 for expanded newborn screening for Krabbe disease on behalf of
- 15 their daughter and other children in this Commonwealth; and
- 16 WHEREAS, As a result of this advocacy, expanded newborn
- 17 screening legislation inspired by Hannah became law October 15,
- 18 2014; and
- 19 WHEREAS, Thanks to "Hannah's Law," infants across this
- 20 Commonwealth will have a better chance at a healthy life; and
- 21 WHEREAS, Hannah's life may have been short, but she has left
- 22 an incredible legacy and is a hero for all newborns; and
- 23 WHEREAS, The House of Representatives mourns the loss of
- 24 Hannah and extends condolences to her parents, Justin Ginion and
- 25 Vicki Pizzullo; her sisters, Faith and Samantha Dydak; her
- 26 maternal grandparents, Victoria and Vincent Pizzullo; her
- 27 paternal grandparents, Jerry Jordan and Anne Matusek; her
- 28 maternal great-grandmother, Alberta Gardner; and her paternal
- 29 great-grandmother, Annette Ginion; therefore be it
- RESOLVED, That the House of Representatives express

- 1 condolences upon the passing of Hannah Rose Ginion of Levittown;
- 2 and be it further
- 3 RESOLVED, That a copy of this resolution be transmitted to
- 4 the family of Hannah Rose Ginion as an expression of condolence
- 5 for their loss and as a token of appreciation for Hannah's vital
- 6 role in strengthening the newborn screening laws in this
- 7 Commonwealth.