THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 1182 Session of 2018

INTRODUCED BY KINSEY, MADDEN, READSHAW, HILL-EVANS, BIZZARRO, MILLARD, RYAN, DIGIROLAMO, LONGIETTI, J. McNEILL, NEILSON, THOMAS AND BURNS, NOVEMBER 2, 2018

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, NOVEMBER 2, 2018

A RESOLUTION

- 1 Recognizing November 15, 2018, as "Ohtahara Syndrome Awareness Day" in Pennsylvania.
- 3 WHEREAS, Ohtahara syndrome is a rare neurological disorder
- 4 that is characterized by seizures and affects infants within the
- 5 first three months of life; and
- 6 WHEREAS, Ohtahara syndrome is most commonly caused by
- 7 metabolic disorders or structural damage in the brain; and
- 8 WHEREAS, The cause of many cases of Ohtahara syndrome cannot
- 9 be determined; and
- 10 WHEREAS, As Ohtahara syndrome progresses, seizures become
- 11 more frequent and approximately one in three infants develop
- 12 other types of seizure disorders; and
- 13 WHEREAS, Developmental delays and motor and cognitive
- 14 problems are often present and can grow increasingly worse; and
- 15 WHEREAS, Treating this condition is extremely difficult as
- 16 the medications that are typically used to treat seizure
- 17 disorders are rarely effective in treating Ohtahara syndrome;

- 1 and
- 2 WHEREAS, Some children may die before they reach two years of
- 3 age, and children who survive are typically left with severe
- 4 physical and cognitive disabilities; and
- 5 WHEREAS, Ohtahara syndrome is classified as a rare disease,
- 6 affecting fewer than 200,000 individuals in the United States;
- 7 and
- 8 WHEREAS, Because the number of individuals suffering from
- 9 Ohtahara syndrome is so small, research efforts to provide
- 10 effective treatments are often slow moving and require greater
- 11 awareness; and
- 12 WHEREAS, The month of November is celebrated as "National
- 13 Epilepsy Awareness Month" in an effort to end the stigma
- 14 surrounding epilepsy and generate compassion for the 3.4 million
- 15 Americans living with an epilepsy disorder such as Ohtahara
- 16 syndrome; and
- 17 WHEREAS, Hope for children with Ohtahara syndrome relies on
- 18 the medical and research community understanding more about this
- 19 rare form of epilepsy and discovering treatments that may be the
- 20 most effective; and
- 21 WHEREAS, "Ohtahara Syndrome Awareness Day" highlights these
- 22 research efforts and acknowledges the devastating impact this
- 23 disorder has on children and their families; therefore be it
- 24 RESOLVED, That the House of Representatives recognize
- 25 November 15, 2018, as "Ohtahara Syndrome Awareness Day" in
- 26 Pennsylvania.