THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 210

Session of 2023

INTRODUCED BY KINSEY, MADDEN, HILL-EVANS, HARKINS, ROZZI, SANCHEZ, FREEMAN, DONAHUE, MALAGARI, HADDOCK, KHAN, CEPEDA-FREYTIZ, CERRATO AND CONKLIN, SEPTEMBER 19, 2023

REFERRED TO COMMITTEE ON HEALTH, SEPTEMBER 19, 2023

A RESOLUTION

- Recognizing November 15, 2023, 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
- 12 WHEREAS, Developmental delays and motor and cognitive
- 13 problems are often present and can grow increasingly worse; and
- 14 WHEREAS, Treating this condition is extremely difficult as
- 15 the medications that are typically used to treat seizure
- 16 disorders are rarely effective in treating Ohtahara syndrome;
- 17 and

- 1 WHEREAS, Some children may die before they reach two years of
- 2 age, and children who survive are typically left with severe
- 3 physical and cognitive disabilities; and
- 4 WHEREAS, Ohtahara syndrome is classified as a rare disease,
- 5 affecting fewer than 200,000 individuals in the United States;
- 6 and
- 7 WHEREAS, Because the number of individuals suffering from
- 8 Ohtahara syndrome is so small, research efforts to provide
- 9 effective treatments are often slow moving and require greater
- 10 awareness; and
- 11 WHEREAS, The month of November is celebrated as "National
- 12 Epilepsy Awareness Month" in an effort to end the stigma
- 13 surrounding epilepsy and generate compassion for the 3.4 million
- 14 Americans living with an epilepsy disorder such as Ohtahara
- 15 syndrome; and
- 16 WHEREAS, Hope for children with Ohtahara syndrome relies on
- 17 the medical and research community understanding more about this
- 18 rare form of epilepsy and discovering treatments that may be the
- 19 most effective; and
- 20 WHEREAS, "Ohtahara Syndrome Awareness Day" highlights these
- 21 research efforts and acknowledges the devastating impact this
- 22 disorder has on children and their families; therefore be it
- 23 RESOLVED, That the House of Representatives recognize
- 24 November 15, 2023, as "Ohtahara Syndrome Awareness Day" in
- 25 Pennsylvania.