

MICHIGAN SENATE

Senate Resolution No. 83

Offered by Senators Nesbitt and Theis

A RESOLUTION TO RECOGNIZE OCTOBER 23, 2025, AS PURA SYNDROME AWARENESS DAY

WHEREAS, PURA syndrome is a rare neurodevelopmental disorder caused by genetic alterations in the Purine-Rich Element Binding Protein A gene, which plays a critical role in brain development and cellular function; and

WHEREAS, Individuals affected by PURA syndrome often experience significant developmental delays, intellectual disabilities, hypotonia, feeding difficulties, and seizures, with many remaining non-verbal and facing lifelong challenges; and

WHEREAS, PURA syndrome was first identified in medical literature in 2014, and although fewer than 1,000 cases have been diagnosed worldwide, increased access to genetic testing is expected to lead to more diagnoses; and

WHEREAS, Families affected by PURA syndrome demonstrate extraordinary resilience and advocacy, working to provide vital support, education, and funding for research to improve the quality of life of those affected; and

WHEREAS, Raising awareness of PURA syndrome is essential to promoting early diagnosis, advancing research, and fostering inclusive communities that support individuals with rare diseases; and

WHEREAS, Advocacy groups and families have designated October 23rd as PURA Syndrome Awareness Day to honor those affected and to encourage public education and support; now, therefore, be it

RESOLVED BY THE SENATE, That the members of this legislative body recognize October 23, 2025, as PURA Syndrome Awareness Day; and be it further

RESOLVED, That we encourage all citizens to learn more about PURA syndrome, support affected families, and promote awareness of rare diseases.

Adopted by the Senate, October 23, 2025.



Secretary of the Senate