

SENATE RESOLUTION NO. 83

Senators Nesbitt and Theis offered the following resolution:

1 A resolution to recognize October 23, 2025, as PURA Syndrome
2 Awareness Day.

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

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

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

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

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

9 Whereas, Advocacy groups and families have designated October
10 23rd as PURA Syndrome Awareness Day to honor those affected and to
11 encourage public education and support; now, therefore, be it

12 Resolved by the Senate, That the members of this legislative
13 body recognize October 23, 2025, as PURA Syndrome Awareness Day;
14 and be it further

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