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SENATE RESOLUTION

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WHEREAS, In 2014, medical literature first described the rare condition of PURA syndrome, and identified the PURA gene on the fifth chromosome as the source of the syndrome; and

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WHEREAS, PURA syndrome is a very rare condition; it causes a variety of neurological symptoms from birth, including difficulty breathing, maintaining body temperature, severe sleepiness, feeding difficulties, and very low muscle tone; and

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WHEREAS, There are approximately 100 confirmed cases of PURA syndrome globally, though it is expected that many more people will be diagnosed in the coming years due to the increased use of 'gene sequencing' technology; PURA syndrome patients range in age from seven months to 29 years; and

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WHEREAS, Nearly all PURA syndrome patients are non-verbal and have various motor difficulties, including challenges with walking independently; and

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WHEREAS, Early intervention is key to aiding children with PURA syndrome; occupational therapy can assist with spinal development, independence, sensory processing, self-care, and motor functioning; and

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1 WHEREAS, The PURA Syndrome Foundation is a global
2 organization that provides support, education, and community
3 for PURA families, helping to fund research for families coping
4 with the effects of PURA syndrome to enhance the quality of
5 life for patients and their families; therefore, be it

6 RESOLVED, BY THE SENATE OF THE ONE HUNDREDTH GENERAL
7 ASSEMBLY OF THE STATE OF ILLINOIS, that we declare April 28,
8 2017 as PURA Syndrome Day; and be it further

9 RESOLVED, That a suitable copy of this resolution be
10 presented to the PURA Syndrome Foundation Team Chicago in
11 recognition and appreciation of the organization's important
12 work.