

HR1075 LRB099 20011 GRL 44414 r

1 HOUSE RESOLUTION WHEREAS, In the United States, rare diseases affect nearly 2 3 30 million Americans; more than half of the population affected 4 by rare diseases are children; and 5 WHEREAS, The Illinois General Assembly recognizes the 6 hardship Illinois families endure when their children are 7 diagnosed with a rare disease or disorder; and 8 WHEREAS, Bilateral Perisylvian Polymicrogyria is a rare 9 neurological disorder that affects the cerebral cortex, the outer surface of the brain, early in children's lives; and 10 11 WHEREAS, Symptoms of Bilateral Perisylvian Polymicrogyria 12 include partial paralysis of muscles on both sides of the face, 13 tongue, jaws, and throat; and 14 WHEREAS, Those who suffer from Bilateral Perisylvian 15 Polymicrogyria have difficulties in speaking, chewing, and swallowing; in some cases, seizures are experienced and, in 16 17 most cases, mild to severe intellectual disability is present; 18 and 19 WHEREAS, The exact cause of Bilateral Perisylvian

Polymicrogyria is not fully understood; it is thought to be due

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- 1 to improper brain development during embryonic growth; and
- 2 WHEREAS, Dorothy Teresea-Marie "Tess" Drainer is a vibrant
- 3 and sweet young Illinois resident who has been diagnosed with
- 4 Bilateral Perisylvian Polymicrogyria; and
- 5 WHEREAS, Tess Drainer suffers from seizures, cerebral
- 6 palsy, scoliosis, and chronic heart and lung disease as a
- 7 result of the rare disorder; and
- 8 WHEREAS, Tess Drainer enjoys painting, riding her pony, and
- 9 watching the movie "Disney Descendants"; above all else, she
- 10 greatly enjoys spending time with her family; and
- 11 WHEREAS, Tess Drainer is an inspiration to all who meet
- 12 her; as Tess battles her rare disease at a young age, she
- 13 continuously serves as an example of a courageous and
- 14 headstrong Illinois citizen; therefore, be it
- 15 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE
- 16 NINETY-NINTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that we
- 17 honor and recognize Dorothy Teresea-Marie "Tess" Drainer by
- 18 spreading awareness of Bilateral Perisylvian Polymicrogyria
- 19 across the State of Illinois and give our encouragement to all
- 20 those battling rare diseases; and be it further

- 1 RESOLVED, That a suitable copy of this resolution be
- 2 presented to Tess Drainer as an expression of our deepest
- 3 admiration.