**A** **SENATE RESOLUTION**

TO RECOGNIZE SEPTEMBER 8, 2019 AS “LISSENCEPHALY AWARENESS DAY” IN SOUTH CAROLINA AND TO URGE ALL CITIZENS OF THIS STATE TO SUPPORT THE SEARCH FOR A CURE AND ASSIST THOSE INDIVIDUALS AND FAMILIES WHO DEAL WITH THE CONDITION ON A DAILY BASIS.

Whereas, rare medical conditions often receive inadequate attention from the medical community and society at large, regardless of their severity; and

Whereas, less than one thousand estimated individuals worldwide have been diagnosed with Lissencephaly, a condition that is characterized by agyria or pachygyria, which means the absence or incomplete development, respectively, of the brain gyri or convolution, causing the brain’s surface to appear unusually smooth; and

Whereas, Lissencephaly is a chronic condition that may cause epilepsy, muscle spasms, partial or complete paralysis, low vision, and severe medical complications; and

Whereas, patients with this condition often live with endless therapies and medical expenses; and

Whereas, it may take years to receive a diagnosis of Lissencephaly, and medical professionals are often inadequately educated on the diagnosis and treatment of Lissencephaly; and

Whereas, an increased awareness and expanded knowledge of the realities of life with Lissencephaly will allow the community at large to better support people who struggle with the challenges of this condition; and

Whereas, We Are R.A.R.E. is a nonprofit charitable organization and initiative made up of parents of children who face these challenges and is aimed at providing research, awareness, and education for rare neurological disorders; and

Whereas, We Are R.A.R.E. and other groups around the country have joined together to promote Lissencephaly awareness and support, including improved education; and

Whereas, in order to promote awareness, the members of the South Carolina Senate and We Are R.A.R.E. urge Lissencephaly patients and their supporters, healthcare providers, and the general public to demonstrate their caring by sharing patients’ journeys and facts about Lissencephaly, including the developing understanding of the etiology of the disorder and any potential treatments; and

Whereas, the community’s focus on Lissencephaly and its impact on patients’ lives will help guarantee hope for a better future for individuals with Lissencephaly. Now, therefore,

Be it resolved by the Senate:

That the members of the South Carolina Senate, by this resolution, recognize September 8, 2019 as “Lissencephaly Awareness Day” in South Carolina and urge all citizens of this State to support the search for a cure and assist those individuals and families who deal with the condition on a daily basis.

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