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LRB100 21519 MST 38477 r

1 HOUSE RESOLUTION

2 WHEREAS, An estimated 10,000 people worldwide have
3 schizencephaly, both diagnosed and undiagnosed, a condition
4 for which there is no known cause or cure; and

5 WHEREAS, Schizencephaly can be a chronic condition that may
6 cause epilepsy, muscle spasms, partial or complete paralysis,
7 low vision, and severe medical complications; and

8 WHEREAS, Patients with this condition often have to learn
9 to live with continued therapies and medical expenses; and

10 WHEREAS, It may take years to receive a diagnosis of
11 schizencephaly, and medical professionals frequently are
12 inadequately educated on the diagnosis and treatment of
13 schizencephaly; and

14 WHEREAS, Increased awareness and expanded knowledge of the
15 realities of life with schizencephaly will allow the community
16 at large to better support people who struggle with the
17 challenges of this condition; and

18 WHEREAS, We Are R.A.R.E. is a nonprofit charitable
19 organization and initiative made up of parents with children
20 facing these challenges and aimed at providing research.

1 awareness, and education for rare neurological disorders; and

2 WHEREAS, We Are R.A.R.E. and other groups around our
3 country have joined together to promote schizencephaly
4 awareness and support, including improved education,
5 diagnosis, research, and treatment; and

6 WHEREAS, We Are R.A.R.E. is urging schizencephaly patients
7 and their supporters, healthcare providers, and the general
8 public to demonstrate their caring by sharing the road patients
9 walk, the facts about schizencephaly, and the ever-growing
10 awareness about the etiology of this disorder and potential
11 treatments; and

12 WHEREAS, Focusing on schizencephaly and its impact on
13 patients' lives will help guarantee hope for a better future
14 for people with schizencephaly; therefore, be it

15 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE
16 HUNDREDTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that we
17 congratulate Illinoisans participating in Schizencephaly
18 Awareness Day on May 19, 2018, and we urge citizens to support
19 the search for a cure and assist those individuals and families
20 who deal with this condition on a daily basis; and be it
21 further

1 RESOLVED, That a suitable copy of this resolution be
2 presented to We Are R.A.R.E. as a symbol of our respect and
3 esteem.