

HJR34 INTRODUCED



1 YKLG6-1
2 By Representative Pringle
3 RFD: RULES
4 First Read: 23-Mar-23
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HJR_____ TO RECOGNIZE MAY 2023 AS TUBEROUS SCLEROSIS COMPLEX AWARENESS MONTH IN ORDER TO RAISE AWARENESS FOR THE NEED FOR RESEARCH, PROPER DIAGNOSIS, AND FAMILY SUPPORT FOR INDIVIDUALS WHO SUFFER FROM TUBEROUS SCLEROSIS COMPLEX.

WHEREAS, May 2023 is recognized as National Tuberos Sclerosis Complex Awareness Month, which makes this month an important time for raising public awareness and understanding about the disorder; and

WHEREAS, Tuberos Sclerosis Complex (TSC) is a genetic disorder that causes non-malignant tumors to form in many different organs, primarily involving the brain, eyes, heart, kidney, skin, and lungs; and

WHEREAS, an estimated 50,000 Americans and 1 million people worldwide have been diagnosed with TSC; and

WHEREAS, TSC is also the leading cause of Epilepsy and a leading genetic cause of Autism; and

WHEREAS, the incidence and severity of the various aspects of TSC can vary widely between individuals - even identical twins; and

WHEREAS, The University of Alabama Birmingham (UAB) Tuberos Sclerosis Clinic serves an estimated 800 residents in Alabama with TSC; the clinic also serves as a Center of Excellence for the Southeastern United States, for both pediatric and adult patients with an established or suspected diagnosis of this complex genetic disorder; and



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29 WHEREAS, the UAB TSC Clinic employs an
30 interdisciplinary team of physicians that includes experts
31 in genetics, neurology, dermatology, and genetic counseling,
32 with ready access to consultants in endocrinology,
33 pulmonology, nephrology, neurosurgery, ophthalmology, and
34 more; and

35 WHEREAS, The UAB Clinic has been one of the leaders
36 in the TSC Clinical Research Consortium and has an active
37 clinical research program giving patients access to
38 cutting-edge, NIH-funded research efforts; since its
39 inception in 2007, the clinic under the guidance of Dr.
40 Martina Bebin has received more than \$10 million in NIH
41 funding; and

42 WHEREAS, the TSC Alliance and other groups around the
43 world have joined together to promote awareness of the
44 disorder to ensure people with TSC get the best possible
45 treatment and proper diagnoses; now therefore,

46 BE IT RESOLVED BY THE LEGISLATURE OF ALABAMA, BOTH
47 HOUSES THEREOF CONCURRING, That we recognize May 15, 2023,
48 as "Tuberous Sclerosis Complex Awareness Day" and May 2023
49 as TSC Awareness Month throughout Alabama and urge all of
50 our citizens to support the search for a cure and assist
51 those individuals and families who deal with this
52 challenging disorder on a daily basis.