

**STATE OF ARKANSAS**  
**EXECUTIVE DEPARTMENT**

**PROCLAMATION**

TO ALL TO WHOM THESE PRESENTS COME – GREETINGS:

WHEREAS: Schizencephaly is an extremely rare congenital disorder characterized by a full-thickness cleft within the cerebral hemispheres. Large portions of the cerebral hemispheres may be absent and replaced by cerebrospinal fluid. Two types of Schizencephaly have been described, depending on the size of the area involved and the separation of the cleft lips; and

WHEREAS: Schizencephaly is listed as a rare disease by the Office of Rare Diseases (ORD) of the National Institutes of Health (NIH). This means that Schizencephaly, or a subtype of Schizencephaly, affects less than 200,000 people in the U.S. population; and

WHEREAS: Babies with clefts in both hemispheres (called bilateral clefts) commonly have developmental delays, delays in speech and language skills, and problems with brain-spinal cord communication. Individuals with clefts in only one hemisphere (called unilateral clefts) are often paralyzed on one side of the body, but may have average to near-average intelligence; and

WHEREAS: Individuals with Schizencephaly may also have an abnormally small head, mental retardation, partial or complete paralysis, or poor muscle tone. Most will experience seizures. Some individuals may have an excessive accumulation of fluid in the brain called hydrocephalus; and

WHEREAS: The prognosis of Schizencephaly is catastrophic, but depends essentially on the size of the clefts and the extent of neurological disabilities and the presence of associated lesions. Usually patient with open-lip Schizencephaly die at an earlier age than patients with the closed-lip form. Sometimes closed-lip Schizencephaly may not present clinically until later during the childhood and may live to early adulthood; and

WHEREAS: The National Institute of Neurological Disorders and Stroke (NINDS) conducts and supports a wide range of studies that explore the mechanisms of normal brain development. The knowledge gained from these fundamental studies provides the foundation for understanding how to prevent or treat developmental brain defects such as Schizencephaly; and

WHEREAS: Only through medical research can effective treatment and prevention strategies for Schizencephaly be identified;

NOW, THEREFORE, I, ASA HUTCHINSON, Governor of the State of Arkansas, by virtue of the authority vested in me by the laws of the State of Arkansas, do hereby proclaim May 19<sup>th</sup>, 2017, as

**SCHIZENCEPHALY AWARENESS DAY**

across the State, and I encourage patients, caregivers, health-care professionals, as well as the wider community, to join together to raise awareness about Schizencephaly and the need for medical research for effective treatment and prevention strategies.

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Arkansas to be affixed this 23<sup>rd</sup> day of January, in the year of our Lord 2017.



Asa Hutchinson, Governor



Attest



Mark Martin, Secretary Of State