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ACR-76 Diffuse Intrinsic Pontine Glioma Awareness Day. (2019-2020)

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Assembly Concurrent Resolution No. 76

CHAPTER 76

Relative to Diffuse Intrinsic Pontine Glioma Awareness Day.

[Filed with Secretary of State June 04, 2019.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 76, Smith. Diffuse Intrinsic Pontine Glioma Awareness Day.

This measure would designate May 17, 2019, as Diffuse Intrinsic Pontine Glioma Awareness Day to honor those who work to make research and resources a reality for children suffering from Diffuse Intrinsic Pontine Glioma and their families.

Fiscal Committee: no

WHEREAS, Diffuse intrinsic pontine glioma (DIPG) is a malignant brain tumor that affects the brain stem. DIPG is almost exclusively a pediatric disease, and it is usually diagnosed between five and nine years of age; and

WHEREAS, DIPG affects 200 to 400 children in the United States each year; and

WHEREAS, Brain tumors are the leading cause of cancer-related death in children; and

WHEREAS, DIPG is the second most common malignant brain tumor of childhood; and

WHEREAS, Children diagnosed with DIPG have a survival time of only nine months; and

WHEREAS, The Legislature recognizes that the quality and character of life in the communities across the State of California are reflective of the concerned and dedicated efforts of those organizations and individuals that are devoted to the welfare of the community and its citizenry; and

WHEREAS, In this regard, the Legislature commends the efforts of the Jack's Angels Foundation and other similar foundations for their continuing efforts to raise awareness of, and fight against, malignant brain tumors; and

WHEREAS, James-William "Jack" Demeter, the namesake of the Jack's Angels Foundation, lost the fight against DIPG at three years of age; and

WHEREAS, According to Dr. Sabine Mueller of the University of California at San Francisco, DIPG is one of the worst diagnoses a patient and the patient's family can face. Progress has been hampered by the perceived risk of biopsy of these tumors. To date, no therapy has been shown to be effective and children with DIPG are often treated on early phase 1 clinical trials with a trial-and-error approach; and

WHEREAS, The Jack's Angels Foundation is a nonprofit corporation that established a DIPG research fund at the Children's Hospital Los Angeles in 2013. The foundation is committed to promoting the most innovative research and clinical trials to help shed light on the nature of DIPG and the genetic anomalies that cause it. In order that there be greater hope for survival, the foundation also actively researches cures for DIPG through medical trials and scientific research; and

WHEREAS, The mission of the Jack's Angels Foundation is also to support the quality of life for patients diagnosed with DIPG and their families; and

WHEREAS, The mission of the Jack's Angels Foundation also includes increasing public awareness and understanding of DIPG, potentially increasing the protocol for pediatric brain tumor research, and increasing investment by pharmaceutical companies in research pertaining to DIPG; and

WHEREAS, It is the intent of the Legislature to call attention to organizations, like the Jack's Angels Foundation, that serve to bring people together for the united purpose of actively pursuing improvements in their communities; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature pause in its deliberations to honor those who raise awareness of, and fight against, malignant brain tumors, including DIPG; and be it further

Resolved, That the Legislature hereby declares May 17, 2019, as Diffuse Intrinsic Pontine Glioma Awareness Day to honor those who work to make research and resources a reality for children suffering from DIPG and their families; and be it further

Resolved, That the Chief Clerk of the Assembly transmit copies of this resolution to the author for appropriate distribution.