

Assembly Concurrent Resolution

No. 151

Introduced by Assembly Member Wilk

May 19, 2014

Assembly Concurrent Resolution No. 151—Relative to Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week.

LEGISLATIVE COUNSEL'S DIGEST

ACR 151, as introduced, Wilk. Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week.

This measure would declare the week of May 25, 2014, to May 31, 2014, inclusive, as Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week to honor those who work to make research and resources a reality for children suffering from DIPG and their families.

Fiscal committee: no.

- 1 WHEREAS, The Legislature recognizes that the quality and
2 character of life in the communities across the State of California
3 are reflective of the concerned and dedicated efforts of those
4 organizations and individuals that are devoted to the welfare of
5 the community and its citizenry; and
6 WHEREAS, In this regard, the Legislature commends the efforts
7 of the Jack's Angels Foundation and other similar foundations for
8 their continuing efforts to raise awareness of, and fight against,
9 malignant brain tumors; and
10 WHEREAS, James-William "Jack" Demeter, the namesake of
11 the Jack's Angels Foundation, lost the fight against Diffuse
12 Intrinsic Pontine Glioma (DIPG) at the age of three; and

1 WHEREAS, DIPG is a malignant brain tumor that affects the
2 brain stem. Only children are afflicted with DIPG and it is usually
3 diagnosed between five and nine years of age; and

4 WHEREAS, According to Dr. Sabine Mueller of the University
5 of California at San Francisco, DIPG is one of the worst diagnoses
6 a patient and his or her family can face. There are essentially no
7 long-term survivors and median survival is only about 9 months.
8 Progress has been hampered by the perceived risk of biopsy of
9 these tumors. To date, no therapy has been shown to be effective
10 and children with DIPG are often treated on early phase 1 clinical
11 trials with a trial-and-error approach; and

12 WHEREAS, The Jack's Angels Foundation is a nonprofit
13 corporation that donates all money raised to establish a new DIPG
14 research fund at the Los Angeles Children's Hospital. The
15 foundation is committed to promoting the most innovative research
16 and clinical trials to help shed light on the nature of DIPG and the
17 genetic anomalies that cause it. In order that there be greater hope
18 for survival, the foundation also actively researches cures for DIPG
19 through medical trials and scientific research; and

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

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

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

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

36 *Resolved,* That the Legislature hereby declares the week of May
37 25, 2014, to May 31, 2014, inclusive, as Diffuse Intrinsic Pontine
38 Glioma (DIPG) Awareness Week to honor those who work to
39 make research and resources a reality for children suffering from
40 DIPG and their families; and be it further

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

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