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SJR-25 Batten Disease Awareness Weekend. (2017-2018)

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Senate Joint Resolution No. 25

CHAPTER 114

Relative to Batten Disease Awareness Weekend.

[Filed with Secretary of State June 29, 2018.]

LEGISLATIVE COUNSEL'S DIGEST

SJR 25, Wilk. Batten Disease Awareness Weekend.

This measure would designate the weekend of June 2, 2018, through June 3, 2018, as Batten Disease Awareness Weekend, and would call upon the President and Congress of the United States to enact legislation that provides more funding for research to be done on potential treatment and cures for rare diseases.

Fiscal Committee: no

WHEREAS, Batten Disease is a family of rare genetic disorders of the nervous system that typically begins in childhood; and

WHEREAS, There are many forms of Batten Disease, and the mutations of at least 14 different genes are known to cause the disease; and

WHEREAS, Symptoms of the fatal disease include vision loss leading to blindness, personality and behavioral changes, seizures, intellectual decline, disruption and loss of speech, dementia, and other debilitating ailments; and

WHEREAS, Depending on the age of onset, Batten Disease usually leads to premature death when the patient is in his or her late teens or early twenties; and

WHEREAS, Batten Disease occurs in an estimated two to four of every 100,000 births in the United States; and

WHEREAS, Due to the many different forms of the disease, there is significant variability in the age of onset and symptom progression for each case; and

WHEREAS, On average, the process to reach the correct diagnosis for a patient with a rare disease could take up to 7.6 years, visits with numerous physicians, and multiple misdiagnoses; and

WHEREAS, There is no known cure for Batten Disease, and the lack of essential funding has hindered scientists' ability to find a potential treatment or cure; and

WHEREAS, The federal government failed to pass House Resolution 971 introduced by Representative Gus Bilirakis in the 114th Congress, which represented an effort to increase the number of treatments for rare diseases, reduce the use of drugs that are not approved by the federal Food and Drug Administration (FDA), and bring down the average cost of rare disease medications; and

WHEREAS, The federal government has not done enough to provide funding for rare diseases, and 95 percent of the 7,000 rare diseases still have no FDA-approved treatment; now, therefore, be it

Resolved by the Senate and the Assembly of the State of California, jointly, That the Legislature does hereby proclaim the weekend of June 2, 2018, through June 3, 2018, as Batten Disease Awareness Weekend; and be it further

Resolved, That the Legislature calls upon the President and Congress of the United States to enact legislation that provides more funding for research to be done on potential treatment and cures for rare diseases; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the President and Vice President of the United States, to the Speaker of the House of Representatives, to the Majority Leader of the Senate, and to each Senator and Representative from California in the Congress of the United States.