

117TH CONGRESS
1ST SESSION

H. RES. 424

Expressing support for the designation of June 1, 2021, as “Batten Disease Awareness Day”.

IN THE HOUSE OF REPRESENTATIVES

MAY 20, 2021

Mr. GARCIA of California submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for the designation of June 1, 2021, as “Batten Disease Awareness Day”.

Whereas Batten disease is a family of rare genetic disorders of the nervous system that typically begins in childhood;

Whereas there are many forms of Batten disease, and the mutations of at least 14 different genes are known to cause the disease;

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;

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;

Whereas Batten disease occurs in an estimated 2 to 4 of every 100,000 births in the United States;

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;

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;

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 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

1 *Resolved*, That the House of Representatives—

2 (1) supports the designation of a “Batten Dis-
3 ease Awareness Day”; and

4 (2) calls for more funding for research to be
5 done on potential treatment and cures for rare dis-
6 eases.

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