

117TH CONGRESS  
1ST SESSION

# H. RES. 424

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

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## 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

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## 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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