

119TH CONGRESS
1ST SESSION

H. RES. 385

Expressing support for the designation of May 2, 2025, as “NKH Awareness Day”.

IN THE HOUSE OF REPRESENTATIVES

MAY 5, 2025

Mr. VINDMAN (for himself and Mr. CLINE) submitted the following resolution;
which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for the designation of May 2, 2025,
as “NKH Awareness Day”.

Whereas a rare disease is defined as a disease that affects fewer than 200,000 people in the United States at any given time;

Whereas children make up more than half of the estimated 25,000,000 to 35,000,000 people in the United States living with a rare disease;

Whereas nonketotic hyperglycinemia (NKH) is a rare genetic metabolic disorder in which abnormally high levels of glycine build up in a patient’s body;

Whereas NKH is also known as glycine encephalopathy;

Whereas NKH affects approximately 1 in 76,000 people worldwide;

Whereas NKH is caused by a mutation in the glycine cleavage enzyme system, meaning that patients cannot break down glycine, resulting in its accumulation throughout the body and especially in the spinal cord and brain;

Whereas NKH has 2 forms, severe and attenuated NKH;

Whereas most children born with NKH do not achieve typical developmental milestones, and those that do may lose these abilities over time;

Whereas NKH may be diagnosed by a combination of a physical exam, biochemical testing, and genetic analysis;

Whereas there are only approximately 500 cases of NKH diagnosed worldwide;

Whereas 4 known patients living with NKH are in Virginia;

Whereas Congress can raise awareness of NKH in the public and in the medical community of the United States; and

Whereas increased awareness of NKH may result in increased research, participation in NKH patient registries, and diagnoses of NKH cases: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the designation of “NKH Awareness Day”; and

3 (2) recognizes the importance of raising awareness and improving education around nonketotic hyperglycinemia (NKH).

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