

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).

○