

119TH CONGRESS
2D SESSION

H. RES. 1223

Expressing support for the designation of Undiagnosed Awareness Month.

IN THE HOUSE OF REPRESENTATIVES

APRIL 28, 2026

Mr. POCAN (for himself, Mr. CLINE, Ms. NORTON, and Mr. RUTHERFORD) submitted the following resolution; which was referred to the Committee on Oversight and Government Reform

RESOLUTION

Expressing support for the designation of Undiagnosed Awareness Month.

Whereas approximately 25,000,000 Americans currently live with rare and undiagnosed diseases, a significant portion of whom remain undiagnosed for years or for life;

Whereas “undiagnosed” is defined as living with a medical condition that has not been identified through clinical evaluation, even after extensive testing and consultation with medical specialists;

Whereas patients with undiagnosed diseases often experience prolonged uncertainty, delayed or inappropriate treatment, psychological distress, and financial hardship;

Whereas the average diagnostic journey for a patient with a rare or ultrarare disease can last over 7 years, often in-

volving multiple referrals, misdiagnoses, and unnecessary procedures;

Whereas, in recognition of the need to establish and develop a domestic capability to coordinate and drive research on rare and unidentified diseases within the United States, the Undiagnosed Diseases Network (in this preamble referred to as “UDN”) was created within the National Institutes of Health in 2015;

Whereas, since the launch of the UDN in 2015, the strategic deployment of clinical sites across the United States utilizing state-of-the-art genomic sequencing and model organism research has led to the diagnosis of more than 1,000 Americans and the discovery and identification of more than ninety novel diagnoses;

Whereas the UDN’s unique decentralized model brings together medical and scientific expertise to push the cutting edge of the Nation’s scientific frontier, is now constituted by 24 UDN Clinical Sites providing access to many Americans and is rapidly innovating by implementing the use of artificial intelligence (commonly known as “AI”) to further enhance diagnostic capabilities;

Whereas the Undiagnosed Diseases Network Foundation (In this preamble referred to as “UDNF”) was created by those living undiagnosed to support and improve access to diagnosis, research, and care for all individuals with rare and undiagnosed diseases, including by championing the work of the UDN;

Whereas the UDNF is a patient-driven nonprofit fostering community, support, innovation, and action for families navigating the uncertainty of rare and undiagnosed diseases;

Whereas the collaborative work of the UDN, NIH (in this preamble referred to as “NIH”), and UDNF offers an opportunity for access to diagnostic tools and greater diagnostic precision so that patients, clinicians, and treatments can be identified because without a diagnosis, there is no treatment;

Whereas greater public awareness and medical education are critical to reducing diagnostic delays and promoting equitable access to genomic and diagnostic technologies;

Whereas the Director of the NIH included in the agency’s fiscal year 2026 Budget Justification executive summary that one of the NIH-wide Strategic Plan Objectives would be to “[b]y 2027, increase the capacity of the Undiagnosed Diseases Network (UDN) to evaluate people with undiagnosed diseases and expand access to individuals who do not typically participate in NIH clinical research”; and

Whereas recognizing April as Undiagnosed Awareness Month and April 29th as Undiagnosed Day honors the courage of patients and families living without answers, acknowledges the dedication of clinicians and researchers pursuing solutions, recognizes the need for a cohesive effort to solve the most difficult medical mysteries, and inspires continued innovation toward timely and accurate diagnosis: Now, therefore, be it

- 1 *Resolved*, That the House of Representatives supports
- 2 the ideals and goals of Undiagnosed Awareness Month.

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