UNDIAGNOSED DISEASE NETWORK FOUNDATION (UDNF) ANNOUNCES ITS ATTENDANCE AT THE 2024 WHITE HOUSE RARE DISEASE FORUM

UDNF Continues to Lead Patient Advocacy Efforts for Undiagnosed and Ultra-Rare Disease Patients

WASHINGTON, DISTRICT OF COLUMBIA, UNITED STATES, February 28, 2024 /EINPresswire.com/ -- The Undiagnosed Diseases Network Foundation (UDNF), a patient-led nonprofit organization committed to improving access to diagnosis, research, and care for people with undiagnosed diseases, announced today that the White House has invited them to attend the 2024 White House Rare Disease Forum convening tonight, February 28th at 5:30 p.m. to 7 pm. EST at the White House Complex, Eisenhower Executive Office Building.

“Undiagnosed and ultra-rare patients and families often experience significant isolation on their diagnostic and treatment odysseys," said Sarah Marshall, UDNF community and patient engagement, and Children’s Minnesota Medical Case Manager. "The UDNF is unique in that it seeks to diminish the isolation by building community where all can belong while finding answers in partnership with clinicians and researchers. I’m proud to help elevate these voices in joining the greater rare community.”

The goal of this event is to drive progress in efforts to address the nearly 10,000 known rare diseases that impact up to 30 million Americans by:

- Elevating the experiences and expertise of people and families facing rare diseases;
- Aligning on the greatest challenges which, if addressed, would achieve better outcomes for people and families facing rare diseases;
- Sharing developments from the Biden-Harris Administration and patient and research communities, and learning from one another to accelerate progress; and

- Exploring policy opportunities to further advance research and access to innovation.

"Patients and families searching for a diagnosis need access to support and resources," said Amy Gray, Chief Executive Officer of UDNF. "We recently launched our Patient Navigation Program, knowing that those with undiagnosed or ultra-rare diseases need the embrace of a wider community to help them navigate our complex healthcare ecosystem. Making a commitment to improve health outcomes for these patients is a step in the right direction."

The White House Rare Disease Forum will bring together individuals living with rare diseases, their family members and caregivers, physicians and clinical care providers, researchers, and administration officials. UDNF will be attending the forum as a leader in the undiagnosed and ultra-rare disease community.

About Undiagnosed Diseases Network Foundation
The Undiagnosed Diseases Network Foundation is a patient-led nonprofit organization founded in 2023 committed to improving access to diagnosis, research, and care for all with undiagnosed diseases. The UDNF aims to foster collaboration among patients, clinicians, and scientists to enhance the quality of life of undiagnosed and ultra-rare disease patients and their families. For more information, please visit www.udnf.org.

About Undiagnosed and Ultra-rare Diseases
The search for a diagnosis for an undiagnosed or ultra-rare disease can be long and difficult. Patients may go from doctor to doctor without answers, and they may face treatment delays, lack of access to specialists, invasive and costly tests, emotional distress, and longing for community. There are more than 10,000 known rare diseases that affect about 1 in 10 people (or 30 million people) in the U.S. Led by undiagnosed and ultra-rare patients and their families, the UDNF offers hope for healthcare that embraces the unknown and pursues clinical and research solutions for patient wellbeing.

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