

# Undiagnosed Diseases Network Foundation Promotes Access and Equity for Undiagnosed and Ultra-Rare Disease Patients

*New nonprofit organization aims to improve access to diagnosis, research, and care for all with undiagnosed and ultra-rare diseases.*

WASHINGTON, DC, USA, April 18, 2023 /EINPresswire.com/ -- Today, a group of undiagnosed and ultra-rare diseases patients and their family members, medical providers, and advocacy partners announced the launch of the Undiagnosed Diseases Network Foundation (UDNF). The organization aims to improve access to diagnosis, research, and care for all with undiagnosed and ultra-rare diseases.



The UDNF was conceived by patients and families enrolled in the [Undiagnosed Diseases Network \(UDN\)](#), a medical study that has set the international standard for researching undiagnosed diseases. The UDNF and UDN will partner together to pursue clinical and research solutions for the wellbeing of undiagnosed and ultra-rare disease patients. The UDNF will serve both pediatric and adult patients through patient navigation, community education programs, and collaboration with the UDN.

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*Isaac Kohane*

“The Foundation will help ensure that patients have access not only to resources and community support but also to the research and clinical care they need – from the very

onset of their symptoms, through their diagnostic journey and, eventually, to treatment,” said UDN principal investigator Isaac Kohane, MD, PhD, Chair of the Department of Bioinformatics at

Harvard Medical School.

Meghan Halley, PhD, MPH, Senior Research Scholar in the Center for Biomedical Ethics at Stanford University, mother to a son with an undiagnosed disease, and President of the UDNF Board of Directors, explained the importance of the UDNF. “By centering those left behind by healthcare—especially undiagnosed patients who often struggle to navigate the healthcare system—we can develop new approaches to comprehensive patient care that benefit everyone.”

UDN participants and caregivers have already demonstrated the power of the undiagnosed community. Thanks to the tireless efforts of undiagnosed patients and family members, funding for the UDN will continue through 2023. On December 22, 2022, Congress passed a spending bill for 2023 that includes \$18M to fund the UDN. While this incredible success secures the immediate future of the UDN, advocacy efforts must continue to guarantee long-term sustainability.

Amy Gray, a nationally recognized rare disease advocate, will oversee the UDNF as its inaugural CEO. Gray brings over 20 years of experience in rare disease focused nonprofits. As the former CEO of the Charcot-Marie-Tooth Association, she is skilled at uniting patients, families, scientists, clinicians, and researchers to advance a shared mission of improving the lives of rare disease patients. The UDNF’s Board of Directors is delighted to welcome Gray as a leading force in achieving the best outcomes for patients.

According to the [Genetic and Rare Diseases Information Center](#), there are more than 10,000 known rare diseases that affect about 1 in 10 people (or 30 million people) in the U.S. For those with an ultra-rare disease, unnamed condition, or an atypical presentation of a rare disease, the search for a diagnosis can take decades and involve going from doctor to doctor without answers. Undiagnosed patients often face treatment delays, lack of access to specialists, invasive and costly tests, emotional distress, and longing for community. 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.

Undiagnosed and ultra-rare patients from historically marginalized communities have especially been left behind by healthcare systems. The UDNF is committed to addressing health disparities



Amy Gray, CEO of the new UDNF

faced by the undiagnosed and ultra-rare communities by prioritizing social justice at all levels of organizational operations and mitigating barriers to program engagement. All patients deserve access to quality healthcare that emphasizes multidisciplinary collaboration, integration of research and clinical care, speedy adoption of technological and scientific advancements, and personalized support at every stage.

Diverse stakeholders assembled this past year to discuss the National Institute of Health (NIH) Common Fund grant scheduled to end in June 2023. In just 10 years, and through funding provided by the NIH Common Fund, the UDN has diagnosed 30% of the participants and identified over 50 new diseases. The UDNF and UDN will partner together to pursue clinical and research solutions for the wellbeing of undiagnosed and ultra-rare disease patients.

The UDNF offers hope for a bright future of healthcare where patients, clinicians, scientists, and industry partners work together to optimize the quality of life for the undiagnosed and ultra-rare community.

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#### About the 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](http://www.udnf.org).

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