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Undiagnosed Diseases Network Foundation Releases Strategic Plan

Highlighting Four Pillars of Growth, Sustainability, Community Engagement & Outreach, Patient & Family Navigation, and Patient-Centered Research & Clinical Care

WASHINGTON, DISTRICT OF COLUMBIA, UNITED STATES, October 10, 2023 /EINPresswire.com/ -- The Undiagnosed Diseases Network Foundation (UDNF) today announced the release of its inaugural strategic plan, which outlines the organization's goals and priorities through 2025. The plan is focused on accelerating progress toward a world without undiagnosed diseases, filling a unique need for patients and families, and fostering partnerships to advance individual and community well-being.

> “
> It provides a roadmap for building a learning healthcare network for rare diseases that enables access to diagnosis, research and care for all in need.”
>
> *Meghan Halley*

"The UDNF's strategic plan reflects extensive conversation with diverse stakeholders across the undiagnosed and ultra-rare disease community. It provides a roadmap for building a learning healthcare network for rare diseases that enables access to diagnosis, research and care for all in need," said Meghan Halley, Board Chair of the UDNF. "We are committed to working with our partners at the Undiagnosed Diseases Network (UDN) and the broader community to accelerate progress toward a world without undiagnosed diseases. We invite the public to join us in this important mission."

The UDNF's strategic plan is built on four pillars:

- Growth and sustainability of the UDN and newly formed Foundation: The UDNF will work to ensure the long-term growth and sustainability of the UDN, as well as its own operations. This will include developing new funding streams, expanding the UDN and building a strong infrastructure to support the needs of the community.

Board Chair of the UDNF, Meghan Halley

Undiagnosed Diseases Network

- Community engagement and outreach: The UDNF is committed to building a community by and for all patients and families with undiagnosed and ultra-rare conditions. The Foundation will serve as the leading resource for trustworthy information about these diseases and services, and will ensure that underrepresented patients have equitable access to diagnosis, research, therapeutics, and support.

- Patient and family navigation: The UDNF is committed to improving medical management, care coordination, access to social services, support, and mental health services for patients and families. The Foundation will launch new initiatives to improve the patient and family experience of the diagnostic process and transition to therapeutics, regardless of when or whether a patient receives a diagnosis.

- Patient-centered research and clinical care: The UDNF is committed to making a diagnosis of rare diseases more accessible, equitable, accurate, and efficient. The Foundation will do this by advancing the diagnosis and knowledge of these diseases through patient-centered research and supporting innovative solutions and new approaches.

“The UDNF’s strategic plan was developed through the hard work and dedication of a diverse group of stakeholders from the undiagnosed, rare, and ultra-rare disease community,” said Amy Gray, CEO of the UDNF. “We are grateful for the contributions of everyone who participated in the planning process, including our board of directors, staff, volunteers, patients and families, scientists and clinicians, and partners.”

The UDNF is committed to working with patients, families, advocacy organizations, researchers, payers, industry, funders, venture philanthropists, and healthcare providers to achieve its goals. The Foundation believes that by working together, we can make a real difference in the lives of patients and families with undiagnosed and ultra-rare conditions.

The full version of the strategic plan can be found here: https://udnf.org/undiagnosed-diseases-network-foundation-strategic-plan-2023-2025/.

The Foundation will hold a public meeting for the community to learn more about the strategic plan initiatives and how to get involved. To sign up for email updates: www.udnf.org.

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.

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 well-being.

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