

# UNDIAGNOSED DISEASES NETWORK FOUNDATION (UDNF) TO PRESENT TODAY AT THE WORLD ORPHAN DRUG CONGRESS 2024

*Nonprofit Speaks to “Building a Learning Healthcare Network for Innovation in Diagnosis and Precision Medicine in Rare Diseases” and Hosts Roundtable Discussion*

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The [Undiagnosed Diseases Network Foundation](#) (UDNF), a patient-led nonprofit organization committed to improving access to diagnosis, research, and care for everyone with undiagnosed and ultra-rare diseases,

announced it will present today at the 2024 World Orphan Drug Conference, Thursday, April 25th in Boston, MA at the Boston Convention and Exhibit Center. The organization’s presentation is entitled “Building a Learning Healthcare Network for Innovation in Diagnosis and Precision Medicine in Rare Diseases.”

"Finding ways to advance the development of orphan drugs, essential for people living with ultra-rare diseases, is of the highest urgency," said Amy Gray, Chief Executive Officer of UDNF, who will host the presentation. "Collaboration - sharing information, data, experiences and expertise between physicians, advocacy groups, researchers, and the wider industry will create a community effort that accelerates development of and promotes access to these potentially life-saving therapies."

The UDNF's presentation will take place at the Boston Convention and Exhibit Center in Hall C-Theater 1 from 4:15 - 4:35 pm ET today. The UDNF will also be hosting a roundtable discussion at the conference, "Navigating the Unknown- Undiagnosed, Partial Diagnosis, or Incorrect Diagnosis."

"Orphan drugs may not be used by a large population, but they are essential to those like me who need them," said Mary Morlino, a UDNF patient navigator who was diagnosed with



Sarcoidosis after seven years of searching for answers. "As a patient and a navigator supporting others in their journey to a diagnosis, I am honored to bring the voice of the patient to this roundtable discussion as we raise awareness of the needs of the undiagnosed and ultra-rare disease communities and work to support ongoing drug development and treatment identification for their benefit."

#### 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 and ultra-rare 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).

#### 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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