

UNDIAGNOSED DISEASES NETWORK FOUNDATION (UDNF) CO-LEADS DISCUSSION ON MENTAL HEALTH AT THE 2024 RARE DISEASE SUMMIT

UDNF Emphasizes Commitment to Improving Patient Experiences for the Ultra-Rare and Undiagnosed

WASHINGTON, DISTRICT OF COLUMBIA, UNITED STATES, March 19, 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 and ultra-rare diseases, has announced Mary Morlino, a Patient

Navigator who supports undiagnosed and ultra-rare patients through the [UDNF's Patient Navigation Program](#), will be co-leading a special session "Combating Mental Health Challenges when Living with a Rare Disease" at the [2024 Rare Disease Summit](#) in Philadelphia, PA.

The session will focus on the unique and often significant mental health challenges that rare disease patients, their families, and their caregivers face due to high levels of stress and uncertainty. Morlino and co-presenter Cristol Barrett O'Loughlin, founder and CEO of Angel Aid, a provider of mental health and wellness services to rare families through sustainable psychosocial training, transformative retreats, and a connective caregiver-to-caregiver multilingual network, will:

- Share the mental health services and resources available and highlight specific support programs that can provide benefits;
- Discuss the type of support that patients need in order to access mental health providers and resources;
- Explain how mental health support for patients and their caregivers benefits all stakeholders involved; and
- Examine how intersectionality may impact certain patients more directly and what can be done



to ensure they are more fully supported.

"The Rare Disease Summit is a great forum to advocate for patient voices," said Morlino. "As a rare disease patient who was undiagnosed for seven years, I have firsthand knowledge of the many challenges patients and their families face during their diagnostic odyssey. Mental health is critical in maintaining a quality of life for undiagnosed and ultra-rare disease patients, which is why it has become a focus of mine as a Patient Navigator in the UDNF's Patient Navigation Program."

The Rare Disease Summit is a yearly conference that connects key stakeholders to drive therapeutic progress, propel commercial strategies and inspire advocacy. The summit unites the rare disease community and seeks to create partnerships between researchers and advocacy organizations such as the UDNF. "Combating Mental Health Challenges when Living with a Rare Disease" will take place on March 21st at 11:45 am ET.

"Addressing mental health concerns is of paramount importance for rare disease patients and families," said Amy Gray, Chief Executive Officer of UDNF. "Their diagnostic journey is filled with unique challenges, and their emotional well-being is as essential as finding answers to their physical symptoms. It's an experience that tests every patient's resilience, strength, and vulnerability. It's critical that organizations like UDNF prioritize building the community resources necessary for supporting patients' emotional well-being."

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.

Glenn Silver

FINN Partners

+1 973-818-8198

glenn.silver@finnpartners.com

Visit us on social media:

Facebook
LinkedIn
Instagram

This press release can be viewed online at: <https://www.einpresswire.com/article/696934043>

EIN Presswire's priority is source transparency. We do not allow opaque clients, and our editors try to be careful about weeding out false and misleading content. As a user, if you see something we have missed, please do bring it to our attention. Your help is welcome. EIN Presswire, Everyone's Internet News Presswire™, tries to define some of the boundaries that are reasonable in today's world. Please see our Editorial Guidelines for more information.

© 1995-2024 Newsmatics Inc. All Right Reserved.