

Patient Advocacy Organizations Partner to Host Undiagnosed Day on April 29, 2023

WASHINGTON, DC, USA, April 28, 2023 /EINPresswire.com/ -- The Undiagnosed Diseases Network Foundation (UDNF) joins forces with patient advocacy organizations around the globe to shine a light on undiagnosed diseases. Undiagnosed Day seeks to educate policy makers, researchers, and health professionals about the need for improved access to diagnosis, research, and care for all with undiagnosed and ultra-rare conditions.



On April 29, the Undiagnosed Diseases Network International (UDNI) and Wilhelm Foundation are hosting the second annual Undiagnosed Day celebration. Activities will include live presentations from experts around the world, a diagnostic hackathon, and engaging social media conversations. Amy Gray, UDNF CEO and long-time rare disease advocate, will speak about new support services for undiagnosed patients and their families. She will be joined by advocates from the Mayo Clinic, National Organization for Rare Disorders (NORD), Undiagnosed Diseases Program (UDP) at the National Institutes of Health (NIH), Boston Children's Hospital, and more.

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“Something more has to be done to solve these mysterious diseases,” explains Helene Cederroth, President of the Wilhelm Foundation and Co-founder of the UDNI. “It's

incredibly difficult to see your child so sick without the doctors being able to explain why.” Undiagnosed Day serves as a reminder of the challenges faced by undiagnosed patients and their families. For one in ten people living with a rare disease, the search for a diagnosis can take years or even decades and result in treatment delays, emotional and financial distress, social stigma, and longing for community.

“By working together with patient advocacy organizations on an international scale, we can change the search for answers from a diagnostic odyssey to an accessible, supported, and timely process for rare disease patients,” said Gray. 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.

Join the conversation on social media by using #UndiagnosedDay, #UndiagnosedDay2023, and #DiagnosticHackathon2023. To participate and learn more about Undiagnosed Diseases Day, visit undiagnosed-day.org.



Undiagnosed Day Logo

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About the Undiagnosed Diseases Network Foundation (UDNF)

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. Visit us at udnf.org.

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