

UNDIAGNOSED DISEASES NETWORK FOUNDATION (UDNF) ENCOURAGES COLLABORATION ON UNDIAGNOSED DISEASES AWARENESS DAY 2024

UDNF Partners with Wilhelm Foundation to Host 3rd Annual Undiagnosed Diseases Awareness Day Educational Event

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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 people with undiagnosed and ultra-rare diseases,

in collaboration with the [Wilhelm Foundation](#) and the [Undiagnosed](#)

[Diseases Network International](#), today joins many other advocacy groups around the world to observe Undiagnosed Diseases Awareness Day.



Specifically scheduled to coincide with Undiagnosed Diseases Day to engage with the international conversation global efforts, to raise awareness and advocate for better resources for undiagnosed patients, a panel of experts from medical science, public policy, and advocacy organizations will be convened by the Wilhelm Foundation and the Undiagnosed Diseases Network Foundation. The live hybrid event will take place today at Harvard Medical School, in the Joseph B Martin conference center auditorium, from 9:00 - 11:30 am EST.

"On this Undiagnosed (Diseases) Day, we want to bring awareness to all who remain undiagnosed or have rare and ultra-rare diseases that have led them on a complex, years-long medical odyssey in search of a diagnosis, a journey for many that takes years of seeking answers," said Amy Gray, Chief Executive Officer of UDNF. "As these individuals and their families wait for a diagnosis, they experience an isolating ordeal while being considered undiagnosed which can be stressful. It is important that today and every day, we continue to spread awareness for the undiagnosed by educating 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.”

Undiagnosed Children’s Day was founded by a mother with an undiagnosed child in the US about ten years ago to raise awareness of undiagnosed diseases that affect children. In 2022, the Wilhelm Foundation thought that it was time, after celebrating the Undiagnosed Children’s Day for 8 years, to be more inclusive and change the name to Undiagnosed Day since about 30% of the undiagnosed diseases affect adults. Undiagnosed Day was established in 2022 by the Wilhelm Foundation, to raise awareness for people living with a disease that has not yet been identified and assigned a name by medical science. The Wilhelm Foundation is an international organization based in Sweden that has been leading the charge in fostering collaborations amongst researchers, patients, and healthcare providers to find answers for individuals and families living with undiagnosed diseases.

Underpinning the Foundation’s work is Helene and Mikk Cederroth’s personal story (the couple lost three children to undiagnosed disease) and their unwavering commitment to creating a supportive ecosystem that leaves no one behind, and where groundbreaking research, patient empowerment, diagnosis, and the promise of medical advancements converge.

“It is estimated that 350 million people according to Illumina live with an undiagnosed disease worldwide,” said Helene Cederroth, President of Wilhelm Foundation. “Today we know that genome sequencing can provide answers for 40% of children and adults with undiagnosed diseases, but around 60% still don’t receive a diagnosis.”

The average time for an accurate diagnosis of an unknown disease is about 4–5 years, though it may take up to a decade. As undiagnosed patients wait, they live in a “holding pattern” without a treatment plan. The Every Life Foundation, which conducted a study on delayed diagnosis in ultra-rare patients, found that “delayed diagnosis worsens outcomes and has a significant financial impact on families, including paying for doctor visits, medical equipment, prescriptions, and transportation that could have been avoided.”

On this day of advocacy, it is important to hear from the many voices of patients and caregivers too. Michele Herndon, MSN, RN and Program Director of UDNF’s Patient Navigation Program understands all too well that journey that so many of the undiagnosed are traveling. “My son Mitchell lived with an undiagnosed disease for five years before passing away shortly after receiving a diagnosis,” said. “Watching your child suffer without knowing why makes you feel hopeless as a parent. My despair was only deepened when others would ask about his condition, forcing me to explain what it means to be undiagnosed. I am proud to now be able to deliver the resources I wish I had through my experience with Mitchell to other families as the director of the Patient Navigation Program at the UDNF.”

To attend the event virtually, please register here: <https://udnf.org/undiagnosed-day/>

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.

About Wilhelm Foundation

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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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