

# Hope Beyond a Name

## Fighting Undiagnosed Diseases Globally

For millions worldwide, their rare diseases defy traditional diagnosis. **Years, even decades, can pass without answers**, leaving individuals and families feeling lost and hopeless (1).

Despite the best efforts of dedicated healthcare professionals, **many of those seeking diagnosis remain without answers**. Some research suggests this number could be as high as 50% of patients affected by rare diseases (2, 3).

With the support of Advocacy Groups such as The Wilhelm Foundation, UDNI pioneers new frontiers in genetic sequencing, bioinformatics and biomarker research, and approach to diagnosis all around the world.

### How can I contribute?

- **Sharing my expertise** on challenging cases and benefitting from a wealth of global knowledge.
- **Advocating for progress** and championing policies and resources that expedite diagnosis and support groundbreaking research.
- **Spreading the word**, raising awareness within my medical communities, and connecting patients to life-changing resources.

1. Adachi T, Imanishi N, Ogawa Y, et al. Survey on patients with undiagnosed diseases in Japan: potential patient numbers benefiting from Japan's initiative on rare and undiagnosed diseases (IRUD). *Orphanet J Rare Dis.* 2018 Nov 20;13(1):208.  
2. Sciascia S, et al. Unmet needs in countries participating in the undiagnosed diseases network international: an international survey considering national health care and economic indicators. *Front Public Health.* 2023 Sep 26;11:1248260.  
3. Taruscio D & Gahl WA. Rare diseases: challenges and opportunities for research and public health. *Nat Rev Dis Primers.* 2024 Feb 29;10(1):13

