

## YALE DIAGNOSTIC CENTER OF EXCELLENCE (YDCOE)

*A clinical research study for patients with unexplained medical conditions*

### Why Refer to the UDN?

- The Undiagnosed Diseases Network (UDN) is a national, **NIH-funded research study for individuals with persistent, unexplained medical conditions**
- Many UDN participants would benefit from seeing multiple specialists available only at academic centers that offer access to **advanced diagnostic technologies** such as WGS, RNA profiling, and high-resolution imaging
- At Yale, the UDN may bring your patient's case to a **multidisciplinary team** of geneticists and other clinicians and researchers dedicated to solving complex medical mysteries
- The UDN research team will try to **find answers** for those who could find them in no other way, with the purpose of improving an individual's long-term care while advancing generalizable medical knowledge

### Who May Be an Ideal Candidate?

Consider referring patients who:

- Have three or more **objective, unexplained findings** or conditions
- Have **multisystem** involvement (e.g., neurological + gastrointestinal + musculoskeletal)
- May have genetic testing that was non-diagnostic or inconclusive
- May have **persistent** abnormal findings on physical exam, imaging, or lab studies
- May have **unique** physical characteristics (e.g., facial/skeletal differences)
- May have chronic conditions starting in childhood
- May have unusual treatment responses
- May have a **family history** of similar, undiagnosed conditions
- May have significant socioeconomic barriers that have prevented clinical genetics work-up in the past

### How Can Providers Support a UDN Referral?

- Inform patients or legal guardians to submit their application:  
<https://undiagnosed.hms.harvard.edu/participate>
- Participants will need:
  - A completed online **questionnaire**
  - A referral/support **letter from a provider** to help us understand the patient's "diagnostic odyssey" (alluding to records from specialists, and any supporting labs, imaging, or other evaluations)
  - Stay informed! Yale UDN will update the patient and the provider on the outcome

### Contact Yale UDN:

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*Searching for answers of the unsolved together*