

The **Undiagnosed Diseases Network (UDN)** is a **research study** funded by the National Institutes of Health. Its purpose is to bring together clinical and research experts from across the United States to solve the most challenging medical mysteries using advanced technologies. Through this study, we hope to both help individual patients and families living with the burden of undiagnosed diseases and to contribute to understanding how the human body works.

## HOW TO SUBMIT A CASE AND WHAT TO EXPECT:

### For providers (physicians, GCs, APRNs, or PAs):

See patient with complex, unexplained condition

Consider UDN as a research study option and discuss with the patient. Confirm willingness to share data/records

Draft **provider recommendation letter**  
Letter examples\*\*: <http://undiagnosed.hms.harvard.edu/wp-content/uploads/ReferralLetterExamples.pdf>

### For participants:

Learn about UDN

Talk with your health care provider to discuss your eligibility

Get your provider recommendation letter + **OPTIONAL: write your story\*** (it is the person's lived experience, told in their voice)

\* Short narrative (usually 1/2-1 page) written by the participant or family that describes: Symptoms in their own words | Timeline (what happened first, how things changed over time) | Daily impact on school, work, mobility, activities, emotions | What has been tried already (tests, treatments, responses) | What concerns the family the most | What they hope the UDN can help with | It is not a medical record.

Submit the case via UDN Gateway  
<https://gateway.undiagnosed.hms.harvard.edu/> \*\*

(PREFERABLE: Patient/family submits. OPTIONAL: providers could submit, if necessary)

Complete form + Upload recommendation letter + Upload any available medical records # + **RECOMMENDED: Upload patient's story \***

# While records are required to be shared for participation, they can be uploaded before or after initial submission (but always before case review) at the participant's preference. Also, if you prefer to share your records through MyChart, please contact us at [undiagnosed@yale.edu](mailto:undiagnosed@yale.edu) before uploading

Takes ~20 minutes for the online form

Case submitted | What to expect:  
Confirmation email

Within 30 days

Additional record collection, as needed

Decision about the case

Within 60 days

Assigned to records-only feedback

**Letter + recommendations** sent to the participant and their provider

Case is closed

Assigned to additional evaluation: comprehensive UDN assessment. Please note that informed consent must be obtained prior to this evaluation.

**Hybrid/virtual evaluation**  
Telehealth, remote DNA kits, and local testing ordered by providers

**Research-focused evaluation**

**In-person evaluation**

**Written summary of findings** shared with the participant and their provider

Case is closed

\*\* Useful information:



Yale UDN Diagnostic Center of Excellence **website**



UDN **Gateway**



Example study recommendation **letters**

**YALE DIAGNOSTIC CENTER OF EXCELLENCE (YDCOE)**

