



### **Information for health care providers**

Your patient has contacted the Undiagnosed Diseases Network (UDN) about participating in this research study. UDN participants are evaluated using a unique combination of scientific and medical expertise and resources at UDN sites around the United States. Participants must have a condition that has not been diagnosed following a thorough medical evaluation. More information about the UDN can be found at <https://undiagnosed.hms.harvard.edu>.

If your patient decides to submit their case for this study, they will need to answer a series of brief questions through our case submission Gateway (<https://gateway.undiagnosed.hms.harvard.edu>) related to the following:

- Contact information
- Demographic information
- Health care provider information (name, address, phone, fax, email)
- Brief medical history questions
- Previous evaluations
- Travel limitations

A study recommendation letter from a health care provider (for example: specialist, primary care physician, nurse practitioner) is also necessary to submit the case online to the UDN. The letter must be written in English, signed, and on letterhead. A relative of the participant cannot write the letter. Your patient will be asked to upload this letter to the online case submission portal. The study recommendation letter must include:

- A summary of the participant's medical problems
- Date when symptoms were first noticed
- For pediatric participants: prenatal and birth history
- Previous diagnoses
- History of evaluations and testing
- History of treatments and medications
- Current medications
- Family history
- Health care provider's diagnostic impressions

If you would like to receive case submission updates, please ask your patient to list your contact information on the case submission.

Your patient will be provided the opportunity to upload a 1-page patient narrative of their history from their perspective and a photo. After a case is submitted, it is then sent to one of the UDN clinical sites to review. The UDN may contact participants within one month of case submission to request additional information, such as medical records. After all the requested information is received by a UDN clinical site, it typically takes 6-8 weeks for the network to decide which evaluation type they will be assigned to.

If your patient's case is assigned to receive medical records review only, the UDN will provide information from the records review to you and your patient. If your patient's case is assigned to receive additional UDN

evaluation, the UDN will provide information from the evaluation to you and to your patient. You will be responsible for your patient's follow-up medical care.

Thank you for considering this opportunity to consult with the UDN on your patient. We appreciate your commitment to providing the best possible care for your patients in ways that help advance medical knowledge and discovery.