Undiagnosed Diseases Network

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 required to submit the case to the UDN. The letter must be written in English, signed, and on letterhead. Neither the participant nor a relative of the participant can 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
- Previous diagnoses
- History of evaluations and testing
- History of treatments and medications
- Current medications
- Family history
- Health care provider's diagnostic impressions
- Prenatal and birth history

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 detailed patient narrative of their history from their perspective and/or a photo/video.

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.

While the UDN has access to state-of-the-art research resources to help diagnose patients, it is important to remember that the UDN is a research study. Participation in the UDN does not replace the long-term, longitudinal care you provide as a member of the patient's care team. The care team at home remains responsible for patient treatment and management.

If the UDN is not able to find a diagnosis for your patient, it is imperative that you and your colleagues on the medical care team continue your local efforts to find a diagnosis and coordinate care. Additionally, participation in the UDN does not preclude participation in other research studies that may help your patient find a diagnosis.

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.