

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 apply for this study, they will need to answer a series of brief questions through our application 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 licensed health care provider is also necessary in order to submit the online application to the UDN. Your patient will be asked to upload this letter to the online application. The study recommendation letter must include:

- A summary of the applicant'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
- For pediatric patients: prenatal and birth history

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

After an application is submitted, it is then sent to one of the UDN clinical sites to review. The UDN clinical sites typically contact applicants within one month of application submission to request additional information, such as:

- Medical records
- Laboratory studies
- MRI, X-ray, or CT images (can be sent on CD)
- Photographs or videos
- Pathology slides and reports
- For pediatric patients: growth curves

In order to help with the application review process, the patient can begin to collect these records now. However, no medical records should not be sent until specific instructions to do so are received from a UDN clinical site.

After all of the necessary information is received by a UDN clinical site, it typically takes 6-8 weeks for the network to decide whether to accept an applicant.

If your patient's case is accepted for 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.