



National Human Genome Research Institute
National Institutes of Health
and
Office of Rare Diseases
National Institutes of Health

10 Center Drive – MSC 1851
Building 10, Room 10C103
Bethesda, Maryland 20892-1851

Undiagnosed Diseases Program

Information for Referring Health-Care Providers

Dear Doctor:

Your patient _____ has contacted the Undiagnosed Diseases Program at the National Institutes of Health about participating in this program. Patient participants will be evaluated using the unique combination of scientific and medical expertise and resources at the NIH Clinical Center in Bethesda, Maryland. Participants must have a condition that has not been diagnosed following a thorough medical evaluation.

There is a stringent referral and review process. If your patient's case is accepted for NIH evaluation, NIH will provide information from the evaluation to you and to your patient. You will be responsible for your patient's follow up medical care.

The following information is needed to determine your patient's eligibility:

1. Verification that this patient has a primary health-care provider who will provide ongoing consultation to the NIH team and appropriate follow-up care for the patient if accepted into the NIH clinical research protocol.
2. A summary letter from you describing your patient's pertinent medical information, including
 - When the undiagnosed condition was first noted;
 - How it presented;
 - The patient's current medical status;
 - Treatments/medications tried and their effects.
3. Copies of reports and results of pertinent diagnostic tests, along with X-rays, MRI results, and other imaging records/studies.
4. Your office address, phone numbers and email address.
5. Your patient's mailing address.

Please mail the information and records to:

National Institutes of Health
National Human Genome Research Institute
Undiagnosed Diseases Program Team
10 Center Drive - MSC 1851
Building 10, Room 10C103
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Once all materials have been received, notification of receipt will be sent to the patient. NIH review is expected to take about six to eight weeks. If your patient is eligible for an existing NIH Clinical Center protocol, he or she will be considered for that protocol. Those applicants who are not eligible for existing protocols will be considered for the general protocol of the Undiagnosed Diseases Program. We plan to invite 50 to 100 patient participants to NIH annually for thorough evaluation and consultation at the NIH Clinical Center under the Undiagnosed Diseases Program protocol. Once a decision has been made you will be notified within a week.

More information about this program is available online at <http://rarediseases.info.nih.gov/Undiagnosed>.

Thank you for considering this opportunity to consult with the NIH 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.

NIH Undiagnosed Diseases Program Team