



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

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

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
Bethesda, Maryland 20892-1851

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.

Physician Letter: Revised 5/20/2008

