

Undiagnosed Diseases Program - Community Input webinar 10/17/12 2:30 pm ET

**Start Time:** 10/17/2012 2:30 PM ET

**Duration:** 90 minutes

**URL:** [https://webmeeting.nih.gov/udp-community\\_input/](https://webmeeting.nih.gov/udp-community_input/)

**Conference Number(s):** 1-800-201-2375

**Participant Code:** 471324

The Office of Rare Diseases Research- NCATS and the National Human Genome Research Institute are hosting a webinar to provide information to the patient community about a new NIH initiative to expand the Undiagnosed Diseases Program (UDP). In addition, significant time will be dedicated to discussing the issues listed below. We will use the information discussed to help in the selection process of clinical sites for the expanded UDP. This webinar is not to solicit new patients nor to answer diagnostic questions.

**The physical and financial costs of the diagnostic odyssey**

**What are the major barriers to obtaining a diagnosis?**

Ready access to specialists, including:

Inability to see a specialist necessary to help obtain an accurate diagnosis

Number of specialists seen in order to get an accurate diagnosis

Issues getting specialists to talk to each other (coordinated care)

Travel requirements (restrictions or limitations due to disease), including:

Number of times have traveled out of town to be seen by a doctor when trying to get an accurate diagnosis

Number of times have traveled out of state to be seen by a doctor when trying to get an accurate diagnosis

Distance needed to travel ever prevented seeing a doctor to get an accurate diagnosis

Farthest distance have traveled in order to be seen by a doctor when trying to get an accurate diagnosis

Ease of Access to Newer Diagnostic tests, including

Problems gaining access to newer imaging or genetic sequencing tests necessary to get an accurate diagnosis

Insurance reimbursement issues for costs related to getting an accurate diagnosis

Amount of time required to get tests approved by insurance companies/3<sup>rd</sup> party payers