

# MINI

NIH MINI Study

Metabolism  
INfection  
Immunity

A clinical research study at the National Institutes of Health

*"The goal of our study is to learn about how Inborn Errors of Metabolism may affect the function of the immune system."*

*Peter J. McGuire, M.D.  
Principal Investigator*

## **Who can participate?**

This study is open to adults and also children starting at age 2 years old.

To join the NIH MINI Study a person must:

- Be at least 2 years of age
- Have a biochemically confirmed IEM or related disorder

There are some reasons why someone may not be able to join the study. For details, please see our Web site:  
<http://www.genome.gov/MINI>

## **Other important information:**

### **What is the cost of the study?**

The visits and all testing are free and there is no cost to you, your family, or your insurance company for participating in this study.

### **What about travel?**

If you live locally (near the NIH) we will give you some money for meals and provide lodging if necessary. If you live further away, we will pay for your transportation to NIH (plane, car mileage, train, etc), lodging, and give you some money for meals. The NIH must arrange all travel.

### **Will I (my child) get paid for joining the study?**

No, IEM participants in the study will not receive any compensation other than some food, travel and lodging expenses.

## **What is involved in the study?**

We will review your (your child's) eligibility for the study with you on the phone. We may ask to review outside medical records.

The MINI study may involve additional visits to the National Institutes of Health in Bethesda, Maryland depending on the level of study participation.

You (your child) may meet with a geneticist to review your medical & family history and receive a physical exam. We will ask you (your child) to allow us to collect urine, draw blood, and perform a detailed nutritional & immunologic assessment.

We will suggest an additional set of evaluations for some participants that we feel is appropriate based on age & level of independence. We will explain the need for those studies to you (your child).

We will offer Hepatitis A and influenza vaccines that are recommended for all IEM patients.

For those who chose to be immunized, at 1-2 months will we determine whether or not your (your child's) immune system was able to respond to the vaccine. You will receive the results of your (your child's) clinical testing.



For more information about the study please visit our Web site:

<http://www.genome.gov/MINI>

or contact the study coordinator, Janet Shiffer, C-RNP

by phone at (301) 451-9145 or by email at [ministudy@mail.nih.gov](mailto:ministudy@mail.nih.gov)

