



The NIH MINI Study: Metabolism Infection and Immunity

A clinical research study at the National Institutes of Health

"Understanding why people with Leigh syndrome decline during infection is the first critical step to improving their wellbeing."

Peter J. McGuire, MD
Principal Investigator

Who can participate?

To join the NIH MINI Study a person must:

- Be at least 2 years of age
- Diagnosed with Leigh syndrome

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, participants in the study will not receive any compensation other than some food, travel and lodging expenses.

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

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

or contact the study coordinator, Shannon Kruk, RN

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

What is involved in the study?

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

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

At your visit, you (your child) will meet with a physician to review your medical & family history and receive a physical exam. We will ask you (your child) to allow us to draw blood, to perform a detailed assessment including:

- 1) Childhood vaccination status
- 2) Immunoglobulin levels
- 3) Immune cell populations and function

We may also perform additional clinical and laboratory evaluations (e.g. neuropsychological testing, eye exam, nutrition assessment) to better characterize the participant's disease status.



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