

Thank you for your interest in our research study! Inside you will find the answers to many frequently asked questions about the study.

For more information, please contact our research group at

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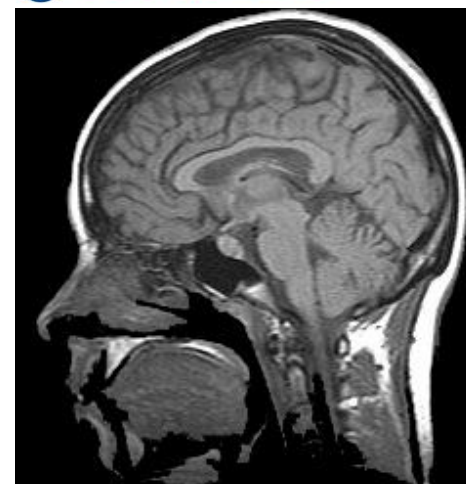
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Niemann Pick Type C Brain Imaging Research Study



Boston Children's Hospital
Until every child is well™



**Division of Genetics & Genomics,
Department of Medicine
&
Department of Anesthesiology,
Critical Care
and Pain Medicine**

Q: Who is eligible?

A: Patients diagnosed with Niemann Pick Type C (NPC) or healthy individuals.

Q: What does this study involve?

A: During this study, we will ask you to complete questionnaires, cognitive task, motor task, give a blood samples, and undergo MRI.

The study visit will last approximately 2-3 hours.

Participation in this research will not alter or interfere with any of the standard clinical procedures or treatment that one would normally receive if not partaking in this research. All research studies will take place at Boston Children's Hospital or McLean Hospital.

Q: What if I live out of town, can I still participate?

A: Yes! If an NPC patient lives outside of the Boston metropolitan area, our lab can help coordinate your visit to Boston. We will also provide reimbursement up to \$500 for travel-related expenses.



Q: Will I get paid to be part of this study?

A: An NPC patient or healthy subject who participates in this study visit will be paid \$150.

Scan Information

Q: What is an MRI scan?

A: MRI (Magnetic Resonance Imaging) is a medical imaging technique that can take pictures of your body.

Q: What are the risks associated with MRI?

A: MRI does not involve any radiation and so there is no risk to most people. It does however involve a strong magnetic field, which although not harmful by itself, may cause implanted medical devices that contain metal to malfunction in patients who have them. Patients with any such devices are not eligible for the study. We will not inject or use any tracer or contrast agent in this study