

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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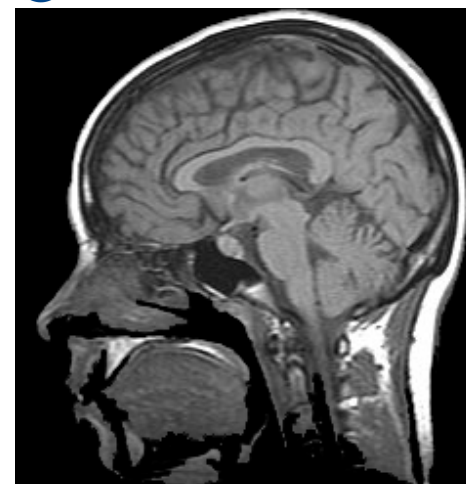
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Niemann Pick Type C Brain Imaging Research Study



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?

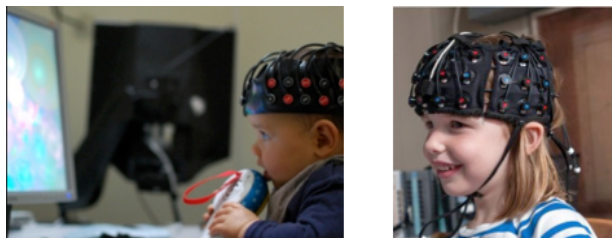
A: Patients diagnosed with Niemann Pick Type C (NPC) or healthy individuals.

Q: What does this study involve?

A: During this study, we will ask you to complete questionnaires, cognitive tasks, motor tasks, give a blood sample, perform tasks via a functional near infrared spectroscopy (fNIRS) tool, undergo muscle integrity and healthy assessment through a non-invasive measure called electrical impedance myography (EIM), and undergo MRI.

The study visit will last approximately 7 hours divided over two days.

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 or do a study visit in the comfort of your own home with our bed-side technologies. We will also provide reimbursement up to \$1000 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. Those only undergoing bed-side assessments (no MRI) will be paid \$75.

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. 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.