



## Repository Core for Neurological Disorders

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The Repository Core for Neurological Disorders ("the Core") is a database of medical information and biological samples, such as a blood or saliva sample.

We are collecting the information and samples from children and their families for scientists who will study these disorders in the future.

The goal of the research is to increase our understanding of neurological conditions, specifically their causes and treatments.

### Who is eligible to participate?

Any child or teen with a neurological disorder who has been seen by a neurologist (or other specialist involved in their care) can enroll in the Core, as well as his or her family members. We are also looking for patients diagnosed with ROHHAD syndrome.

### What does participation involve?

Participating in the Core involves a one-time visit, which can either be included in one of your child's regular visits to Boston Children's Hospital, or can also be done at another time that is convenient for you. Families who are located outside of the Greater Boston Area can also arrange to speak with our research coordinator to discuss the possibility of remote enrollment. You are not required to travel to participate.

If you participate in the Core, the process is as follows:

1. Your informed consent is obtained. Informed consent is a legal term. It means that you are fully aware of the facts and risks of participating in the Core before agreeing to it.
2. The research team asks you a few questions regarding you or your child's medical history. We also obtain other medical information from you or your child's medical record and doctors.
3. Samples are collected. Samples of interest include blood, spinal fluid (CSF), tumor tissue and possibly saliva. The research team may also ask to see tissue or other samples collected by your/your child's doctor from prior or future procedures.
4. All of the information and samples that we collect are coded with ID numbers instead of you or your child's name. The information and samples are stored in a secure database and freezers for studies of neurological disorders.

### How long will participation take? Does it cost anything to participate?

This process takes roughly an hour of your time. There is no fee to take part in the Core, and there will be no payment for your participation.

### Can I see the results?

When these samples are used in the future, research on them will be done in a laboratory. This means that we cannot directly release results to you. However, you can call or email the Core at any time to ask questions or to check in on the overall progress of the program.

We can also contact you if clinically important information and/or genetic testing become available.

# Family Education Sheet • Repository Core for Neurological Disorders

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## Will my participation be confidential?

To protect you and your child, all information and samples gathered are accessible only by Core staff and approved researchers.

Everything stored in the Core is confidential and is **not** placed in the medical record of participating children or their families.

## Contact Us

### Research Study Coordinator

Neurology Core Research Coordinator

Tel: 617-919-6965

[lauren.kerr@childrens.harvard.edu](mailto:lauren.kerr@childrens.harvard.edu)

[neurocore@childrens.harvard.edu](mailto:neurocore@childrens.harvard.edu)

### Principal Investigator

Mustafa Sahin, MD, PhD

Tel: 617-919-4518

[mustafa.sahin@childrens.harvard.edu](mailto:mustafa.sahin@childrens.harvard.edu)

### Co-Principal Investigator

Leslie Benson, MD

Tel: 857-218-4794

[leslie.benson@childrens.harvard.edu](mailto:leslie.benson@childrens.harvard.edu)