



Repository Core for Neurological Disorders **PI: Mustafa Sahin, MD, PhD**

Exploring the causes of ROHHAD Syndrome through brain inflammation and hormones
Leslie Benson, MD

(Parents of) _____
Street Address
City, State, Zip code of Parent

Date

Dear Parents of _____,

We are writing to tell you about an opportunity for your child to participate in a research study at Boston Children's Hospital. Records indicate that some time ago your child was diagnosed with ROHHAD syndrome. We have obtained permission from your child's treating neurologist to contact you.

ROHHAD syndrome remains difficult to diagnose and its cause is unknown. The purpose of this research is to collect samples for further research, examine whether an autoimmune attack on the nervous system could be associated with its development, and determine whether tumor tissue holds clues to the cause and assess for obesity hormone dysregulation. We hope that this research will help us find the cause of ROHHAD syndrome and improve our understanding and treatment of this condition.

If you choose to participate, there would be no cost to you or your family. Your participation would entail filling out an information sheet, storing existing samples (blood, CSF, serum, tumor tissue) and possibly contributing additional blood samples in order to test these hypotheses. A brochure and contact information is attached to this letter to inform you about the Repository Core.

We hope to have the opportunity to speak with you.

Yours sincerely,

Leslie Benson, MD



**Boston
Children's
Hospital** | Translational
Neuroscience Center

Until every child is well™

HARVARD
MEDICAL SCHOOL 

If interested in learning more, please contact:

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