

ROHHAD Banking

Sites: Harvard Brain Tissue Resource Center, USA

Ann & Robert H. Lurie Children's Hospital of Chicago, USA

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In collaboration with Lurie Children's Hospital and ROHHAD Fight Inc., the Harvard Brain Tissue Resource Center (HBTRC) is coordinating registration for prospective post-mortem brain donations from ROHHAD families. A post-mortem brain donation is a gift of knowledge that is of critical importance in furthering our understanding of ROHHAD and in helping future ROHHAD patients and families. Although we know death is a difficult thing to consider when it may be decades away, the time to start thinking about tissue donation is now. Early discussion reduces the stress of such decisions at the time of death and allows for arrangements to be set in advance. We encourage all ROHHAD families to carefully consider and discuss this important research.

READ MORE @ <https://hbtrc.mclean.harvard.edu/>

OR

<https://www.luriechildrens.org/en/specialties-conditions/autonomic-medicine/research/rohhad-studies/>