

6/8/2018

Dear Collaborator,

At Boston Children's Hospital we have preliminary data from patients with CDKL5 deficiency disorder enrolled in the CDKL5 Clinic Study at Boston Children's Hospital. We are now teaming up with basic scientist Dr. Michela Fagiolini and clinician-scientist Jurriaan Peters, also at Boston Children's Hospital/Harvard Medical School, for a parallel study in patients and mice to evaluate functional and anatomic connectivity. This is funded through the University of Pennsylvania Orphan Disease Center/Lou Lou Foundation. To make the human study feasible we need to recruit patients. It is important to first evaluate this finding using data that has already been collected in order to avoid sedating patients for research MRI scans.

Instructions for Collaborators

MRI must meet the following technical details:

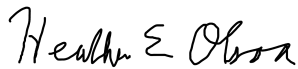
- 3T MRI*, high-resolution structural T1-weighted isotropic 1x1x1 mm MPAGE, all available T2w and FLAIR sequences, and 15 direction or more diffusion imaging.

*for 1.5T scanners, the T1-weighted MPAGE resolution can be 1.5x1.5x1.5 mm

When in doubt about specifications, please send us any MRI data from all patients with CDKL5.

If you have CDKL5 families who are interested in participating, you can have them contact our CDKL5 research team at cdkl5@childrens.harvard.edu or 617-355-5230 or please provide them with a copy of the attached MRI Letter Request.

Sincerely,



Heather E. Olson, MD MS
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