University of Rochester Medical Center

presents a new Batten study led by Heather Adams, Ph.D.

Characterizing Sleep in Batten Disease

This study aims to gather more information about sleep function in individuals with CLN2 and CLN3 Batten Disease. Study activities include:

- <u>Affected individuals</u>: provide saliva samples to test melatonin concentration and wear an actigraph (i.e. wrist-watch style activity monitor)
- <u>*Parents/caregivers*</u>: complete daily sleep/activity logs, questionnaires about the impact of sleep problems on the well-being of affected individuals and family, and help the affected individual with study participation

We are looking for individuals who...:

- Have a confirmed genetic or enzyme-based diagnosis of CLN2 or CLN3 disease and
- Have any symptoms of CLN2 or CLN3 disease and
- Are at least 2 years old and
- Live at home with at least one primary caregiver
- Have not taken oral melatonin (supplement), or are able/willing to stop taking melatonin during study participation (approx. 9-12 days).

To learn more, please contact the study team at <u>BattenSleepStudy@URMC.Rochester.edu</u> or call study coordinator Marianna Pereira-Freitas at (585) 274-0205.

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