



# University of Rochester Batten Center Research Study

## *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:

*Affected individuals*: provide saliva samples to test melatonin concentration and wear an actigraph (wrist-watch style activity monitor)

*Parents/caregivers*: 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
- Live at home with at least one primary caregiver
- Have not taken oral melatonin (supplement) in the past 2 weeks, or has only taken it occasionally (no more than 3 times per week).

### **FAQs:**

**Q: *How long does the study last?***

**A:** Study participation is approximately 7-10 days long

**Q: *Will my affected child wear the actigraph only at night-time?***

**A:** We will ask that your child wear the actigraph continuously during day and night-time, as much as they can. At the beginning of the study, we will discuss strategies to help your child get used wearing the actigraph.

**Q: *How long will you be recruiting people for the study?***

**A.** At this time we do not have an “end date” for recruitment, but we will notify the Batten community if this changes.

**Q: *We live outside of the United States. Can we still participate?***

**A:** Unfortunately due to some new guidelines for international shipping and for transport of samples, only residents of the USA can participate.

To learn more, contact: [BattenSleepStudy@URMC.Rochester.edu](mailto:BattenSleepStudy@URMC.Rochester.edu) or call Study Coordinator Marianna Pereira-Freitas at: (585) 274-0205.