



# 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 (i.e. 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
- 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).

### **FAQs:**

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

**A:** Study participation is approximately 9-12 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 accustomed to 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 the study team will notify the Batten community if this changes.

**Q: *Will I have to travel to participate in the study?***

**A:** No travel is required to participate. All study activities will be completed virtually.

**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, please contact the study team at [BattenSleepStudy@URMC.Rochester.edu](mailto:BattenSleepStudy@URMC.Rochester.edu) or call study coordinator Marianna Pereira-Freitas at (585) 274-0205.