



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 or call study coordinator Marianna Pereira-Freitas at (585) 274-0205.