

Cerebra Sleep Project: Exploring sleep and impulsivity in children with rare genetic syndromes

Researchers: Mr. Rory O'Sullivan, Dr. Stacey Bissell, Prof. Andrew Bagshaw, Prof. Caroline Richards.

What is the study looking at?

The aim of this study is to examine how sleep and impulsivity are associated in children with Cornelia de Lange syndrome (CdLS). With this study, we hope to better understand the impact of sleep on daytime behaviour, and the impact of daytime behaviour on sleep, in young people with CdLS.

What taking part involves

1 - Online survey

The online survey asks about children's behaviour and sleeping habits. This will take about 30 minutes to complete.

2 - Interviews

Caregivers will complete a telephone interview with the researchers. Caregivers will be asked questions regarding their child's functioning and day-to-day behaviours. This will take approximately 90 minutes to complete.

3 - 10-day sleep and behaviour assessment

This 10-day assessment can be completed at home.

Across ten days, children will wear an activity monitor (a motionwatch) which measures their sleep. Caregivers will be asked to keep a paper sleep diary that includes information about their child's bedtime, night waking, and wake-up time, as well as daytime behaviours.

During these ten days, children will also complete play-based and tablet-based games. These games assess aspects of behaviour and cognition. Each game session takes about 10 minutes to complete, and will be done on 5 days of the 10-day sleep assessment. All the game sessions will take place on Zoom with the primary researcher (Rory O'Sullivan).



After taking part

We will provide you with a feedback report. This report will summarise your child's sleep, and include findings from the online survey, interview, and games.



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Who can take part?

Children aged 4 to 15.5 years with CdLS

Children can take part regardless of whether they experience poor sleep, are taking sleep medication, or are taking part in a clinical trial.

How will this study benefit individuals with CdLS and their families?

We hope that this study will improve our understanding of how sleep and daytime behaviours are associated in children with CdLS. Understanding the mechanisms that link poor sleep and daytime behaviour is essential in the design of clinical interventions. By examining the properties of sleep and behavioural measures in children with CdLS, we also hope to understand how researchers and clinicians can robustly evaluate these clinical targets.

How to take part?

If you would like to take part, please follow this link: <https://redcap.link/2t44bs1y>

You can also contact Rory O'Sullivan at rxo165@bham.ac.uk or 0121 414 7206

Ethical approval

The study has been approved by the Science, Technology, Engineering and Mathematics Ethical Review Committee, University of Birmingham [ERN_21-0754AP2].

