



RACP Foundation Research Awards

FINAL REPORT

Project / Program Title	Evaluation of the Impact of Treatment for Sleep Disorders in Children with Down Syndrome	
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Administering Institution	The University of Queensland	
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PROJECT SUMMARY

The adverse effects of poor sleep in children are increasingly recognised and may be particularly significant to children with Down syndrome (DS) due to the fact that sleep disorders are very common in this condition. International guidelines recommend regular screening for sleep problems as part of routine clinical care for children with DS. However resources for sleep evaluation are limited and often both clinicians and parents are unaware of the possible negative impact of leaving sleep problems untreated in children with DS. In fact, it is sometimes felt that these problems require less attention in children with disability and can be ignored due to the fact that these children already have intellectual impairment whereas we do not know whether the impact may even be greater for children with neurocognitive challenges.

In this study we are following children with Down syndrome who are referred to the sleep clinic at the Lady Cilento Children's Hospital (LCCH) over a 12 month period. The children undergo baseline assessments of their sleep, function, development and behaviour, which are then repeated at 6 and 12 months. Alongside this we track any sleep treatments that have been undertaken by their specialist during this time. In this way we hope to understand whether treating sleep problems in children with DS improves their sleep, function, development and behaviour. Results from this study may indicate that children with DS need to be prioritised for evaluation by sleep specialists, identifying the need to restructure current clinical pathways.

To date 40 children with DS aged 3-16yrs have undertaken baseline assessments and 16 have undergone 6 month follow up review. Preliminary review of baseline data is currently underway and recruitment of healthy control subjects has commenced. Early results show that children attending our sleep clinic, not surprisingly, have scores suggestive of sleep difficulties on the Child Sleep Habits Questionnaire. Additionally they have high total scores on the Child Behaviour Checklist. These scores are in fact considerably higher than previous studies have found in

children with DS. This may suggest that behaviour is more difficult in those children with DS and sleep problems.

Assessment of any improvements at 6 and 12 month follow up in children who have undergone clinical sleep interventions during the study will be important to understand if there is a true relationship between sleep and behaviour in this group. If found to be the case, this would support the importance of treating sleep problems in children with DS to improve overall outcomes.

PROJECT AIMS / OBJECTIVES

The aim for this study is to evaluate the impact of treatment of sleep disorders in children with Down syndrome (DS) on their neurodevelopmental and functional outcomes. We hypothesise that standard treatments will improve sleep patterns, enhance accomplishment of daily life habits and positively alter developmental trajectory and behavioural outcomes. The secondary aim is to determine if the effect of treating sleep disorders is more pronounced in children with DS compared to typically developing (TD) children.

SIGNIFICANCE AND OUTCOMES

If this study demonstrates that sleep interventions are associated with improved outcomes in children with DS and that the effect of treatment is greater than in TD children, it would necessitate the development of specific care-pathways for the management of sleep disorders in this population and confirm that these problems cannot be ignored or left untreated. These findings could be transferrable nationally and internationally, with the potential to improve the care and outcomes of children with DS worldwide. In addition, our results may also have significance for researchers who are currently working to understand the link between poor sleep and increased risk of development of dementia and Alzheimer's disease in adult patients with DS.

Data-analysis planned following completion of 6 and 12 month follow up will include evaluation of changes in outcome over time and in relation to clinical interventions, using repeated measure regression models.

Given the success in recruitment and to further the impact of our study results we have applied for additional funding to expand our numbers further. We now aim to recruit 60 children with DS for this study. 12 month longitudinal data is therefore expected to be available in 2019.

PUBLICATIONS / PRESENTATIONS

1. Poster Presentation at World Sleep Oct 2017 Evaluation of Behavioural outcomes in children with Down syndrome and co-existing sleep problems.
2. Book Chapter Sleep in Down Syndrome for Advances in Research on Down Syndrome (published by Intech Open Science)
3. Symposium at ASA Sleep Down Under 2017: Sleep Problems in Down Syndrome
4. Further manuscripts in preparation including planned submission of abstracts for ASA Sleep Down Under 2018