

Sleep and CdLS Research

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Studies show that 1-4 percent of children have moderate to severe sleep-disordered breathing (SDB); however, sleep disturbance is not well characterized in CdLS. In 2010, a team of researchers surveyed the caregivers of 22 patients with CdLS using three validated Sleep Questionnaires: Pediatric Sleep Questionnaire (PSQ), Pediatric Daytime Sleepiness Scale (PDSS), and Obstructive Sleep Apnea-18 (OSA-18). The questionnaires use a number of inquiries to measure symptoms of sleep-disordered breathing, daytime sleepiness, snoring, and inattentive/hyperactive behavior. Results of the study illustrated that 35-36 percent of those with CdLS had symptoms consistent with SDB; while, 23-36 percent of participants were characterized as sleepy.

Previous evaluations of individuals with Smith-Magenis Syndrome, who have similar levels of self-injurious behavior and intellectual disability as CdLS, suggest there is a correlation between sleep disturbance and insomnia or circadian rhythm disorders. In 2012, we collated the results of a sleep history questionnaire completed by the caregivers of 31 patients with CdLS to assess the prevalence of insomnia or circadian rhythm disorders. The results showed that the CdLS study population had significant difficulty falling asleep (75 percent pediatric, 33 percent adult) and difficulty staying asleep (52 percent pediatric, 33 percent adult). The data suggests that individuals with CdLS have a predisposition towards insomnia and circadian rhythm disorders; however, more study is necessary to better characterize the relationship between sleep disturbance and CdLS.

To further characterize this relationship, we are currently asking caregivers of patients with CdLS to complete a survey that more specifically looks at these symptoms. It is available in print or online at: <http://bit.ly/Mztf97>. We are also collecting sleep studies already carried out at home institutions. Please contact us with any questions or concerns at researchsleep@gmail.com.