



Communicating Research in Clear Language

Sleep Disturbances in Rett Syndrome

What is the research about?

Sleep problems are very common in girls and women with Rett Syndrome (RS). They lead to fatigue and stress in both the person with Rett and their families and caregivers. Understanding what kind of sleep disturbances are occurring and in which age groups is important for developing successful treatments.

What did the researchers do?

The researchers analyzed data on 320 Australian children, adolescents, and adults aged 2 to 36, with a diagnosis of Rett Syndrome. Their parents/caregivers were interviewed 6 times over a 12-year period about whether their daughter had sleep problems, night screaming, night laughing, or night waking. They were also asked to report on the use and effectiveness of different types of medications.

What did the researchers find?

The researchers found that more than 80% of the girls and women followed in this study had sleep problems. Two major groups emerged from the data analysis. The largest group had sleep problems that started when the girls were 7 years old or younger and persisted into adulthood. The second group had sleep problems that started before the age of 13, which tended to diminish as the girls got older. The researchers could not locate any large, well-conducted studies that could state with certainty which medications or other treatments helped with sleep problems in all girls and women with Rett Syndrome.

Take home message

Studies such as this one provide useful information by showing what is and is not known about a condition. This study showed that sleep and nighttime screaming or laughing are found in most girls/women with Rett syndrome. It also showed that there is not enough information from solid research to say what treatments, if any, are effective. The study also points to the need for large scale studies to find effective treatments. The authors also urged that there be easy access to respite care to help ensure the health and wellbeing of the families.

NOTE: The original [Research Report](#) was written by K. Wong and associates and was published in the *Journal of Sleep Research*. 2015.