

Sarah H. Elsea, Ph.D.
Virginia Commonwealth University
Richmond, VA

Sleep in RAI1 Disorders

Children and adults with Smith-Magenis syndrome or Potocki-Lupski syndrome (*RAI1* disorders) have sleep disturbances that impact their daily lives. Individuals affected with these syndromes may have difficulty staying awake during normal activities, such as school or playing with friends, and they may have difficulty sleeping. Children and adults with these disorders frequently have intellectual deficits and behavioral problems, and poor sleep may contribute to these difficulties. The goal of this study is to gather information on the sleep and activity habits of individuals with SMS or PTLs in order to better understand exactly how their daily lives are affected and what if any interventions are currently in place. Further, the effect of chronic sleep disturbance on the primary caregiver will also be investigated. Surveys will be collected from parents of children with *RAI1* disorders, as well as teachers or other school personnel that have significant interaction with these children on a daily basis. While the goal of these surveys is to collect the information about sleep patterns and disruptions in daily life, the long-term goal is to be able to use this information to better implement tools and therapies that will help the children succeed in school and attempt to normalize daily activities as much as possible.