

## Implementing telehealth support to increase physical activity in girls and women with Rett syndrome

### Jenny Downs, PhD

The University of Western Australia

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### Scientific Abstract:

Individuals with Rett syndrome generally have difficulties with gross motor skills. Whilst the majority can sit, fewer than half can walk independently and less than one quarter can move from sitting to standing independently. Those who can either walk independently or with assistance have low levels of physical activity and high levels of sedentary time. Adequate and regular use of standing and walking as physical activity is difficult for individuals with Rett syndrome, potentially due to the neurological impairments, lack of appropriate knowledge about how carers could plan physical activity for individuals with disability and/or difficulties in accessing appropriately experienced service providers. As with other rare disorders, individuals with Rett syndrome are scattered geographically and therapists typically see small numbers of cases. This limits the capacity of local therapists and carers to develop expertise for supporting use of physical skills. Drawing on the literature and our recent pilot study, our investigative team will develop a comprehensive manual for physical activity assessment and support that will be relevant to children and adults with Rett syndrome.

*Telehealth* is a mechanism that can counter poor access to health services and has already been used for the delivery of rehabilitation services, particularly for those who live in rural settings. *Telehealth* support has the capacity to support individuals with Rett syndrome by building on available resources and strengths, responding to locally identified needs, and empowering families and service providers to provide appropriate support for the individuals under their care. We will recruit the parents/carers of 60 individuals who have 1) a genetically confirmed diagnosis of Rett syndrome, 2) can walk whether independently or with assistance, and 3) live in a rural setting in Australia, Denmark or Israel. Thereafter, we will conduct a randomized waitlist controlled trial. Data will be collected on health, gross motor skills, current routines and participation to guide the development of each individual's program which will be delivered over a 12-week period. The immediate intervention group will receive the intervention following the baseline assessment whereas the waitlist control group will receive the intervention after the 12 week assessment. Data to describe sedentary behaviour, physical activity and quality of life will be collected from both groups at baseline, at 12 and again at 24 weeks. The investigators will work with caregivers using technologies such as Skype to identify, implement and monitor the physical therapy program.

Knowledge translation strategies will include an online version of the assessment and treatment manual, suitable for both families, carers and therapists, and dedicated to support individuals with Rett syndrome to live active lives. This study will be the first to examine *Telehealth* strategies in Rett syndrome in clinical trial conditions and will then disseminate the assessment and treatment manual online as a knowledge translation strategy.

