



## Individualized home based remote rehabilitation programs for individuals with Rett syndrome and their families

**Meir Lotan, PhD**

Ariel University

Neuro-Habilitation HeART Award

\$ 109,175

### **Scientific Abstract:**

**Background:** Those affected with Rett syndrome (RTT), are scattered geographically and local therapists are limited in their capacity to develop particular expertise to provide the very best care for a clients with RTT. Yet we know that The more involved the family becomes, the more consistent therapeutic management becomes<sup>2</sup>. Therefore, the health care professional must involve family members in all areas of planning, delivery, and evaluation of health and developmental services. Moreover, a Cochrane review found that home based programs appear to be superior to center- based programs in terms of the adherence to exercise, especially in the long-term.

There is existing and accumulating evidence suggesting the effectiveness of individually tailored therapy on patient outcome in physical therapy. Such a program should be constructed based on scientific evidence, therapist experience and client's specific needs. Moreover, previous findings from relevant/similar projects suggest that evaluated children with (A project of 160 individuals in Italy) presented challenges (not walking enough, not standing enough, not using their hands enough, not challenged to become more active) which can be relatively easily handled by inexperienced personnel (such as caregivers and parents), thereby **raising the possible effectiveness of a home-based program for this population**. In Ireland a remote physical therapy rehabilitation program was conducted by the author with significant results for the participants and high level of involvement and satisfaction by the parents.

**Goals:** To implement and assess a remote supervision physical therapy enhanced intervention program

**Participants:** 40 individuals (in agreement with power calculation), genetically diagnosed with RTT, ages 10-40

**Procedure:** Participants will be randomly divided into research and control model within a single-subject cross over multiple baseline design. They will each be evaluated twice before treatment initiation and receive an activity program for a duration of four months, which will be constructed according to each child's needs and with cooperation with the family. The program implementation will be supported through bi- weekly Skype consultation talks through a Participatory Action Research design. A post evaluation and a follow up evaluation will also be performed in four months interval. The evaluations of each child will be videoed and then later evaluated by a blind assessor. Improvement of each child will be evaluated

through Goal Attainment Scale (GAS).

**Outcome measures:** Pre and post and follow up evaluations will assess hand function, spinal deformity through X-ray, Gross motor ability, physical fitness, parental satisfaction and anxiety level.

**Analyses:** Baseline characteristics of functional abilities and physical activity will be compared before and after the intervention period. The differences in the functional change that occurred in the control group and research group will be assessed by using T-Test and confirming the results by using Wilcoxon signed-rank test as a non- parametric statistics method needed for testing the hypothesis of the **paired** small sample. Content analyses will identify positive and negative aspects of the study processes.