

**Abstract Submission: 4<sup>th</sup> European Congress on Rett Syndrome, Roma, Italy October 30<sup>th</sup> - November 1<sup>st</sup> 2015**

## **Oral Presentation**

### **Tools for Assessment of Communication in Rett Syndrome**

Helena Wandin<sup>a</sup>, Theresa Bartolotta<sup>b</sup>, Sally-Ann Garrett<sup>c</sup>, Anna Urbanowicz<sup>d</sup>  
Gillian Townend<sup>e</sup>

<sup>a</sup>Swedish National Rett Center, Frösön, Sweden; <sup>b</sup>School of Health Sciences, Stockton University, Galloway, NJ, USA; <sup>c</sup>Isle Talk, Killorglin, County Kerry, Republic of Ireland; <sup>d</sup>University of Western Australia & Edith Cowan University, Perth, WA, Australia. <sup>e</sup>Rett Expertise Centre - GKC, Maastricht University Medical Centre, Maastricht, The Netherlands

Presenting authors: Helena Wandin, Theresa Bartolotta, Gillian Townend

Contact: [helena.wandin@regionjh.se](mailto:helena.wandin@regionjh.se)

**Background:** Currently, there are no widely-agreed guidelines for assessment, intervention or follow-up of communication in Rett syndrome. Some tools for assessment of communicative skills have been used in studies with participants with Rett syndrome. In this presentation three instruments will be discussed, along with the use of dynamic assessment.

**Summary:** Assessment of communication in RTT is complicated by the diversity of behaviors demonstrated by individuals with the disorder. Formal assessment tools may not help clinicians develop meaningful intervention programs in the population. There is some evidence that behavioral observations combined with standardized assessments may yield useful data (Sigafoos et al., 2011). Challenges to this approach include difficulty validating observations. In everyday clinical practice, therapists can use dynamic assessment strategies to assess real-life situations where individuals with RTT interact with communication partners (e.g. family members, caregivers, educators) who know them best and can interpret their behaviors.

In this session, the presenters will review a number of useful tools for gathering information on communication including the *Inventory of Potential Communicative Acts*, the *Communication Matrix*, and the *Pragmatics Profile*. These tools use interview and observation to gather information on how an individual with complex communication impairment expresses many of the communicative forms and functions of language. Strategies for utilizing the data from these assessments to generate intervention plans will be discussed.

The presenters invite the audience to enter into discussion and hope for this to be a step forward in reaching consensus guidelines for communication assessment and interventions in Rett syndrome.

#### **References:**

Sigafoos, J., Aurthur-Kelly, M., & Butterfield, N. *Enhancing everyday communication for children with disabilities*. Baltimore, MD: Brookes. 2006.

Sigafoos, J. Kagohard, D., van der Meer, L., Green, V.A., O'Reilly, M.F., Lancioni, G.E., Lang, R., Rispoli, M., & Zisimopoulos, D. Communication assessment for individuals with Rett syndrome: A systematic review. *Research in Autism Spectrum Disorders*. 2011; 5:692-700.