Dr. Rose was awarded a Neuro-Habilitation Research Grant for the project “Cognitive Outcome Measures for Rett Syndrome: Assessment of Reliability and Stability”. To better understand what is happening inside the lab, we answer some common questions about this research below.

What are Cognitive Outcome Measures? In terms of clinical trials, outcome measures are described as the measurements that are used to determine the effect of an intervention/treatment on participants. For observational studies, an outcome measure is used to describe patterns of diseases or traits, or risk factors, or treatment. Types of outcome measures include primary outcome measures and secondary outcome measures. Outcome measures are essential to clinical trial design. In Rett syndrome, researchers are developing and improving on outcome measures to better design clinical trials with measure that can reliably assess changes in the participants.

Cognitive function is dynamic – as you learn more and age, you can change, develop, and grow your cognitive function. A cognitive function test is a key identification tool when exploring learning disabilities. There are many different types of cognitive tests to measure cognitive function, and there are different ways (i.e. verbal, visual) to make assessments. Cognitive assessment can measure: motor skills, attention, perception, and executive skills.

Motor Skills  Motor function is a cognitive function. Many times, difficulty with fine motor skills can indicate a potential cognitive impairment.

Attention Many cognitive assessments will use a scale to measure the attention of the person being assessed, that is to say, the subject’s ability to focus on internal or external stimuli, while other assessments are concerned with the length of the individual’s focus, or attention span.

Perception Perceptive tests measure a subject’s ability to identify or recognize external stimuli using their senses of sight, hearing, touch, and sometimes smell.

Executive Skills Much of cognitive function falls under the umbrella of “executive skills”, which include an individual’s ability to self-regulate, ignore or act upon inhibitions, etc. Probably the most easily recognizable executive skill is the ability to make decisions, either after lengthy consideration or on the fly.

What will be tested in this project? These studies involved the testing of 45 children with classical Rett syndrome ages 3-18. The participants will take part in a series of cognitive assessments using eye-gaze technology that include tasks of scanning, recognition memory, anticipation, and three key aspects of attention. The goal is to determine whether these measures are reliable and stable (defined below) to be used as future clinical trial outcome measures.

What is Reliability? Reliability is defined by researchers and statisticians as an indicator that provides information about the uniformity of a test when repeated measures are conducted. It involves the use of the same test repeated over time and is defined as the extent to which test material can be relied on to measure a characteristic consistently over time with the same test material.

What is Stability? Stability is an aspect of reliability and many researchers report that a highly reliable test indicates that the test is stable over time – meaning that test scores taken by an individual would remain the same if that person took the test later in time.

Goal at the end of the two year project:

Today, there are no cognitive outcome measures for assessing the effects of therapeutic interventions for Rett Syndrome (RTT). After two years, the goal is to develop useful outcome measures for clinical trials that use eye tracking technology to measure memory, anticipation (an executive function), and attention.

For the scientific abstract of this project, visit https://www.rettsyndrome.org/file/18-research-files/Rose-Abstract.pdf