

## Neuro-Habilitation Research

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### The Research

Dr. Rose is leading research to better understand and assess learning with eye-gaze technology. She intends to demonstrate that they can measure memory, anticipation, and attention with eye-gaze and use those as outcome measures for clinical trials. This is follow-up research based on previous results.

For a more in-depth look at the research, visit <https://www.rettsyndrome.org/file/18-research-files/Rose-In-Depth.pdf>

### The Hope

Improving patients' quality of life, and their ability to learn and communicate, is one goal of novel therapies which will help to bridge the gap between those with and without RTT. Because attention is a gateway to all other cognitive abilities, determining the strengths and weaknesses in this multi-faceted ability is essential for understanding the cognitive phenotype of Rett syndrome and determining the proper targets for intervention.

### The Answers to your Questions

*What is the most exciting/hopeful aspect of this project and its possible results?*

I find this project exciting on two fronts. One, it continues our work showing that it is indeed possible to assess cognitive functioning in children with Rett Syndrome. Being able to do this represents a breakthrough and let's us begin, for the first time, to understand the cognitive phenotype of this disorder. Second, it opens the way for both designing meaningful interventions and for assessing the effects of the many clinical treatments on the horizon.

*Why is this work important to helping my child?*

If the measures prove reliable and stable, then we will be able to use them to assess changes in your child's cognitive abilities, both spontaneous changes and those brought about by intervention. We will have a yardstick, so to speak, to assess those abilities that are considered to provide the foundation of cognitive growth.

*Is there any way for families to help with your project?*

Families could definitely help by enrolling their children in this study. There are two assessments, 3-6 months apart. Each takes only 20-30 minutes. During the assessment, the child watches a computer screen while we record eye gaze. The displays are visually appealing and most are dynamic and eye catching. We would love to have you and your child participate!

### **The Researcher**

Dr. Rose is a Professor of Pediatrics and of Psychiatry and Behavioral Sciences at Albert Einstein College of Medicine. With funding from Rettsyndrome.org, Dr. Rose teamed up with Dr. Aleksandra Djukic, who heads the Tri-State Rett Syndrome Center at Montefiore Health System, to adapt these visually-based tasks for use in children with Rett Syndrome. Because of difficulties in speaking or using their hands purposively, most standard neuropsychological testing is precluded. Using eye-tracking technology with these visually-based measures, her team has identified problems in three key areas: recognition memory, anticipation (an executive function), and attention. Dr. Rose's current efforts focus on establishing the reliability and stability of these measures to determine their usefulness for clinical trials that will assess the effectiveness of therapeutic interventions.