



Project VAP

a storybook reading
investigation

Dr. Sofia Benson-Goldberg at the University of Oregon is conducting a research study of to understand how children with CDKL5 Deficiency Disorder use their vision during storybook reading interactions with their parents/ caregivers. The study is designed to: (1) identify what children look at on digital book “pages” during parent-child interactions involving familiar and unfamiliar storybooks; (2) explore the impact of features of digital children’s books on what children look at; and (3) determine how specific types of parent interactions might influence children’s visual attention to features of the book. We believe that this study may lead to a clinically-useful indicator of emerging literacy knowledge and skills in children with CDKL5 Deficiency Disorder.

Children ages 36-120 months (3-10 years) with CDKL5 Deficiency Disorder and their parents/ caregivers are being recruited to participate in this study. The study is limited to individuals who live in the United States. The study is being conducted in families’ homes, with surveys to be completed prior by parents/ caregivers. The study protocol includes:

1. An online survey of parent/ caregivers’ views of reading and of children’s current communication and vision profiles to be completed by parents/ caregivers.
2. Parents will be asked to read four digital storybooks on a computer equipped with eye-tracking technologies with their child. Video cameras will also be used to record the interaction. Dr. Benson-Goldberg will be available to monitor the equipment and answer questions
3. Parents will be taught a specific storybook reading strategy and coached in its use. Then the parents and child will be recorded again as they implement this strategy in four more readings. Total family commitment is anticipated to be 3 hours for the assessments, computer and eye-tracker set-up, training, and recorded readings. The reading themselves are anticipated to take no more than 3 minutes each.

If you are interested in participating contact Dr. Benson-Goldberg by email at sofiabg@uoregon.edu or phone at 541-346-0177. Please provide your contact details and indicate that you are interested in participating in the “CDKL5 Storybook Study.” You may contact Research Compliance Services at (541) 346-2510. Please reference IRB Study #00001535. This study is funded by the International Foundation for CDKL5 Research

We look forward to working with you and your child!

