

## **Parent Consent Form**

**Purpose:** You and your child are invited to participate in a study about how children who have visual impairment explore objects. We hope to learn what specific object features children who have visual impairment prefer to explore with their mouths versus their hands. To obtain this information we will video record children who have visual impairments and also children who are typically sighted playing with objects.

**Participant Selection:** Your child was selected to participate in this study because he meets one of the two following criteria: 1. Your child has an age between 6 months and 6 years, and has a visual impairment, or, 2. Your child has an age between 6 months and 6 years, and is typically sighted. Approximately 40 children will be invited to join this study.

**Explanation of Procedures:** If you agree to participate in this study, the following will occur:

- At a child proof room in one of the participating institutions (Envision, Children's Center for the Visually Impaired, Donna Vanier Children's Center), your child will sit at a table. Your child will sit on your lap or by himself depending on age and preference. In either case, you will remain in the same room during the procedure. An experimenter will place, one at a time, a series of objects on the table. These objects will differ from each other with respect to a particular feature (e.g., smooth versus textured). Your child will be allowed to explore each object in whichever way he prefers. Objects will be sized to eliminate choke hazard. Objects will be sanitized before each video session. This will take a maximum of 30 minutes. Your child will be video recorded throughout this activity. There is a Research Media Release Form attached that outlines several possible uses and asks for your specific permission to use the video recordings in each way. We will not use video recordings in any way that you do not provide your specific permission for.
- Your child will have his vision assessed using the Preferential Looking Technique. During the test, the child has merely to sit on your lap and look at a board held by the tester. One side of the board has a visual stimuli (blackand-white stripes). The tester, who is unaware of the visual stimuli's location (to the left or right of a viewing peephole), determines the stripes location based on your child's looking behavior. This test does not put your child under stress or discomfort; no eye drops are placed. This will take about 15-20 minutes.
- After the procedures described above, the experimenter will ask you about your own observations on how your child explores objects. You will also be asked, as appropriated, about your child's gender, age, education level, visual diagnosis, time since visual impairment onset, visual levels, comorbidities, Braille usage/training, low vision device usage/training, orientation and mobility usage/training, ethnicity. We expect this to take about 20 minutes. Only you, your child, and the experimenter will be in the room as you respond to the questions, nobody else will hear your answers.

**Discomfort/Risks:** There are no known risks to you and your child associated with participation in this study. It is possible that your child will become fussy during the procedure, but you will be free to comfort and soothe him at any time you wish. If your child becomes distressed or fatigued, the procedure can be ended at any time per your decision. Because you understand your baby's behavior best, you will decide how to proceed.

**Benefits:** There is no direct benefit to you and your child for participating in this study. However, study results will inform early-intervention practices to promote healthy development in infants with visual impairments.

**Confidentiality:** Data from this study will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. Your and your child's name will not be linked to video-recordings or any other data collected. However, your child's face and voice (and possible your face/voice if your child is sitting on your lap, or if your child interacts with you during the video recording) will not be concealed, as the research's purpose requires them to be coded. We will store all physical data (paper, video) in a locked file drawer at Envision, and all electronic data in a secure network server, using encryption or password protection software. In this way, data will only be accessible to research personnel involved in the conduct of this study.

In order to make sure the study is done properly and safely there may be circumstances where this information must be released. By signing this form, you are giving the research team permission to share information about you with the following groups:

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Wichita State University Institutional Review Board

Retaining research records: We will retain this study information for at least 5 years after the study is completed, or until the data is no longer suitable for studies similar in purpose to the current study.

<u>Compensation or Treatment for Research Related Injury</u>: Wichita State University does not provide medical treatment or other forms of reimbursement to persons injured as a result of or in connection with participation in research activities conducted by Wichita State University or its faculty, staff, or students. If you believe that you or your child have been injured as a result of participating in the research covered by this consent form, you can contact the Office of Research and Technology Transfer, Wichita State University, Wichita, KS 67260-0007, telephone (316) 978-3285.

**Payment:** Participants will be given a \$50 gift card at the institute were testing takes place (Envision, Children's Center for the Visually Impaired, Donna Vanier Children's Center) after their participation is complete. Study payments are taxable income. You will be asked to complete a W9 form which requires your name, address, and social security number in order for you to receive study payments. A Form 1099 will be sent to you and to the Internal Revenue Service if your payments are \$600 or more in a calendar year.

**<u>Refusal/Withdrawal</u>**: Participation in this study is entirely voluntary. Your decision whether or not to participate will <u>not</u> affect your current nor future relations with Wichita State University nor any of the participating institutions (Envision, Children's Center for the Visually Impaired, Donna Vanier Children's Center). If you agree to participate in this study, you are free to withdraw from the study at any time without penalty.

<u>Contact</u>: If you have any questions about this research, you can contact Andrea Urqueta Alfaro at 316-440-1520 and/or at andrea.urquetaalfaro@envisionus.com. You can also contact Laura Walker at 510-504-4013 and/or at laura.walker@envisionus.com. If you have questions pertaining to your rights as a research subject, or about research-related injury, you can contact the Office of Research and Technology Transfer at Wichita State University, 1845 Fairmount Street, Wichita, KS 67260-0007, telephone (316) 978-3285.

You are under no obligation to participate in this study. Your signature below indicates that:

- You have read (or someone has read to you) the information provided above,
- You are aware that this is a research study,

- You have had the opportunity to ask questions and have had them answered to your satisfaction, and
- You have voluntarily decided to participate.

You are not giving up any legal rights by signing this form. You will be given a copy of this consent form to keep.

(Please sign your name in the line above)

Child's Name (Please Print)

Child's Birthday (Month/Day/year)

Your relationship to the child

Printed Name of Witness

Witness Signature

Date

Date