Screening Consent to Participate as a Child Control in a Research Study

Dear Parent of Potential Participant:

Thank you for expressing interest in our research study of language, learning and memory at the Autism Center of Excellence at the University of Pittsburgh School of Medicine. This study compares test results of individuals with ASD to healthy individuals from the community. Before individuals enter the study, they must go through a screening process.

The first step is to sign this consent form for your child and mail or fax both pages to the address provided. We will then contact you to conduct a 15-minute telephone screening, to determine if your child may be eligible for the study. Because of the sensitive nature of some of the questions, all information is kept strictly confidential. At any time during the study, you may choose not to respond to certain questions that you feel uncomfortable with, or may withdraw your child from participating altogether. To formally withdraw consent for data collected from your child for this research study you should provide a written and dated notice of this decision to the Principal Investigator of this research study. Should you decide to have your child’s research information destroyed, we ask you to specify this in the notice. Otherwise, all of your child’s research data, including videotapes, will be maintained for use by the Investigator.

When the telephone screening is completed, your child may be scheduled for the next step, which involves completing additional screening questionnaires, an intelligence (IQ) test and a measure of academic achievement. The total time for your child to complete these tests is 1 hour. Your child will receive $25 for completing the IQ and achievement tests and $10 for completing the additional screening questionnaires. Your child may also be asked to participate in a diagnostic assessment if there is an indication from the questionnaires of a developmental delay. This will take one hour to complete. Your child will receive $10 for completing this test. Your child will be asked to sign an additional consent form before completing these tests. You will then receive a brief summary report of the results from the IQ testing and academic screening.

This study is part of a National Institutes of Health (NIH) collaborative research effort. NIH has asked us to combine our data with the data collected by other sites, nationally and internationally that are doing ASD-related research. This will allow national and international teams to work together to study the brain in autism-spectrum disorders, other disorders and typical development. Research data may also be stored by the National Institutes of Health (NIH) in a central repository. NIH will make data in the repository available to other scientists who want to perform research on autism-spectrum disorders, other disorders, and typical brain development. This will allow data to be part of a national resource. Scientists, both now and in the future, will use new methods of studying the data in the repository to advance the understanding of typical and disordered brain growth and development.

Parent’s Name (print) Parent signature (if subject is less than 18 years) Date

Subject name (print) Subject signature (ages 14 and older) Date

ACE Consent ID: 630
Participant’s privacy and confidentiality will be protected at all times. All data shared with research collaborators will be “de-identified” and assigned a unique code number. Any access to the data in the NIH repository by other scientists would first need to be approved by NIH.

If your child meets the eligibility requirements, he/she will then be invited to participate in the study. If your child does not meet these requirements, we would like to keep your child’s records on file to contact him/her for future participation in the study. At any time, if you have questions or comments, feel free to call 1-866-647-3436 or contact us by email at autismrecruiter@upmc.edu. Please sign below if you are in agreement with these procedures and return to us. Thank you very much for your help, as we continue to work together for a better future for people with ASD and for their families.

<table>
<thead>
<tr>
<th>Parent’s Name (print)</th>
<th>Parent signature (if subject is less than 18 years)</th>
<th>Date</th>
<th>Relation to Child</th>
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<table>
<thead>
<tr>
<th>Subject name (First, Middle, Last)</th>
<th>Gender</th>
<th>Subject signature (ages 14 and older)</th>
<th>Date</th>
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<table>
<thead>
<tr>
<th>Child’s Date of Birth</th>
<th>Child’s City of Birth</th>
<th>Child’s Native Language</th>
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<table>
<thead>
<tr>
<th>Street address</th>
<th>City</th>
<th>State</th>
<th>Zip</th>
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<thead>
<tr>
<th>Telephone number</th>
<th>Cell</th>
<th>Phone Number</th>
<th>email address</th>
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Was your child adopted?  
Yes/No (If so, please send a copy of supporting legal documentation of adoption)

What is your child’s race and ethnicity? (Note: You have the option to not answer questions related to race and/or ethnicity. If you choose to not answer, this will not impact your participation in the research study.)

**Race:**  
White  
Black/African American  
Asian  
Native Hawaiian or other Pacific Islander  
American Indian/Alaskan Native  
Other  
More than one race

**Ethnicity:**  
Non-Hispanic  
Hispanic

What is the best time to reach you? _________ A.M./P.M.  
What is the best way to reach you? Telephone/Email/Text

How did you learn about our study?  
___________________________________________________________________

Have any other family members participated in Dr. Minshew’s research?  Yes/No