

**UNIVERSITY OF NEVADA, RENO SOCIAL BEHAVIORAL INSTITUTIONAL REVIEW BOARD  
CONSENT AND PARENTAL PERMISSION FOR A CHILD TO PARTICIPATE IN A RESEARCH  
STUDY**

**TITLE OF STUDY: Educational Development in Individuals with Extra X Chromosomes**  
**INVESTIGATOR(S): Dr. Donald R. Bear 775-784-4951, Mina Avery 775-425-2367**  
**PROTOCOL #: SA07/08-152**  
**SPONSOR: None**

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**Parent Consent, Parental Permission for Child to Participate, and Child Assent  
for Participation in Research Study.**

**PURPOSE**

You are being asked to allow your dependent child to participate in a study of reading and writing development in individuals with extra X chromosomes. Your child is being asked to participate in the spelling test to provide information about current spelling and writing knowledge. The study hopes to find patterns in the development of these individuals.

**PARTICIPANTS**

You are being asked to participate because you are a parent of a child who has been diagnosed with an extra X chromosome. Your child's participation is based on the diagnosis of 47,XXX or 47,XXY.

The study expects to collect spelling tests, surveys and existing test data from thirty or more subjects.

**PROCEDURES**

If you and your child agree (or consent) to participate in this research study you will download consent forms, a spelling test, directions for the spelling test and a survey from [www.anextrakiss.com](http://www.anextrakiss.com) you will also be asked to submit copies of your child's academic test scores. The survey and spelling test are both designed to take no more than twenty minutes to complete. You will then mail the completed survey, spelling test and copies of your child's academic test scores to the E.L. Cord Center for Learning and Literacy. The signed consent allows researchers to use data obtained not only from the spelling test but also data from the survey and academic test scores.

If you or your child becomes uncomfortable with filling out the survey, completing spelling test or copying academic test scores you may end your participation in the study immediately.

**DISCOMFORTS, INCONVENIENCES, AND/OR RISKS**

This study will take twenty minutes of your time to complete the parent survey. The spelling test will take your child approximately the same amount of time. Your child may become uncomfortable with the spelling test as the words get harder near the end of the test. The test is very brief and the child should not feel penalized for misspellings. There may be unknown or unforeseen risks in having your child's test scores analyzed or in completing the spelling test. It is possible that the spelling assessment and analysis may indicate that your child's scores are different than expected. This data is to guide you or professionals working with your child in selecting appropriate instructional materials but should not be considered a diagnosis. You will only receive the test results if your request them and they will be sent to the e-mail address or postal address you

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designate. Participants will be assigned a number and names will not be associated with academic test scores, surveys or spelling inventories.

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### BENEFITS

There may be no direct benefit to your participation or that of your child in this study. A review of the spelling assessment will be sent to you with researcher's interpretation of the results; at your request only. This interpretation of the spelling assessment will provide you or professionals working with your child with a guide in selecting instructional level spelling words and reading materials.

The results of the parent survey and academic test score analysis will be made available to the participants at the completion of the study, via the support group websites and anextrakiss.com. This information will not be specific to your child as the data is looking for patterns within this population not individual strengths and weaknesses.

### CONFIDENTIALITY

Your identity and the identity of your child will be protected to the extent allowed by law. Neither you nor your child will be personally identified in any reports or publications that may result from this study.

The Department of Health and Human Service (HHS), other federal agencies as necessary, the University of Nevada, Reno Social Behavioral Institutional Review Board may inspect your study records.

Your consent forms will be stored in a locked file cabinet at the E.L. Cord Foundation Center for Learning and Literacy at the University of Nevada, Reno for the duration of five years.

Spelling tests, parent surveys and copies of your child's academic test scores will be stored in a separate locked file cabinet at the E.L. Cord Foundation Center for Learning and Literacy at the University of Nevada, Reno for the duration of five years.

### COSTS/COMPENSATION

There will be minimal cost to you as you will be paying for photocopying your child's academic test scores and mailing them, plus the survey and spelling test to the researcher. You will not be compensated for participating in this research study.

### DISCLOSURE OF FINANCIAL INTERESTS

The researcher has no financial interest in this study.

### RIGHT TO REFUSE OR WITHDRAW

You or your child may refuse to participate or withdraw from the study at anytime and still receive the care you and your child would normally receive if you were not in the study. If the study design or use of the data is to be changed, you will be so informed and your consent re-obtained. You will be told of any significant new findings developed during the course of this study, which may relate to your willingness to continue participation.

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**QUESTIONS**

If you have questions about this study or wish to report a research-related injury, please contact Dr. Donald R. Bear at 775-784-4951 or Mina Avery at 775-425-2367 at any time. You may also contact Mina Avery at mavery@anextrakiss.com with questions or clarifications anytime during the study.

You may ask about your rights as a research subject or you may report (anonymously if you so choose) any comments, concern, or complaints to the University of Nevada, Reno Social Behavioral Institutional Review Board, telephone number (775) 327-2368, or by addressing a letter to the Chair of the Board, c/o UNR Office of Human Research Protection, 205 Ross Hall / 331, University of Nevada, Reno, Reno, Nevada, 89557.

**CLOSING STATEMENT**

I have read ( ) this consent form or have had it read to me ( ). [Check one.]

\_\_\_\_\_ has explained the study to me and all of my questions have been answered. I have been told of the risks or discomforts and possible benefits of the study.

If I or my child do not take part in this study, my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty.

My child and I have been told our rights as a research subject, and we voluntarily consent to participate in this study. My child and I have been told what the study is about and how and why it is being done. All my questions have been answered.

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I will receive a signed and dated copy of this consent form.

I agree to participate and give my child permission to participate in this study:

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Signature of Parent

Date

I agree to participate in this study

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Signature of child

Date

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Signature of Investigator

Date