

UNIVERSITY OF NEVADA, RENO SOCIAL BEHAVIORAL INSTITUTIONAL REVIEW BOARD
CONSENT 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

ADULT PARTICIPANT CONSENT FORM

PURPOSE

You are being asked to participate in a research study. The purpose of this study is to examine the Reading and writing development in individuals with extra X chromosomes. The study hopes to find areas of strength and weakness in literacy development.

PARTICIPANTS

You are being asked to participate because you have been diagnosed with an extra X chromosome. The study expects to collect spelling tests, surveys and existing test data from thirty or more subjects.

PROCEDURES

If you agree (or consent) to participate in this research study you will download a one page survey from www.anextrakiss.com. You will also download directions on administering the spelling assessment. The survey and spelling test are both designed to take no more than twenty minutes to complete. You will then mail this consent form, the completed survey, spelling inventory and copies of your academic test scores to:

E.L. Cord Center for Learning and Literacy,
Attention Dr. Donald R. Bear and Mina Avery
College of Education
Mail Stop 288
University of Nevada, Reno
Reno, Nevada 89557-0217

If you become uncomfortable completing spelling assessment or sharing copies of your academic test scores you may end your participation in the study immediately. Please note your name will not be associated with the spelling test or the test scores.

DISCOMFORTS, INCONVENIENCES, AND/OR RISKS

This study will take twenty minutes of your time to complete the survey. The spelling assessment takes approximately the same amount of time. You may become uncomfortable with the spelling inventory as the words get harder near the end of the test. The test is very brief and you should not feel penalized for misspellings. There may be unknown or unforeseen risks in having your test

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

scores analyzed or in completing the spelling assessment. The assessment is being conducted in a uncontrolled environments and should not be considered to be diagnostic. You will be encouraged to seek independent evaluation if the spelling assessment evaluation information is contrary to your current understanding of your literacy levels. Discomfort may be caused in reviewing the population test score analysis as patterns of weakness may be identified. These risks are hoped to be minimized by the assigning of numbers rather than names to subject data and by the short time required to complete the tasks.

BENEFITS

There may be no direct benefit to your participation 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. The results of the survey and academic test score analysis will be made available to you at the completion of the study via support group websites and posting on www.anextrakiss.com. This information will not be specific to you as the data is looking for patterns within this population not individual strengths and weaknesses.

CONFIDENTIALITY

Your identity will be protected to the extent allowed by law. You will not 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 inventories, surveys and copies of your academic test scores will be stored in a locked file cabinet (not the same cabinet as the consent forms) 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

You will have to pay for the copying of your academic test scores. You will also need to pay the postage to mail your consent forms, survey, spelling inventory, and academic test scores to the E.L. Cord Center for Learning and Literacy at the University of Nevada, Reno.

You will not earn any money by participating in the research.

DISCLOSURE OF FINANCIAL INTERESTS

The researcher has no financial interest in this study.

UNR Social Behavioral IRB Approval 05/21/09
EXPIRATION DATE 06/06/10

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

RIGHT TO REFUSE OR WITHDRAW

You may refuse to participate or withdraw from the study at any time and still receive the care you 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.

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 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 [or loss of other benefits to which I am entitled].

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

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

Signature of Participant	Date
Signature of Person Obtaining Consent	Date
Signature of Investigator	Date

UNR Social Behavioral IRB Approval 05/21/09
EXPIRATION DATE 06/06/10