**University of Colorado Boulder**

**The Adolescent Brain Cognitive Development (ABCD) Study**

**Addendum to ABCD Protocol: Blood Draw (Parent)**

Investigator: John K. Hewitt

In addition to the ABCD study procedures described, we are also asking for a blood sample from your child because you are participating at the University of Colorado Boulder. This is an additional procedure here and at several other places in the study. This will be done at every annual visit. In later years this may be part of the study everywhere.

**Procedure**

We will draw some blood from a vein in your child’s arm. Your child will have the option of using some numbing cream before the blood draw.

**Purpose**

The blood sample that children provide will be used for genetic research, to study how genes influence brain differences, behavior, and health. Unique individually identifiable genetic information will be generated as part of the research. For twin pairs, they will also be used to determine whether twins are identical (monozygotic). Part of the blood samples will be used to extract DNA (the "instruction book" for the cells that make up our bodies), which we will use to look at how your child(ren)’s genes are similar to and different from genes of the other children in the study, and how that relates to differences in the brain and behavior.

Sometimes genetic tests are performed to identify changes in genes associated with medical conditions, so that a patient or his/her doctor can use this information. This kind of medical test will not be performed on the sample. If you are interested in having genetic testing performed you should consult your doctor.

Children’s genetic data will be included in one or more computer databases that qualified investigators can study. Data will be stored without names or other information that directly identifies you or your children, on secure computers that are password protected. The only people who will have access to these data will be qualified investigators who agree to keep the data secure and not attempt to identify you or your children.

**Risks**

* Children may feel brief pain when we draw their blood, or get a bruise.
* Children may feel dizzy or faint during or after the blood draw.
* Children will have the option of using numbing cream before we draw their blood, which may reduce the discomfort.
* If they use the cream, there may be redness or temporary whitening in places where we use the cream, and they may have itching and a numb feeling.
* If they use the cream and are allergic to the cream, they may get a rash.

**Compensation**

Children will receive an extra $10 for providing a blood sample.

**Sample processing**

Samples that we collect from children will be stored in a repository called the Rutgers University Cell and DNA Repository (RUCDR). For security reasons, information that would directly identify children (for example, name or address) will not be sent to RUCDR or stored with their samples; instead, we will identify samples only with a code that does not directly identify participants.

RUCDR may send cell lines and/or DNA made from children’s blood sample or saliva samples to other qualified investigators (either academic or commercial) for use in their research. A cell line is cells that are grown in a laboratory and can be reproduced indefinitely. Any use of materials from RUCDR would first need to be reviewed and approved by the National Institutes of Health. The scientists who use these materials will not know children’s names or other information that directly identifies you or your child(ren). Investigators will not try to identify subjects. However, RUCDR and other investigators may be given some information that does not identify participants, such as the year of birth or gender.

**Rights to the DNA Sample**

If you decide later that you do not want the DNA collected from your child to be used for future research, you may tell this to Dr. Hewitt, who will use his best efforts to stop any additional studies. However, in some cases, such as if your cells are grown up and are found to be generally useful, it may be impossible to locate and stop such future research once the materials have been widely shared with other researchers. RUCDR may keep the specimens indefinitely.

**Prohibited uses of genetic information**

Federal and State laws generally make it illegal for health insurance companies, group health plans, and most employers to discriminate against people based on genetic information. This law generally will protect you in the following ways: a) Health insurance companies and group health plans may not request genetic information that we get from this research; b) Health insurance companies and group health plans may not use genetic information when making decisions regarding eligibility or premiums; c) Employers with 5 or more employees may not use genetic information that we get from this research when making a decision to hire, promote, or fire anyone or when setting the terms of your employment. Be aware that these laws do not protect you against genetic discrimination by companies that sell life insurance, disability insurance, or long-term care insurance.

Dr. Hewitt, the NIH, and the ABCD Investigators will be responsible for deciding how the sample will be used. The specimens collected from you and the DNA that they contain may also be used in additional research to be conducted by the ABCD investigators collaborating in this research. These specimens, DNA, and their derivatives may have significant therapeutic or commercial value. You consent to such uses.

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\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of staff explaining blood draw

By signing this form, you are agreeing to your child providing a blood sample as part of the study.

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Child’s name – printed

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Signature of Parent/Guardian

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Name of Parent/Guardian- printed

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Date