NATIONAL HEALTH AND NUTRITION EXAMINATION SURVEY (NHANES)

Consent and Parental Permission for Specimen Storage and Continuing Studies Using DNA

Print name of participant _____ _____ _____
First Middle Last

Q **Why will a sample of my DNA be kept for future health studies?**

A Genes are the "instruction book" for people. Genes are made out of DNA. The DNA of a person is about 99.9% the same as the DNA of another person, but no two people have the same DNA except identical twins. Differences in DNA are called genetic variations and explain differences such as eye color and partly explain why some people get certain diseases. To look at these variations many genetic tests may be done on your blood sample. We will keep the DNA for an unlimited time. Studies of human genes are helping us learn about many diseases and health conditions. The information from people who are part of NHANES could help that effort.

We will store part of the blood sample that we collect in the exam center for future genetic studies. These samples will be frozen and kept in a specimen bank for as long as they last. Your participation is voluntary and no loss of benefits will result if you refuse.

Q **What genetic studies will be done with the samples?**

A Science and medicine are continually advancing. New tests and new ways of looking at results will be developed in the future. We can't predict what test will be done or what the results will mean for your health

Q **Who can use the stored DNA samples for further study?**

A Researchers from Federal agencies, universities, and other scientific centers can submit proposals to use the stored specimens. These proposals will be reviewed for scientific merit and then by a separate board that determines if the study proposed is ethical. The NHANES program will always know which samples belong to you, but we will not give other researchers any information that could identify you.

We will keep strictly confidential all health data and samples that we collect in NHANES, as required by Federal law. By confidential we mean that the information that we release to the public can not be used to identify you. Our staff is not allowed to discuss that any person is part of this survey under penalty of Federal laws: Section 308(d) of the Public Health Service Act (42 USC 242m), the Privacy Act of 1974 (5 USC 552A), and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347).

Q **Will I receive results from any future testing of my specimens?**

A The NHANES program will not contact you or your family with results from these future studies. We will describe the completed studies on our website. If you are interested in your results from any of these studies, you may call our toll-free number, 1-800-452-6115, to request your specific results as they become available.

Q **What are the benefits and risks for giving a blood sample for future genetic studies?**

A You will not directly benefit but these studies may eventually help the health of people in the future. The risk of giving a sample includes the minor risk associated with taking the blood sample. There may also be a risk that some people may use the information from the genetic studies to exaggerate or downplay differences among people. The ethics board that will review all studies using these samples will attempt to prevent any misuse of the information gained from the NHANES DNA samples.

Q **How can I remove my DNA samples from the specimen bank?**

A In the future, if you want samples removed from the specimen bank, call us toll-free at 1-800-452-6115.

The results of continuing studies of your stored specimens may help find new ways to prevent, treat, and cure many diseases.

Only for **persons ages 20 and over**, check a box

☐ I agree that my blood may be kept for future studies using my genes to help understand genetic links to medical conditions, and that I will not be contacted with the results from these studies.

☐ I disagree

_____ _____
Signature of participant age 20 or over Date

I observed the interviewer read this form to the person named above and he/she agreed to participate by signing or marking this form.

_____ _____
Witness (if required) Date

Name of staff member present when this form was signed:

_____

___ ___ ___ ___ ___ ___
SP ID