

Attachment 19

Questions about Genetic Testing for Liver Health in NHANES

What is genetic testing for liver health in NHANES?

We do genetic testing by taking DNA from your blood and from the blood of other NHANES participants to look at genes, or segments of DNA, to see how genes affect liver health.

How will you collect my DNA?

We will use the DNA that is in the blood sample you provide in our Mobile Exam Center.

What are the risks?

There is no risk to genetic testing procedure. However, the risk of having blood drawn is minimal. You may have mild pain and some bruising at the site where blood is drawn.

What kind of genetic tests will be done on my DNA sample?

Your DNA sample, and samples from other NHANES participants, will only be used by researchers to look at specific genes that may be related to liver disease and related health conditions.

Will you store my DNA or use it for future studies?

No, your DNA will only be used for current testing. Once this testing is complete the remaining DNA sample will be destroyed. Your DNA will **NOT** be stored after testing is complete and will **NOT** be used for any future studies.

Who will use the genetic data obtained from testing?

The data will only be available to researchers who access your data at the National Center for Health Statistics Research Data Center, which is a secure location. Your personally identifiable information (such as name, address, social security number, etc.) will never be given to researchers.

Will I get results of this testing?

No, we will not provide you with results from this testing. The tests will be used only for studies. Your genetic data will not be tested for anything known to require medical care or treatment.

Can I say no to this testing but still participate in the NHANES?

Yes. You can refuse genetic testing at any time and still participate in NHANES. You can also still have your blood drawn for non-genetic tests. Please tell an NHANES staff member if you refuse to have the genetic test done on your blood sample.

Can the genetic information from this testing be used to identify me?

In general, DNA is unique to only you and therefore may identify you. For this reason, we only store your genetic data in a secure place and restrict researchers' access to the data for specific purposes that would not identify you. We are required by law to protect your privacy and the confidentiality of your data and we take these laws very seriously.

Could information from this genetic testing be used against me?

Individual identifiable genetic information will **NOT** be available to researchers or anyone such as a health insurance company or doctor's office.