

**NEW YORK STATE
INFORMED CONSENT FOR GENETIC TESTING**

The purpose of this form is to allow you to make an informed decision in regard to whether or not you wish to undergo genetic testing. You may wish to obtain professional genetic counseling before you sign this form. If you do not sign this form, no genetic tests will be performed on your behalf.

I understand that the purpose of this test, and its potential benefit, is to obtain the possible diagnosis of an inherited metabolic disease. It may also determine which of my family members may be carriers of the disease. For prenatal diagnosis, it may determine the genetic status of the fetus.

I understand that a positive test result is an indication that I (or my child) may be predisposed to or have the specific disease or condition tested for. If I (or my child) receive a positive test result, I understand that I (or my child) may benefit from further independent testing, consultation from my physician, or pursuing genetic counseling.

I understand that genetic testing has been recommended for me (or my child). I understand that the genetic testing requires analysis of the chromosomes, Deoxyribonucleic acid (DNA), Ribonucleic acid (RNA), or protein obtained from a sample of blood, skin, cheek brushings or other body tissues. I understand that no other tests than those authorized will be performed and that my biological sample will not be saved without my authorization.

I understand that the following diseases or conditions will be tested for:

I understand that a positive test result for _____ disease or condition serves as a _____ percentage predictor of such disease. Or, in the alternative, as explained to me, no level of certainty has been established for the disease or condition which I am being tested for.

I understand the specific test that I (or my child) is having and its accuracy. I understand that the results of this test may be inconclusive or uninformative (not tell me anything).

I understand that incorrect information about family relationships may affect the test result.

I understand that this test may reveal private information such as non-paternity (someone's father not being who they think they are) or adoption. I understand that such information, if obtained through this test, will NOT be revealed to me, my child, or to anyone else, under any circumstances.

I understand that I am responsible for the costs of genetic testing. If I choose to have my (or my child's) insurance company pay for the testing, it is my responsibility to contact the company to determine that they cover such testing. I understand that if the insurance company pays for the testing they may have a right to learn the test results. I understand that I can choose not to have the insurance company pay for the testing, in which case I will pay for the test myself. I understand that in some cases payment is required before the genetic testing is performed.

I understand that whether it is the insurance company or me that pays for the testing, the results may become part of my (or my child's) permanent medical record. I understand that having this information in the medical record may make it more difficult for me (or my child) to get health, disability, long-term care or life insurance. I have also considered the possible financial impact of the test result.

I understand that my genetic sample will be destroyed at the end of the testing process or not more than sixty days after my sample was taken, unless I authorize a longer period of retention.

I authorize the results of this test to be disclosed to the following persons/organizations:

I have explained to _____ the possible risks, benefits and limitations of the genetic test _____ (name of the test).

Provider Signature: _____ Date: _____

Institution: _____ Phone number: _____

I have read (or had read to me) the above information and received a copy of this form. All of my questions and concerns about genetic testing have been addressed. I understand that I can contact the person listed above if I have additional questions.

Patient _____ Date: _____

If patient is a minor:

Parent or guardian: _____ Date: _____

Witness: _____ Date: _____

I hereby authorize my genetic sample to be retained by the testing organization for a length of time as they see fit, in order that they may use my sample for anonymous research. I understand that this is entirely optional and that my refusal to allow my sample to be used for anonymous research will in no way affect my ability to have my genetic test performed. By signing below, I understand that my sample may be held longer than the sixty day period stated above.

Patient _____ Date: _____

If patient is a minor:

Parent or guardian: _____ Date: _____

Witness: _____ Date: _____