

UCLA ORPHAN DISEASE TESTING CENTER

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Informed Consent for New York Residents Requesting Genetic Testing

I have been counseled and understand that:

1. My health care provider wants me to have a test for _____.
2. Patients residing in New York State are required to give informed consent prior to having a genetic test. This should occur after discussing with my health care provider or consulting geneticist or genetic counselor the purpose of the test, its predictive or diagnostic capability, and its relative benefits and potential drawbacks.
3. The genetic tests offered by the UCLA Orphan Disease Testing Center are performed to identify mutations (gene changes) that may cause or predispose to disease. Targeted tests are performed when a family gene change is known; mutation identification or full sequence tests are performed to search for an unknown gene change.
4. Genetic tests can be offered to confirm or rule out a diagnosis, to test for a disease before symptoms develop, to determine carrier status or for prenatal diagnosis. My health care provider will tell me about why he/she would like to order genetic testing.
5. A negative genetic test for a disease, in many cases, will not completely rule out that disease. I may still have or be a carrier for that disease. My health care provider will use my health and family history to interpret what the negative result means for me.
6. A positive result may mean that I have or am predisposed to developing a genetic disease, though the actual degree of which may vary and is often less than 100%. I may consult with my health care provider or ask to be referred to a genetic professional to discuss any additional testing or counseling that may be helpful.
7. Results will only be released to authorized personnel.
8. When the testing is done, my sample may be retained to be used for quality control purposes or research after de-identification.

Signature _____ Date _____

Printed Name _____

Physician/Counselor/Clinician Statement:

I have explained DNA testing to the patient/parent/guardian. The consent form and limitations of genetic testing were reviewed with the patient/guardian. I accept responsibility for pre- and post- test genetic counseling.

Signature _____ Date _____