STONY BROOK
STATE UNIVERSITY OF NEW YORK

UNIVERSITY HOSPITAL AND
MEDICAL CENTER, LEVEL 5, SUITE 2

Division of Genetics
Genetic Counseling

MRN #: _____

INFORMED CONSENT – CYSTIC FIBROSIS / MOLECULAR TESTING

DNA Indication
_____ No Family History (Screening)
_____ Family History: Relative: _____

Ethnicity:
_____ N. European Caucasian
_____ S. European Caucasian
_____ Asian
_____ Native American
_____ Ashkenazi Jewish
_____ African American
_____ Sephardic Jewish
_____ Other: _____

PATIENT NAME: _____

By signing below, I hereby authorize Patricia Galvin-Parton, MD and/or David H. Tegay, DO and their genetic counselor associate(s) to obtain a sample for cystic fibrosis testing. I have read about cystic fibrosis and/or have talked with a genetic professional. I have had the opportunity to ask all my questions, and I have all the information I want. It has been explained to me and I understand that:

1. The purpose of this test is to determine whether I (or the patient, if different from self) may be a carrier of or affected with cystic fibrosis.
2. DNA testing, which is done on a small sample of blood or other tissue, looks at mutations in the particular gene known to cause cystic fibrosis. Genes contain the information that tells the body how to work. A change in the genetic information (also called a mutation) can result in an abnormal gene that doesn't work properly.
3. Mutations are often different in different populations. Providing the laboratory with accurate information about family history and ethnic background is essential for the most accurate interpretation of the test results.
4. The test results may indicate that I am affected with or carry a mutation for cystic fibrosis. However, results may be indeterminate because of the limitations of current technology. Consulting with a doctor or a genetic counselor is recommended to learn what the results mean for the individual and for the family.
5. When the DNA testing does not show a known mutation, the change that the person is a carrier or is affected is reduced. However, there is still a chance to be a carrier or to be affected because the current testing cannot find all the possible changes within a gene.
6. In some families, DNA testing might discover non-paternity (someone who is not the real father), or some other previously unknown information about family relationships, such as adoption.
7. The sample will be tested for cystic fibrosis only. After completion of the test (within 60 days), the sample will be discarded. The DNA sample may be retained or laboratory quality control. If retained, all patient identification will be removed from the specimen; it will become anonymous.
8. These results will become part of my medical record. All results will be communicated to me, and copies will be forwarded to my referring physician.

_____ _____
Signature Date
Relationship to patient: □ *Self* □ *Parent*

_____ _____
Witness Date

STONY BROOK, NEW YORK 11794-7535 - TEL: 631-444-2790 - FAX: 631-444-2761