ARUP LABORATORIES

A nonprofit enterprise of the University of Utah and its Department of Pathology

500 Chipeta Way
Salt Lake City, UT 84108-1221
phone: 801-583-2787 | toll free: 800-242-2787
fax: 801-584-5249 | aruplab.com

THIS IS NOT A TEST REQUEST FORM. Please complete and submit with the test request form or electronic packing list.

PATIENT HISTORY FORM FOR CYSTIC FIBROSIS (CF) TESTING

Patient Name: _____ **Date of Birth:** _____

Sex Assigned at Birth: ☐Female ☐Male ☐Intersex **Gender Identity (optional):** ☐Female ☐Male ☐_____

Ordering Provider: _____ **Provider's Phone:** _____

Practice Specialty: _____ **Provider's Fax:** _____

Genetic Counselor: _____ **Counselor's Phone:** _____

Patient's Ethnicity (check all that apply)

☐ Black/African American ☐ Asian ☐ Hispanic or Latino ☐ Native American or Other Pacific Islander
☐ Ashkenazi Jewish ☐ White ☐ Middle Eastern ☐ Other: _____

Is the patient pregnant? ☐ No ☐ Yes ☐ N/A

Does the patient have symptoms? ☐ No ☐ Yes (check all that apply)

☐ Azoospermia ☐ COPD ☐ Pancreatitis
☐ Bilateral absence of the vas deferens ☐ Failure to thrive ☐ Pneumonia
☐ Bronchiectasis ☐ Fetal echogenic bowel ☐ Positive newborn screen
☐ Chronic cough ☐ Meconium ileus ☐ Pseudomonas
☐ Other symptoms: _____

Has sweat chloride testing been performed? ☐ No ☐ Yes ☐ Unknown

If yes, what was the result? ☐ normal (<30) ☐ borderline (30-60) ☐ elevated (>60) ☐ QNS ☐ Unknown

Has the patient undergone previous DNA testing for CF? ☐ No ☐ Yes ☐ Unknown

If yes, describe the test(s) and results: _____

Does the patient have a family history of CF? ☐ No ☐ Yes ☐ Unknown

If yes, specify the relationship of the family member to the patient: _____

Indicate if the relative is: ☐ a healthy carrier ☐ affected with CF List CF variant(s): _____

Is the patient's reproductive partner a CF carrier? ☐ No ☐ Yes If yes, list the variant: _____

Does the patient's reproductive partner have a family history of CF? ☐ No ☐ Yes ☐ Unknown

If yes, specify the relationship of family member(s) to the partner: _____

Is the partner's relative ☐ a healthy carrier or ☐ affected?

Master Label

For questions, contact an ARUP genetic counselor at 800-242-2787 ext. 2141.

ARUP LABORATORIES | NATIONAL REFERENCE LABORATORY

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INFORMED CONSENT FOR GENETIC TESTING

Patient Name _____ Date of Birth _____ Sex ☐ F ☐ M

Sample Type _____ Test Indication _____ Test(s) to be Performed _____

- Participation in genetic testing is completely voluntary. Genetic counseling is recommended prior to and following genetic testing. See www.nsgc.org or www.acmg.net to find a medical genetics professional.
- Providing accurate information about symptoms and family history enables correct test selection and interpretation. In cases where a family member has tested positive for a genetic change, a copy of that report may be required by the laboratory before testing can be started.
- Results from genetic testing may be positive, negative or inconclusive.
  - A positive result may confirm whether a person is affected with, a carrier of, or at risk for developing a genetic condition.
  - A negative result does not exclude the possibility of being affected with or a carrier of a genetic condition. Genetic conditions may have many causes, some of which may not be completely known or testable.
  - An inconclusive result may occur due to limitations of laboratory methods, limitations in knowledge of the meaning of identified variant(s), or poor sample quality. Inconclusive results from biochemical tests may occur due to an individual's clinical status (fasting, illness, etc.) at the time the sample was drawn.
- Identified genetic variants are interpreted using current information in the medical literature and scientific databases. Since this information can change, ARUP may issue a revised report if the meaning of the variant changes. Individuals with a variant of uncertain significance should contact their healthcare provider periodically to determine if new information is available.
- Genetic testing results may provide information that was not anticipated, such as:
  - Identifying a genetic risk unrelated to the original reason for testing.
  - Predicting another family member has, is at risk for, or is a carrier of a genetic condition.
  - Revealing non-paternity (the person stated to be the biological father is not, in fact, the biological father).
  - Suggesting the parents of the individual tested are blood relatives.
- Although genetic test results are usually accurate, several sources of error are possible, including: clinical misdiagnosis of a condition, inaccurate information provided regarding family relationships, sample mislabeling or contamination, transfusion, bone marrow transplantation, and maternal cell contamination of prenatal or cord blood samples.
- If a genetic variant is identified, insurance rates, the ability to obtain disability and life insurance, and employability could be affected. The Genetic Information Nondiscrimination Act of 2008 extends some protections against genetic discrimination (http://www.genome.gov/10002328). All test results are released to the ordering health care provider and those parties entitled to them by state and local laws.
- Because ARUP is not a storage facility, most samples are discarded after testing is completed. Some samples may be stored indefinitely for test validation or education purposes after personal identifiers are removed. All New York samples are discarded 60 days following test completion. You may request disposal of your sample by calling ARUP Laboratories at (800) 242-2787 ext. 3301.
- In cooperation with the National Institutes of Health's effort to improve understanding of specific genetic variants, ARUP submits HIPAA-compliant, de-identified (cannot be traced back to the patient) genetic test results and health information to public databases. The confidentiality of each sample is maintained. If you prefer that your test result not be shared, call ARUP at (800) 242-2787 ext. 3301. Your de-identified information will not be disclosed to public databases after your request is received, but a separate request is required for each genetic test. Additionally, patients have the opportunity to participate in patient registries and research. To learn more, visit ARUP's Genetics Resources website at www.aruplab.com/genetics/resources.

My signature below constitutes my acknowledgment that the benefits, risks, and limitations of this testing have been explained to my satisfaction by a qualified health professional and I have been provided the additional technical information (as applicable) describing the test(s) to be performed at www.aruplab.com.

Patient/Guardian Printed Name _____ Signature _____ Date _____

Physician/Genetic Counselor: I have explained this genetic test, its risks, benefits and alternatives to the patient or legal guardian and addressed all their questions.

Physician/Genetic Counselor Printed Name _____ Signature _____ Date _____