Mutation Analysis Program† Enrollment Form

The Johns Hopkins Genomics DNA Diagnostic Laboratory (JHGDDL)

†Funded by the Cystic Fibrosis Foundation

Shipping address:

Johns Hopkins Genomics - DDL
1812 Ashland Ave
Sample Intake, Room 245
Baltimore, MD 21205

Fax completed forms to 410-367-3266. For questions, call the JHGDDL at 833-818-2750.

All fields must be complete and legible. Provider and patient stamps or stickers are *not* valid. Information must be typed or handwritten.

***MAP Authorization #:** _____ **Date:** _____ *For JHGDDL Use Only*

Indicate whether this is the patient's first enrollment, or whether the patient is eligible for re-enrollment. Please visit the Program website for eligibility requirements.

☐ First-Time Enrollment ☐ Qualified Re-Enrollment, CFFMAP Genetic ID: _____

Referrer Information

Referring Physician: _____ NPI: _____

Nurse/Genetic Counselor/Social Worker: _____ Email: _____

CF Care Center Name: _____ CF Care Center ID #: _____

Address: _____

City: _____ State: _____ Zip: _____

Contact Phone: _____ Results to be faxed to: _____

Institutional/Reference Lab/Sendout Lab Fax # (if applicable): _____

Patient Information

**Two or more of these identifiers must appear on the sample*

*Patient Name: Last _____ First _____ Middle _____

*Date of Birth (mm/dd/yyyy): _____ Sex assigned at birth: _____ Gender identity: _____

Address: _____

City: _____ State: _____ Zip: _____

*Sample Accession # or Patient's Medical Record (MRN) #: _____

Clinical Information

Please attach a copy of the patient's most recent clinic note.

Lowest sweat chloride concentration(s): _____ (mmol/L)

Has the patient ever received DNA testing? ☐ No ☐ Yes Were variant(s) identified by previous DNA testing? ☐ No ☐ Yes

If yes, indicate which variant(s): _____

Has the patient had a **bone marrow transplant**? ☐ No ☐ Yes

Has the patient had a **transfusion**? ☐ No ☐ Yes, pRBC only ☐ Yes, other - Please provide details below or contact the lab

Type of transfusion: _____

Date of transfusion: _____

For Internal Use Only		
Accession #:	Date Received:	ID #:
Notes:		

Sample Collection Please select the type of sample to be submitted for testing.

☐ Venous blood	☐ Saliva	☐ Previously Submitted Specimen
To be completed by provider after approval.	*Not suitable for patients under 5 years of age.*	For patients qualified for re-enrollment, the lab will determine whether there is sufficient DNA remaining for processing.
Do not collect sample without prior approval.	Do not use non-CFFMAP collection kits.	**If a new sample is required, the lab will contact the provider.**
Date blood sample collected: _____	**A CFFMAP saliva kit will be sent to patient on approval.**	

Mutation Analysis Program Informed Consent

Provider Consent: Read and Sign

I certify that I am the referring provider for the patient identified above, and have assisted the patient in completing this form. I certify that the patient identified above has a confirmed or strongly suspected CF diagnosis. I also understand that the Mutation Analysis Program (MAP) is not intended to be used to diagnose patients with CF, but rather used to identify the patient's unknown genetic mutation(s). I certify that I have discussed the purpose of this genetic testing with the patient and explained to the patient that the testing may take up to six months to complete.

X _____

Signature of Provider (Required) **Signature Date (Required)**

Patient Consent: Read and Sign

I understand that my physician is requesting the Johns Hopkins Genomics DNA Diagnostic Laboratory (JHGDDL) to perform the Mutation Analysis Protocol on me/my dependent, and that my physician may provide a limited amount of health information with the request. The purpose and accuracy of this testing have been reviewed by my health care provider and my questions about these issues have been answered. I understand that in most cases, a negative test result does not necessarily rule out a hereditary condition. Results of DNA testing should be considered with the results of other types of testing and clinical evaluation. Test results may disclose non- paternity or other genetic conditions. No clinical tests other than those authorized will be performed; however, any remaining sample may be used for quality control purposes or research after de-identification. My physician will receive a clinical report, but the laboratory cannot guarantee turn-around time or that a result will be obtained on any sample. Release to other parties requires written consent of the patient.

I have read and agree to the Program Informed Consent section above.

_____

Patient Name (Printed) **Date of Birth (MM/DD/YYYY)**

X _____

Signature of Patient/Parent/Guardian (Required) **Signature Date (Required)**

_____

Parent/Guardian Name (Printed) Relationship to patient

I would describe my race/ethnicity as (please select all that apply):

- ☐ Black, African American, or of African descent
- ☐ East Asian
- ☐ Middle Eastern, Southwest Asian, North African
- ☐ Hispanic, Latino/Latina/Latinx
- ☐ Native American, Alaska Native, First Nations
- ☐ Native Hawaiian, Pacific Islander
- ☐ South Asian
- ☐ Southeast Asian
- ☐ White
- ☐ Other: _____
- ☐ Prefer not to respond