

**ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
FOLLOW-UP VISIT FORM - PART B**

Form Completion Instructions:

The units for reporting each laboratory measurement are indicated on the form. If the value is reported to the Clinical Center in units other than those listed the Clinical Center must convert the value to the correct units and record that value on the form DO NOT cross off the pre-printed unit of measure to write in another.

<u>QUESTION #</u>	<u>ITEM</u>	<u>INSTRUCTIONS</u>
6-10	Bloodwork	Record the results of each of the specified tests that were analyzed at your Clinical Center's laboratory. If, for instance, blood gases were not done, record "00/00/00" for the date and skip each of the items listed below it or indicate "NOT DONE" in large print over the entire section of tests not performed. If a series of tests were done, but the test tube breaks or becomes contaminated and results can be determined, enter a "9" in each of the dashes.
8	Serum Level	An Alpha 1-antitrypsin serum level may be obtained at each follow-up visit. If the patient is receiving augmentation therapy, the alpha 1-antitrypsin level should be obtained immediately prior to infusion of the therapy or within one day prior to infusion. Record results in micromolar units. To convert: $\text{mg/dl} \times .1923 = \text{lab value in } \mu\text{M}$. See Section 4.11.
11-12	Chest X-Ray	Results from a chest x-ray within the past six months <u>can</u> be recorded at the time of each follow-up visit to the Clinical Center. CT scan results can be recorded in the comment section.
13	Urinalysis	Routine lab report results should be entered here. Enter 9's if unknown.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
Follow-Up Visit Form - Part B

This form should be completed for every follow-up visit. Except for medical history, a non-physician should complete this form.

1. Date form completed:..... F5BQ01 fzd (fuzzed) ___/___/___
month day year
2. Patient Registry ID:..... Newid (scrambled)
3. Patient name code:..... namecode (censored)
4. Clinical Center code number:..... clinic (censored)
5. Date of visit:..... F5BQ05 fzd (fuzzed) ___/___/___
month day year
Visit number vsno

LABORATORY RESULTS

Complete Blood Count

6. a. Date Blood Drawn:..... F5BQ06A fzd (fuzzed) ___/___/___
month day year
- b. Location of test:..... F5BQ06B (1)Registry Clinical Center (code: ^{F5BQ06B2} censored)
____(2)Local Physician's office
____(3)Other (Specify): never entered
____(9)Unknown
- c. White Blood Count ($\times 10^3$ mm³):..... F5BQ06C
- d. Hemoglobin (g/dl):..... F5BQ06D
- e. Hematocrit (%):..... F5BQ06E

Serum Chemistries/Enzymes

7. a. Date blood drawn:..... F5BQ07A fzd (fuzzed) ___/___/___
month day year
- b. Location of test:..... F5BQ07B (1)Registry Clinical Center (code: ^{F5BQ07B2} censored)
____(2)Local Physician's office
____(3)Other (Specify): never entered
____(9)Unknown
- c. Creatinine (mg/dl):..... F5BQ07C
- d. Blood Urea Nitrogen (mg/dl):..... F5BQ07D
- e. SGPT (IU/L):..... F5BQ07E

White/Yellow: Clinical Coordinating Center, Pink: Clinical Center

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Patient Registry ID: _____
Date of Visit: ____/____/____
month day year

Serum Chemistries/Enzymes, continued:

- f. SGOT (AST) (IU/L): F5BQ07F
- g. Alkaline Phosphatase (IU/L): F5BQ07G
- h. Total Bilirubin (mg/dl): F5BQ07H
- i. Serum Bicarbonate (measured) (mEq/L) HCO₃: F5BQ07I

Alpha 1-Antitrypsin Serum Level

- 8. a. Date Blood Drawn: F5BQ08A-fzd (fuzzed) ____/____/____
month day year
- b. Location of test: F5BQ08B (1)Registry Clinical Center (code: F5BQ08B2 ~~censored~~)
____(2)Local Physician's office
____(3)Other (Specify): never entered
____(9)Unknown
- c. Alpha 1-antitrypsin serum level (micromolar): F5BQ08C
- c. 1. Is this an adjusted value? (See Forms Instructions) F5BQ08C1 (1)Yes ____ (2)No
- d. If female, is patient pregnant? F5BQ08D (1)Yes ____ (2)No
- e. If YES, how many months pregnant? F5BQ08E

Arterial Blood Gases

- 9. a. Date Blood Drawn: F5BQ09A-fzd (fuzzed) ____/____/____
month day year
 - b. Location of test: F5BQ09B (1)Registry Clinical Center (code: F5BQ09B2 ~~censored~~)
____(2)Local Physician's office
____(3)Other (Specify): never entered
____(9)Unknown
 - 1. ABGs taken in relationship to PFT bronchodilator: F5BQ09B1 (1)Pre-BD ____ (2)Post-BD
 - c. Position: F5BQ09C (1)Sitting ____ (2)Recumbent ____ (3)Semi-recumbent
 - d. Is patient on supplemental oxygen? F5BQ09D (1)Yes ____ (2)No
- If YES, complete Questions 9e - f. If NO, skip to Question 9g.
- e. Duration of time off oxygen before sample taken: F5BQ09E1 F5BQ09E2
hour min
 - f. Usual Liter Flow (L/minute): F5BQ09F

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