ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
INITIAL 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.

QUESTION #	ITEM	INSTRUCTIONS
6-9	Bloodwork	Record the results of each of the specified tests that were done with the ± 3 month time window. If, for instance, blood gases are not done or not available, record "00/00/00" for the date and skip each of the items listed below it or write in "NOT DONE" over the entire section. If a series of tests are done, but the test tube breaks or becomes contaminated and results cannot be determined, enter a "9" in each of the dashes. Identify whether the arterial blood gases were drawn pre- or post-bronchodilator.
10-11	Chest X-Ray	Results from a chest x-ray within the past year should be recorded at the time of the initial visit to the Clinical Center. Results of CT scans can be written in the comment section following the x-ray questions.
12	Urinalysis	Routine lab report results should be entered here. Enter 9's if unknown. Be as complete as possible.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
Initial Visit Form - Part B

This form should be completed at the patient's first Registry visit. Non-physician personnel can complete this form.

1. Date form completed: F2BQØ1-f2d (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: F2BQØ5-f2d (fuzzed) ___ ___/ ___ ___/ ___ ___ (month day year)
   visit number vsno

LABORATORY RESULTS

It is preferred that laboratory tests be done at the Clinical Centers, however, data from outside laboratories will be accepted.

Complete Blood Count

6. a. Date Blood Drawn: F2BQØ6A f2d (fuzzed) ___ ___/ ___ ___/ ___ ___ (month day year)

   b. Location of test: F2BQØ6B ___(1)Registry Clinical Center (code: F2BQØ6B2 censored)
   ___(2)Local Physician's office
   ___(3)Other (Specify): never entered
   ___(9)Unknown

   c. White Blood Count (x10^3 mm^3): F2BQØ6C ___ ___ ___.___

   d. Hemoglobin (g/dl): F2BQØ6D ___ ___.___

   e. Hematocrit (%): F2BQØ6E ___ ___.___

Serum Chemistries/Enzymes

7. a. Date Blood Drawn: F2BQØ7A-f2d (fuzzed) ___ ___/ ___ ___/ ___ ___ (month day year)

   b. Location of test: F2BQØ7B ___(1)Registry Clinical Center (code: F2BQØ7B2 censored)
   ___(2)Local Physician's office
   ___(3)Other (Specify): never entered
   ___(9)Unknown

   c. Creatinine (mg/dl): F2BQØ7C ___ ___.___

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Patient Registry ID: ___ ___ ___ ___ ___
Date of Visit: ___ ___/ ___ ___/ ___ ___
month day year

Serum Chemistries/Enzymes, continued:

d. Blood Urea Nitrogen (mg/dl): F2BQØ7D ___ ___ ___

e. SGPT (IU/L): F2BQØ7E ___ ___ ___ ___

f. SGOT (AST) (IU/L): F2BQØ7F ___ ___ ___ ___

g. Alkaline Phosphatase (IU/L): F2BQØ7G ___ ___ ___ ___

h. Total Bilirubin (mg/dl): F2BQØ7H ___ ___.___

i. Serum Bicarbonate (measured) (mEq/L) HCO_3: F2BQØ7I ___ ___.___

Arterial Blood Gases

8. a. Date Blood Drawn: F2BQØ8A-f2d (fuzzed) ___/ ___ ___/ ___ ___
month day year

b. Location of test: F2BQØ8B ___(1)Registry Clinical Center (code: F2BQØ8B2 censored)
___(2)Local Physician's office
___(3)Other (Specify): _____
___(9)Unknown

1. ABGs taken in relationship to PFT bronchodilator: F2BQØ8B1 ___(1)Pre-BD ___(2)Post-BD

c. Patient position: F2BQØ8C ___(1)Sitting ___(2)Recumbent ___(3)Semi-recumbent

d. Is patient on supplemental oxygen? F2BQØ8D ___(1)Yes ___(2)No

If YES, complete Questions e-f. If NO, skip to Question g.

e. Duration of time off oxygen before sample taken: F2BQØ8E1 ___ : F2BQØ8E2 ___
hour min

f. Usual Liter Flow (L/minute): F2BQØ8F ___ ___ ___

g. PaO_2 (mmHg): F2BQØ8G ___ ___ ___

h. $PaCO_2$ (mmHg): F2BQØ8H ___ ___.___

i. pH: F2BQØ8I ___.___ ___

j. Carboxyhemoglobin (%): F2BQØ8J ___ ___.___

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Patient Registry ID: ___ ___ ___ ___ ___
Date of Visit: ___ ___/ ___ ___/ ___ ___
month day year

Hemoglobin Oxygen Saturation (SaO_2)

9. a. Date of SaO_2 measurement.....F2BQ09A-fzd (fuzzed) ___ ___/ ___ ___/ ___ ___
month day year

b. Location of SaO_2 test:...F2BQ09B..... ___(1)Registry Clinical Center (code: F2BQ09B2 censored)
___(2)Local Physician's office
___(3)Other (Specify): never entered
___(9)Unknown

c. How was SaO_2 measured:....F2BQ09C..... ___(1)by blood gas analysis
___(2)by pulse oximeter
___(3)calculated

d. SaO_2 (%).....F2BQ09D..... ___ ___ ___ . ___

CHEST X-RAY

10. a. Date of chest x-ray: ....F2BQ10A-fzd (fuzzed) ___ ___/ ___ ___/ ___ ___
month day year

b. Location of test:.....F2BQ10B..... ___(1)Registry Clinical Center (code: F2BQ10B2 censored)
___(2)Local Physician's office
___(3)Other (Specify): never entered
___(9)Unknown

11. a. Results of chest x-ray:.....F2BQ11A..... ___(0)Normal ___(1)Abnormal

If Abnormal,

b. Evidence of Hyperinflation: .....F2BQ11B..... ___(1)Yes ___(2)No

c. Bullae: .....F2BQ11C..... ___(1)Yes ___(2)No

d. Cancer:.....F2BQ11D..... ___(1)Yes ___(2)No

e. Interstitial Lung Disease: .....F2BQ11E..... ___(1)Yes ___(2)No

f. Cardiomegaly: .....F2BQ11F..... ___(1)Yes ___(2)No

g. Pneumothorax: .....F2BQ11G..... ___(1)Yes ___(2)No

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Patient Registry ID: ___ ___ ___ ___ ___
Date of Visit: ___ ___/ ___ ___/ ___ ___
month day year

Chest X-Ray, continued:

h. Other Abnomal Findings (Specify in comments section): F2BQ11H (1)Yes ___(2)No

i. Evidence of hyperlucency: F2BQ11I ___(1)Yes ___(2)No

If YES,
1. Location of hyperlucency: F2BQ11I1
___(1) Diffuse (Upper and lower lung zones only)
___(2) Lower lung zones only (one or both sides)
___(3) Upper lung zones only (one or both sides)

Comments regarding chest x-ray: never entered

j. Other radiological evidence of emphysema (1) yes (2) No F2BQ11J

Urinalysis

12. a. Date of urinalysis: F2BQ12A-F2d (fuzzed) ___ ___/ ___ ___/ ___ ___
month day year

b. Location of test: F2BQ12B ___(1)Registry Clinical Center (code: censored) F2BQ12B2
___(2)Local Physician's office
___(3)Other (Specify): never entered
___(9)Unknown

c. Glucose: F2BQ12C ___(0)Neg/Normal ___(3)3+(1000mg/dl)
___(5)Trace (100mg/dl) ___(4)4+(>2000mg/dl)
___(1)1+(250mg/dl) ___(9)Unknown
___(2)2+(500mg/dl)

d. Bilirubin: F2BQ12D ___(0)Neg/Normal ___(3)3+(large)
___(1)1+(small) ___(9)Unknown
___(2)2+(moderate)

e. Ketones: F2BQ12E ___(0)Neg/Normal ___(3)80
___(5)Trace (5) ___(4)>160
___(1)Small (15) ___(9)Unknown
___(2)Moderate (40)

f. Specific gravity: F2BQ12F ___ . ___ ___ ___

g. Blood, occult: 12BQ12G ___(1)Yes ___(2)No ___(9)Unknown

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Patient Registry ID: ___ ___ ___ ___ ___
Date of Visit: ___ ___/ ___ ___/ ___ ___
month day year

Urinalysis, continued:

h. pH: F2BQ12H ___.___

i. Protein: F2BQ12I ___(0)Neg/Normal ___(3)3+(300mg/dl)) ___(5)Trace ___(4)4+(>2000mg/dl) ___(1)1+(30mg/dl) ___(9)Unknown ___(2)2+(100mg/dl)

j. Casts: F2BQ12J ___ ___ ___/LPF
If casts = "000," skip to end of form.

If casts >0, identify type of casts:

1. RBC: F2BQ12J1 ___(1)Yes ___(2)No ___(9)Unknown
2. WBC: F2BQ12J2 ___(1)Yes ___(2)No ___(9)Unknown
3. Hyaline: F2BQ12J3 ___(1)Yes ___(2)No ___(9)Unknown
4. Granular: F2BQ12J4 ___(1)Yes ___(2)No ___(9)Unknown
5. Other: F2BQ12J5 ___(1)Yes ___(2)No ___(9)Unknown

Specify: never entered

For WBC, RBC, Epithelial Cells, and Bacteria use the following scale:

0=0-5/HPF, negative, trace, rare, occasional, few
1=6-20/HPF, 1+, 2+, some, moderate
2=>20/HPF, 3+, 4+, great, many, too numerous to count
9=Unknown

k. WBC: F2BQ12K ___

l. RBC: F2BQ12L ___

m. Epithelial Cells: F2BQ12M ___

n. Bacteria: F2BQ12N ___

Form Completed By (Name): never entered

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Notes on Coding:

Additional variables coded by the CCC:

Question 11j. Other radiological evidence of emphysema:. . . . . ___(1)Yes ___(2)No

Coded by CCC personnel based on comments provided in question 11.

Variable name: F2BQ11J