ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
PARTICIPANT SURVEY FORM

Form Completion Instructions:

This form was created after the end of the enrollment period, during the follow-up period. It was designed to collect additional socioeconomic information on each Registry subject.

Questions 4-7 (employment status, occupation, income, health coverage) refer to the patient's employment status, etc. at baseline, i.e., at the time they enrolled in the Registry.

For patients who never have received augmentation therapy, the form also collects more detailed information on the reason why the patient did not receive augmentation therapy.

NO PUBLIC DATASET

Alpha 1-Antitrypsin Deficiency Registry
PARTICIPANT SURVEY FORM

The information in this form is needed to complete the Registry data base and will remain confidential without release to anyone or any organization. DATA SET CENSORED

1. Patient Registry ID ....ID.... ____
2. Patient Name Code ..namecode.... ____
3. Clinical Center code number ..clinic.... ____
Date form received...f21date

Part I. The following questions refer to you **at your first visit** for the Registry:

JOB

4. **At your first visit,** what was your employment status? .F21Q04.... ____

1 = Employed Full-Time
2 = Employed Part-Time
3 = Unemployed (Medical Reasons)
4 = Unemployed (Other Reasons)
5 = Retired (Medical)
6 = Retired (Age)
7 = Full-Time Homemaker
8 = Unknown
9 = Other (Specify) F21Q04OT

5. **At your first visit,** what had been your usual occupation or job -- the one you had worked at the longest?
F21Q05 (see next page with occupation codes) ___ sas use only

INCOME

6. **At your first visit,** what was your gross annual household income? .F21Q06.... ____

1 = less than $7,500
2 = $7,500 - 14,999
3 = $15,000 - 24,999
4 = $25,000 - 39,999
5 = $40,000 - 49,999
6 = $50,000 - 74,999
7 = greater than $75,000
9 = unknown

HEALTH COVERAGE

7. **At your first visit,** who was covering your health expenses? .F21Q07.... ____

1 = Insurance by Employer (through your job or your spouse)
2 = Insurance by Medicaid
3 = Self-insured
4 = Medicare (no supplemental)
5 = Medicare (with supplemental)
6 = No coverage

Part II. The following refers to **Prolastin Augmentation Therapy**

8. Have you ever received Prolastin Augmentation Therapy since entry into the Registry? F21Q08 1 = yes, 2 = no ____

8A. If No, why? ....F21Q08A.... ____

Medical reason:
1 = Not recommended by physician, because lung function is normal or only slightly below normal
2 = Not recommended by physician, because lung function is too far below normal
3 = Not recommended by physician because you smoke
4 = You received lung transplant
5 = Medical reasons other than transplant

Financial reason:
6 = No insurance
7 = Insurance does not cover cost

None of the above: 8 = Other F21Q08OT

9. Who completed this form? F21Q09 ___ Participant (1) ___Study Coordinator (2) ___ Participant's Doctor (3)
___Spouse/Others (4) ___ Others (5) (relationship) F21Q09OT

10. Type of communication: F21Q10 In person___ (1) By Phone___(2) By letter/Fax___(3) F21Q10OT Other___(4)

Signature of Clinical Center Personnel never entered
(PI or Study Coordinator)

Notes on Coding:

Question 5. Occupation, coded at the CCC.

Codes used:

1	Professional, technical, and kindred workers
2	Managers and administrators, except farm
3	Sales workers
4	Clerical and kindred workers
5	Craftsmen and kindred workers
6	Operatives, except transport
7	Transport equipment operatives
8	Laborers, except farm
9	Farmers and farm managers
10	Farm laborers and farm foremen
11	Service workers, except private household
12	Private household workers
13	Unknown - Not in work force
14	Unknown - retired