ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
TELEPHONE CONTACT FOLLOW-UP FORM

Form Completion Instructions:

QUESTION #	ITEM	INSTRUCTIONS
9.	Comments	Several lines are provided to allow the person completing this form an opportunity to record important information that may assist them in further communications with the patient. More detailed information regarding augmentation therapy (i.e., dosage, frequency of administration, etc.) may be recorded in this section.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
Telephone Contact Follow-up Form

This form should be completed on each patient for whom a Clinical Center visit has not been held within the past six months.

1. Date form completed: F8AQ01_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 target follow-up visit: F8AQ05_Fzd (fuzzed) __ __ / __ __ / __ __ (month / day / year)
6. a. Person contacted: F8AQ06A __(1)Patient __(3)Patient's M.D. __(4)Relative __(2)Other: F8AQ06SI (specify) __(5)Spouse
   b. Date of patient status: F8AQ06B_Fzd (fuzzed) __ __ / __ __ / __ __ (month / day / year)
   c. Status of patient: F8AQ06C __(1)Alive __(9)Unknown __(2)Dead (Complete Form #06A, #06B, and #06C)
7. a. Has augmentation therapy status changed since last visit? F8AQ07A __(1)Yes __(2)No __(9)Unknown
   b. Did patient start augmentation therapy? F8AQ07B __(1)Yes __(2)No
   c. Date augmentation therapy started: F8AQ07C_Fzd (fuzzed) __ __ / __ __ / __ __ (month / day / year)

This data never entered on Form 8A SEE FORM 11

1. Has pt experienced any problems related to the augmentation therapy since last visit? Never entered (See Form 11) __(1)Yes __(2)No

   If YES, complete Form #11 - Adverse Reaction Form.

2. When did the reaction(s) occur? NEVER ENTERED
   - __(1)During the infusion
   - __(2)Immediately after the infusion but within 24 hours
   - __(3)Greater than 24 hours after the infusion
   - __(4)Other (Specify) _____
   - __(9)Unknown

   NEVER ENTERED

3. With what frequency did the reaction(s) occur?
   - __(1)Single episode
   - __(2)"Two or three" times
   - __(3)Greater than three times
   - __(4)"After every infusion"
   - __(5)Other (Specify) _____
   - __(9)Unknown

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

Registry ID # ___ ___ ___ ___ ___
Date Form Completed: ___ ___/ ___ ___/ ___ ___
month day year

See Form II

4. Was hospitalization or emergency room treatment required?: NEVERENTERED ___(1)Yes ___(2)No

5. Did the reaction require medication and/or contact with local physician?: ___(1)Yes ___(2)No

d. Did patient discontinue therapy permanently? ___(1)Yes ___(2)No

1. If YES, for what reason(s) did patient permanently discontinued therapy: F8AQ07D

___(1)Financial
___(2)Adverse Reaction
___(3)Medical
___(4)Other (Specify) never entered
___(9)Unknown/Unspecified

e. If therapy discontinued, date of last therapy received: ~~F8AQ07E-F2d~~ (fuzzed) ___ ___/ ___ ___/ ___ ___
month day year

8. Reason for not coming to the Clinical Center: F8AQ08

___(1)Too sick due to COPD to travel.
___(2)Too sick - other condition (Specify: F8AQ08S1 (CENSORED)).
___(3)No semi-annual visit was planned / Phone Contact
___(4)Other reason (Specify: F8AQ0852 - (CENSORED)).
___(9)Unknown

9. Comments: F8AQ09 - (CENSORED)

Form Completed By (Name): never entered

Physician Signature: never entered

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