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: New ID (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: F8AQ06S1 (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)

   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
      NEVER ENTERED
      ___(4)Other (Specify) _____
      ___(9)Unknown

   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

This data never entered on Form 8A
SEE FORM 11

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 ___(4)Other (Specify) never entered

___(2)Adverse Reaction ___

___(3)Medical ___(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: F8AQ08S2 - (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