ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
FINAL DEATH NOTIFICATION FORM

Form Completion Instructions:

This form should be completed within 60 days after a patient expires.

Be as thorough as possible in completing all questions.

If attempts were made to get particular reports, indicate what was done so the Committee can start where you left off.

In item #15, indicate your impression of the primary cause of death from the information you have at this time.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
Final Death Notification Form

This form should be completed within 60 days after a patient dies.

1. Date form completed: F6BQ01_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 death: F6BQ05_fzd (fuzzed) ___/___/___ (month day year)
6. Has a copy of the Death Certificate been obtained and enclosed with this form? F6BQ06a ___(1)Yes ___(2)No

   If NO, explain: F6BQ06B1 (censored)

7. Was an autopsy performed? F6BQ07 ___(1)Yes ___(2)No ___(9)Unknown
8. If YES, which of the following reports have been enclosed with this form?
   a. Preliminary Autopsy Report: F6BQ08A ___(1)Yes ___(2)No
   b. Final Autopsy Report: F6BQ08B ___(1)Yes ___(2)No

   If an autopsy was performed, and copy of the reports are not enclosed, explain why: F6BQ08C1 (censored)

9. Was the patient hospitalized at the time of death, or within 3 months prior to death? F6BQ09 ___(1)Yes ___(2)No ___(9)Unknown

   If YES, Complete the following:

   Hospitalized at time of death: F6BQ10thru F6BQ14 (dropped)

10. a. Date of hospital admission: Not Research related ___/___/___ (month day year)

    b. Name of hospital: _____

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PWO 1869

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Patient Registry ID: ___ ___ ___ ___ ___

c. Location of hospital (street): dropped, Not research related

(city): _____

(state): _____

d. Has a copy of the Hospital Discharge Summary been obtained and enclosed with this form? ..... ___(1)Yes ___(2)No

If summary is not enclosed, explain why: _____

e. Has a copy of the complete medical records of this hospitalization been obtained and enclosed with this form? ..... ___(1)Yes ___(2)No

If not enclosed, explain why: _____

Hospitalized within 3 months prior to death (record most recent hospitalization first):

11. a. Date of hospital admission: ..... ___ ___/ ___ ___/ ___ ___ (month / day / year)

b. Date of hospital discharge: ..... ___ ___/ ___ ___/ ___ ___ (month / day / year)

c. Name of hospital: _____

d. Location of hospital (street): _____

(city): _____

(state): _____

e. Has a copy of the Hospital Discharge Summary been obtained and enclosed with this form? ..... ___(1)Yes ___(2)No

If summary is not enclosed, explain why: _____

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PWO 1869

Patient Registry ID: ___ ___ ___ ___ ___

f. Has a copy of the complete medical records of this hospitalization been obtained and enclosed with this form? ____(1)Yes ____(2)No

If not enclosed, explain why: dropped, Not research related

12. a. Date of hospital admission: ___ ___/ ___ ___/ ___ ___ (month day year)

b. Date of hospital discharge: ___ ___/ ___ ___/ ___ ___ (month day year)

c. Name of hospital: _____

d. Location of hospital (street): _____

(city): _____

(state): _____

e. Has a copy of the Hospital Discharge Summary been obtained and enclosed with this form? ____(1)Yes ____(2)No

If summary is not enclosed, explain why: _____

13. a. Date of hospital admission: ___ ___/ ___ ___/ ___ ___ (month day year)

b. Date of hospital discharge: ___ ___/ ___ ___/ ___ ___ (month day year)

c. Name of hospital: _____

d. Location of hospital (street): _____

(city): _____

(state): _____

e. Has a copy of the Hospital Discharge Summary been obtained and enclosed with this form? ____(1)Yes ____(2)No

If summary is not enclosed, explain why: _____

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PWO 1869

Patient Registry ID: ___ ___ ___ ___ ___

In order to help determine the cause(s) of death, a member of the Death Review Committee may desire to interview the patient's physician(s). In order to facilitate this process, please list those physicians who have a knowledge of the patient's illness or death.

14. a. Physician Name: dropped. Not research related

Address: _____

_____

_____

Phone: _____

b. Physician Name: _____

Address: _____

_____

_____

Phone: _____

c. Physician Name: _____

Address: _____

_____

_____

Phone: _____

d. Physician who performed autopsy: _____

Address: _____

_____

_____

Phone: _____

15. Although the Death Review Committee will independently determine the cause(s) of death utilizing all available information, we are interested in your impression of the cause(s) of death:

a. Cardiac (specify): F6BQ15A1 — F6BQ15A ___(1)Yes ___(2)No ___(9)Unknown

b. Pulmonary (specify): F6BQ15B1 — F6BQ15B ___(1)Yes ___(2)No ___(9)Unknown

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PWO 1869

Patient Registry ID: ___ ___ ___ ___ ___

c. Infection (specify): F6BQ15C1 — F6BQ15C ___(1)Yes ___(2)No ___(9)Unknown

d. Renal (specify): F6BQ15D1 — F6BQ15D ___(1)Yes ___(2)No ___(9)Unknown

e. Trauma/Accident (specify): F6BQ15E1 — F6BQ15E ___(1)Yes ___(2)No ___(9)Unknown

f. Other (specify): F6BQ15F1 — F6BQ15F ___(1)Yes ___(2)No ___(9)Unknown

Comments: CENSORED

Form Completed By (Name): Never entered into database

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PWO 1869