ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
INITIAL VISIT FORM - PART A

Form Completion Instructions:

This form should be completed at the patient's initial visit by non-physician personnel. A physician, however, should review the medical history and medications sections of the form.

QUESTION #	ITEM	INSTRUCTIONS
9-22	Symptom History	These questions should be asked of the patient. Be careful to skip questions as indicated. If the patient is in doubt, check the "No" response.

The following are specific details on completing these questions. Use the exact wording of each question. If the respondent expresses doubt as to the meaning of the question, repeat it exactly. Emphasizing individual words or phrases often makes the meaning clear. Further explanation may be needed, but do not cross-examine the respondent. When after brief explanation doubt remains as to whether the answer should be "Yes" or "No", the answer should be recorded as "No".

9 **COUGH**
If respondent answers "No" to 9a, skip 9b, but 9c and 9d must be asked of all respondents. Do not ask questions 9e and 9f, unless there is a positive response to one of the previous questions. For question 9f, record actual number of years. (Use 9 or 99 where appropriate if answer to question is unknown.)

10 **PHLEGM**
If respondent answers "No" to 10a, skip 10b, but ask 10c, and 10d of all respondents. Emphasis should be placed upon phlegm as coming up from the chest and post-nasal discharge is discounted. This may be determined by "Do you raise it up from your lungs, or do you merely clear it from your throat?" Some subjects admit to bringing up phlegm without admitting to cough. This claim should be accepted without changing the replies to "cough". Phlegm coughed up from the chest but swallowed counts as positive. Include, if volunteered, phlegm with first smoke or "on first going out-of-doors".

Do not ask questions 10e and 10f unless there is a positive response to one of the previous questions. For question 10f, record actual number of years.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
INITIAL VISIT FORM - PART A

Form Completion Instructions:

DEFINITIONS

Three (3) months ("e" under cough and phlegm) means 3 consecutive months. "On getting up" ("c" under cough and phlegm) may be at night for night workers.

11 EPISODES OF COUGH AND PHLEGM

This question is to identify persons with exacerbations of their symptoms. They may or may not have lost time from work or been confined to their homes. For question 11b, record actual number of years.

12 WHEEZING

This question is intended to identify subjects who have occasional and/or frequent wheezing. Those questions pertaining to asthma are asked in question 13, but these questions may check that diagnosis. Subjects may confuse wheezing with snoring or bubbling sounds in the chest; a demonstration "wheeze" will help if further clarification is requested. Can ask, "Does your husband (or wife) regularly complain of your wheezing (not snoring) at night?" Ask 2 parts of question a of everyone; do not ask 12a3 or 12b if answers to 12a1 and 12a2 are "No".

14-15 BREATHLESSNESS

This question refers only to shortness of breath, not to any other debilitating conditions. If a subject volunteers that he is disabled from walking by any condition other than heart or lung disease, or obviously is confined to a wheelchair or uses crutches continuously, then the sequence of questions (15a-e) is not to be asked. If asked, the questions refer to that average condition during the preceding winters. No attempt is to be made to separate out cardiac breathlessness. If question 15a is "No", skip remaining questions b-e. Ask through e if any a-d are positive.

16 CHEST COLDS

This refers only to colds in the head being followed by or occurring simultaneously with (increased) cough and sputum. Disregard "occasionally" and regard "usually" as more than half of the colds. This question may be modified on inquiry by the respondent: "That is, do colds usually settle in your chest before they leave you?" Force the respondent to decide whether more than half go to his chest. If he is in doubt, the answer should be coded "No".

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
INITIAL VISIT FORM - PART A

Form Completion Instructions:

17 **CHEST ILLNESSES**

A chest illness is defined as one with cough or phlegm (or increased cough or phlegm in the case of those respondents who regularly have cough or phlegm). Do not ask b or c if answer to a is "No". The 3-year time period (in question c) refers to any illness within 3 years prior to the day of interview. Record 7 for 7 or more illnesses, 8 for not applicable, and 9 for answer unknown.

19. **TOBACCO SMOKING**

19a. A cigarette smoker is defined as a person who has smoked at least 20 packs of cigarettes or at least 1 cigarette per day for at least 1 year (or cigarettes rolled from 12 oz of tobacco) in a lifetime. For subject who has not smoked that many cigarettes, skip to question 20a.

19b. A current cigarette smoker is a person who was a regular cigarette smoker up to a month ago.

19d. Is asked only if the respondent answered "no" to 19b, "Do you now smoke cigarettes?"

19e. Some persons may respond that they buy cigarettes by the carton. Must know the number of packages per carton (usually 10 packages) and the number of cigarettes per package (usually 20 cigarettes per package in the United States). The interviewer can then convert the answer to this question and question 19f to cigarettes per day.

Note: Questions 9-19 are taken from the ATS-DLD questionnaire. Ferris BG. Epidemiological Standardization Project. Am Rev Respir Dis, 118(Suppl 1-120), 1978.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
INITIAL VISIT FORM - PART A

Form Completion Instructions:

QUESTION #	ITEM	INSTRUCTIONS
23-33	Medical History	For each general system, the questions in bold print should be asked first. If the answer is "No", the list of specific diseases should be skipped. If, however, the answer to the general question is "Yes", ask the patient to tell you what problems they have had. Each of the individual diseases listed need not be asked except to help the patient, to prod their memory. Put a check in the space next to each of the diagnoses mentioned. If they indicate ever having the problem, then ask whether they have been hospitalized for it in the last year. If a hospital chart is available and can be reviewed prior to asking these questions, it should help you in interviewing the patient.
34	Medications	It may help to remind the patient to bring in their pills in order to complete this section of the form most accurately. This section refers to Prescription drugs only. Yes or No should be checked for each item.
34q	Supplemental Oxygen	These questions have been added and are mandatory.
35	Augmentation Therapy	If patient has never been on augmentation therapy, indicate "No" and skip to the very end of the form. If the patient has EVER been on therapy indicate "Yes" and continue. Is the patient currently on augmentation therapy regimen.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
INITIAL VISIT FORM - PART A

Form Completion Instructions:

QUESTION #	ITEM	INSTRUCTIONS
36	Discontinued	Answer "Yes" only if therapy has been permanently discontinued with no intention presently of receiving therapy in the future.
37a	Date Current Therapy	This is the date of the initial therapy regimen given. enter only **the actual date** of therapy. Do not enter the anticipated start date of therapy.
37b	Most Recent	This is the date of the most recent session.

REGISTRY OF PATIENTS WITH DEFICIENCY OF ALPHA 1-ANTITRYPSIN

MEDICATIONS LIST

BY

REGISTRY CATEGORY / TRADE NAME / GENERIC NAME

REGISTRY OF PATIENTS WITH DEFICIENCY OF ALPHA 1-ANTITRYPSIN

MEDICATION LIST

REGISTRY CATEGORY	TRADE NAME	GENERIC NAME
INHALED BRONCHODILATORS (BDS)/SYMPATHOMIMETICS:	ALBUTEROL	SALBUTAMOL ALBUTEROL
	ALUPENT	METAPROTERENOL
	BRETHAIRE	TERBUTALINE
	BRONKAID	EPINEPHRINE
	BRONKOMETER	ISOETHARINE
	BRONKOSOL	ISOETHARINE
	ISUPREL	ISOPROTERENOL
	MAXAIR	PIRBUTEROL
	MEDIHALER-EPI	EPINEPHRINE
	MEDIHALER-ISO	ISOPROTERENOL
	METAPREL	METAPROTERENOL
	NORISODRINE	ISOPROTERENOL
	PRIMATENE	EPINEPHRINE
	PROVENTIL	SALBUTAMOL ALBUTEROL
	ROTACAPS	ALBUTEROL
	TORNALATE	BITOLTEROL
	VENTOLIN	SALBUTAMOL ALBUTEROL
INHALED BRONCHODILATORS (BDS)/ANTICHOLINERGICS:	.	ATROPINE SULFATE
	.	ATROPINE METHONITRATE
	ATROVENT	IPRATROPIUM BROMIDE
	ROBINUL	GLYCOPYRRPOLATE
ORAL BRONCHODILATORS:	.	SYMPATHOMIMETICS
	ALUPENT	METAPROTERENOL
	BRETHINE	TERBUTALINE
	BRICANYL	TERBUTALINE
	METAPREL	METAPROTERENOL
	PRIMATENE	EPINEPHRINE
	PROVENTIL	SALBUTAMOL ALBUTEROL
	VENTOLINE	SALBUTAMOL ALBUTEROL
THEOPHYLLINE /XANTHINE DRUGS:	.	AMINOPHYLLINE
	AEROLATE	THEOPHYLLINE
	ASBRON	THEOPHYLLINE
	CHOLEDYL	OXTRIPHYLLINE

REGISTRY OF PATIENTS WITH DEFICIENCY OF ALPHA 1-ANTITRYPSIN

MEDICATION LIST

REGISTRY CATEGORY	TRADE NAME	GENERIC NAME
THEOPHYLLINE /XANTHINE DRUGS:	CONSTANT-T	THEOPHYLLINE
	DILOR	DYPHYLLINE
	ELIXOPHYLLIN	THEOPHYLLINE
	LUFYLLIN	DYPHYLLINE
	MARAX	THEOPHYLLINE
	QUADRINAL	THEOPHYLLINE
	QUIBRON	THEOPHYLLINE
	RESPBID	THEOPHYLLINE
	SLO-BID	THEOPHYLLINE
	SLO-PHYLLINE	THEOPHYLLINE
	SOMOPHYLLINE	THEOPHYLLINE
	TEDRAL	THEOPHYLLINE
	THEO-24	THEOPHYLLINE
	THEO-DUR	THEOPHYLLINE
	THEOBID	THEOPHYLLINE
	THEOCHRON	THEOPHYLLINE
	THEOLAIR	THEOPHYLLINE
	THEOVENT	THEOPHYLLINE
	UNIPHYL	THEOPHYLLINE
CROMOLYN:	INTAL	CROMOLYN SODIUM
SYSTEMIC CORTICOSTERIODS:	.	PREDNISONE
	ARISTOCORT	TRIAMCINOLONE
	CELESTONE	BETHAMETHASONE
	CORTONE	CORTISONE
	DECADRON	DEXAMETHASON
	HYDROCORTONE	HYDROCORTISONE
	MEDROL	METHYLPREDNISOLONE
	PEDIAPRED	PREDNISOLONE
INHALED CORTICOSTERIODS:	AEROBID	FLUNISOLIDE
	AZMACORT	TRIAMCINOLONE
	BECLOVENT	BETAMETHASONE
	DECADRON RESPIHALER	DECADRON
	DECASPRAY	DECADRON
	VANCERIL	BETHAMETHASONE

REGISTRY OF PATIENTS WITH DEFICIENCY OF ALPHA 1-ANTITRYPSIN

MEDICATION LIST

REGISTRY CATEGORY	TRADE NAME	GENERIC NAME
OTHER BRONCHODILATORS:		
BETA-BLOCKERS:	BLOCADREN	TIMOLOL MALEATE
	CORGARD	NADOLOL
	INDERAL	PROPRANOLOL HYDROCHLORIDE
	LOPRESSOR	METOPROLOL TARTRATE
	NORMODYNE	LABETALOL HYDROCHLORIDE
	TENORMIN	ATENOLOL
	VISKEN	PINDOLOL
INSULIN:	HUMULIN	HUMAN INSULIN
	ILETIN	PROTAMINE ZINC INSULIN
	LENTE INSULIN	ZINC INSULIN CRYSTALS
	MIXTARD	ISOPHANE PURIFIED PORK INSULIN
	NOVOLIN	HUMAN INSULIN
	NPH INSULIN	INSULIN
	SEMILENTE	PROTAMINE ZINCE INSULIN
	VELOSULIN	PURIFIED PORK INSULIN
NITROGLYCERINE & OTHER NITRATES:	CARDILATE	ERYTHRITL TETRANITRATE
	DUOTRATE	PENTAERYTHRITOL TETRANITRATE
	ISORDIL	ISOSORBIDE DINITRATE
	NITRO-BID	TRINITROGYLCERINE
	NITRO-DUR	TRINITROGYLCERINE
	NITROCINE	TRINITROGYLCERINE
	NITRODISC	TRINITROGYLCERINE
	NITROGARD	TRINITROGLYCERINE
	NITROGLYCERINE	TRINITROGYLCERINE
	NITROL	TRINITROGYLCERINE
	NITROSTAT	TRINITROGYLCERINE
	TRANSDERM-NITRO	TRINITROGYLCERINE
DIGITALIS:		DIGITALIS
	CRYSTODIGIN	DIGITOXIN
	LANOXICAPS	DIGOXIN
	LANOXIN	DIGOXIN

REGISTRY OF PATIENTS WITH DEFICIENCY OF ALPHA 1-ANTITRYPSIN

MEDICATION LIST

REGISTRY CATEGORY	TRADE NAME	GENERIC NAME
ANTICOAGULANTS:	.	DICUMAROL
	COUMADIN	WARFARIN
	PANWARFIN	WARFARIN SODIUM
	PERSANTINE	DIPYRIDAMOLE
ANTI-ARRHYTHMICS:	CARDIOQUIN	QUINIDINE GLUCONATE
	CORDARONE	AMIODARONE
	ENKAID	ENCAINIDE HYDROCHLORIDE
	NORPACE	DISOPYRAMIDE PHOSPHATE
	PROCAN	PROCAINAMIDE HYDROCHLORIDE
	PROCAN SR	PROCAINAMIDE HYDROCHLORIDE
	PRONESTYL	PROCAINAMIDE HYDROCHLORIDE
	QUINAGLUTE	QUINIDINE GLUCONATE
	TONOCARD	TOCAINIDE HYDROCHLORIDE
ORAL CONTRACEPTIVES:	BREVICON	NORETHINDRONE
	DEMULEN	.
	LEVLEN	LEVONORGESTREL
	LO/OVRAL	NORGESTREL
	LOESTRIN	NORETHINDRONE ACETATE
	MICRONOR	NORETHINDRONE
	MODICON	NORETHINDRONE
	NOR-QD	NORETHINDRONE
	NORDETTE	LEVONORGESTREL
	NORINYL	NORETHINDRONE
	NORLESTRIN	NORETHINDRONE ACETATE
	NORLUTIN	NORETHINDRONE
	ORTHO-NOVUM	NORETHINDRONE
	OVRAL	NORGESTREL
	OVRETTE	NORGESTREL
	TRI-LEVLIN	LEVONORGESTREL
	TRI-NORINYL	NORETHINDRONE
	TRIPHASIL	LEVONORGESTREL
TRANQUILIZERS:	ATIVAN	LORAZEPAM
	BUSPAR	BUSPIRONE
	CENTRAX	PRAZEPAM

REGISTRY OF PATIENTS WITH DEFICIENCY OF ALPHA 1-ANTITRYPSIN

MEDICATION LIST

REGISTRY CATEGORY	TRADE NAME	GENERIC NAME
TRANQUILIZERS:	DEPROL	MEPROBAMATE
	MEPROSPAN	MEPROBAMATE
	MILTOWN	MEPROBAMATE
	PAXIPAM	HALAZEPAM
	RESTORIL	TEMAZEPAM
	TRANXENE	CHLORAZEPATE DIPOTASSIUM
	XANAX	ALPRAZOLAM
TRANQUILIZERS /BENZODIAZEPINES:	DALMANE	FLURAZEPAM
	LIBRIUM	CHLORDIAZEPOXIDE
	SERAX	OXAZEPAM
	VALIUM	DIAZEPAM
TRANQUILIZERS /PHENOTHIAZINES:	COMPAZINE	PROCHLORPERAZINE
	MELLARIL	THIORIDAZINE
	PROLIXIN	FLUPHENAZINE HYDROCHLORIDE
	STELAZINE	TRIFLUOROPERAZINE
	THORAZINE	CHLORPROMAZINE
	TRILAFON	PERPHENAZINE

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

This form should be completed at the patient's first Registry visit. The physician should review this form with the patient, particularly the medical history and medication sections.

1. Date form completed: F2AQ01_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 visit: F2AQ05-fzd (fuzzed) ___ ___/ ___ ___/ ___ ___ (month / day / year)

visit number vsno

DEMOGRAPHIC INFORMATION

6. What is your marital status: F2AQ06
   - ___(1)Never Married
   - ___(2)Widowed
   - ___(3)Married
   - ___(4)Separated
   - ___(5)Divorced
   - ___(9)Unknown

7. How many years of eduation have you completed? (highest grade completed) F2AQ07
   - ___(1)College graduate with advanced training
   - ___(2)College graduate
   - ___(3)At least one year of college
   - ___(4)High school graduate
   - ___(5)Completed 10-11 years of school
   - ___(6)Completed 7-9 years of school
   - ___(7)Completed < 7 years of school
   - ___(9)Unknown

OCCUPATIONAL HISTORY

8. a. What is your current employment status? F2AQ08A
   - ___(1)Unemployed (Medical Reasons)
   - ___(2)Unemployed (Other Reasons)
   - ___(3)Employed Part-Time
   - ___(4)Employed Full-Time
   - ___(5)Retired (Medical)
   - ___(6)Retired (Age)
   - ___(7)Full-Time Homemaker
   - ___(8)Other (specify): never entered.
   - ___(9)Unknown

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

Occupational History, continued:

8. b. Have you ever worked for three or more months in a job where you were regularly exposed to dust or fumes? .....F2AQ08B.....___(1)Yes ___(2)No ___(9)Unknown

c. If YES,

Specify Job	Number of Years Worked at Job	Last Year Employed at This Job
F2AQ08C1	F2AQ08C2	F2AQ08C3
F2AQ08D1	F2AQ08D2	F2AQ08D3
F2AQ08E1	F2AQ08E2	F2AQ08E2

SYMPTOM HISTORY

These questions pertain mainly to your chest symptoms. Please answer YES or NO, if possible. If you are in doubt about an answer, check NO.

COUGH

9. a. Do you usually have a cough?.....F2AQ09A.....___(1)Yes ___(2)No

(Count a cough with first smoke or on first going out of doors. Exclude clearing throat.) (If NO, skip to 9c.)

b. Do you usually cough as much as 4 to 6 times a day, 4 or more days out of the week?.....F2AQ09B.....___(1)Yes ___(2)No

c. Do you usually cough at all on getting up, or first thing in the morning? .....F2AQ09C.....___(1)Yes ___(2)No

d. Do you usually cough at all during the rest of the day or night?.....F2AQ09D.....___(1)Yes ___(2)No

If YES to any of the above (9a - d), answer Questions 9e - f.
If NO to all, skip to Question 10a.

e. Do you usually cough like this on most days for 3 consecutive months or more during the year?.....F2AQ09E...___(1)Yes ___(2)No

f. For how many years have you had this cough?....F2AQ09F.....___ ___

PHLEGM

10. a. Do you usually bring up phlegm from your chest?...F2AQ10A___(1)Yes ___(2)No

(Count phlegm with the first smoke or on first going out-of-doors.
Exclude phlegm from the nose. Count swallowed phlegm.)
(If NO, skip to 10c.)

b. Do you usually bring up phlegm like this as much as twice

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month day year

a day, 4 or more days out of the week? F2AQ10B ___(1)Yes ___(2)No

c. Do you usually bring up phlegm at all on getting up, or first thing in the morning? F2AQ10C ___(1)Yes ___(2)No

d. Do you usually bring up phlegm at all during the rest of the day or night? F2AQ10D ___(1)Yes ___(2)No

If YES to any of the above (10a - d), answer Questions 10e-f.
If NO to all, skip to Question 11a.

e. Do you usually bring up phlegm like this on most days for 3 consecutive months or more during the year? F2AQ10E ___(1)Yes ___(2)No

f. For how many years have you had trouble with phlegm? F2AQ10F ___ ___

EPISODES OF COUGH AND PHLEGM

11. a. Have you had periods or episodes of (increased*) cough and phlegm lasting for 3 weeks or more each year? F2AQ11A ___(1)Yes ___(2)No

*(For persons who usually have cough and/or phlegm)

If NO, skip to Question 12a.

If YES,
b. For how long have you had at least 1 such episode/year (years)? F2AQ11B ___ ___

WHEEZING

12. a. Does your chest ever sound wheezy or whistling:
1. When you have a cold: F2AQ12A1 ___(1)Yes ___(2)No
2. Occasionally apart from colds: F2AQ12A2 ___(1)Yes ___(2)No
3. Most days or night: F2AQ12A3 ___(1)Yes ___(2)No

If NO to all of the above, skip to Question 13a.
If YES to any of above in 12a,

b. How many years has this been present? F2AQ12B ___ ___

13. a. Have you ever had an attack of wheezing that has made you feel short of breath? F2AQ13A ___(1)Yes ___(2)No

If NO, skip to Question 14.
If YES,

b. How old were you when you had your first such attack? F2AQ13B ___ ___

c. Have you had 2 or more such episodes? F2AQ13C ___(1)Yes ___(2)No

d. Have you ever required medicine or treatment for the(se) attack(s)? F2AQ13D ___(1)Yes ___(2)No

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

BREATHLESSNESS

14. Are you disabled from walking by any condition other than heart or lung disease? F2AQ14 ___(1)Yes ___(2)No

If YES, specify condition(s): F2AQ14O

15. a. Are you troubled by shortness of breath when hurrying on the level or walking up a slight hill? F2AQ15A ___(1)Yes ___(2)No

If NO, skip to Question 16a.
If YES,

b. Do you have to walk slower than people of your age on the level because of breathlessness? F2AQ15B ___(1)Yes ___(2)No

c. Do you ever have to stop for breath when walking at your own pace on the level? F2AQ15C ___(1)Yes ___(2)No

d. Do you ever have to stop for breath after walking about 100 yards (or after a few minutes) on the level? F2AQ15D ___(1)Yes ___(2)No

e. Are you too breathless to leave the house or breathless on dressing or undressing? F2AQ15E ___(1)Yes ___(2)No

f. For how many years have you been this short of breath? F2AQ15F ___ ___

CHEST COLDS AND CHEST ILLNESSES

16. a. How often do you get colds? F2AQ16A
___(1) Never
___(2) 2-4 Times per Year
___(3) Once a Year
___(4) 5 or More Times per Year

b. If you get a cold, does it usually go to your chest? ("Usually" means more than 1/2 the time): F2AQ16B ___(1)Yes ___(2)No ___(3)I don't get colds

17. a. During the past 3 years, have you had any chest illnesses that have kept you off work, indoors at home, or in bed? F2AQ17A ___(1)Yes ___(2)No

If NO to Question 17a, skip to Question 18.
If YES,

b. Did you produce phlegm with any of these chest illnesses? F2AQ17B ___(1)Yes ___(2)No

c. In the last 3 years, how many such illnesses, with (*increased) phlegm, did you have which lasted a week or more (If none, enter 00)? F2AQ17C ___ ___

*(For persons who usually have phlegm)

Symptom History Section Completed By: never entered
(Name)

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

ALCOHOL

18. Do you drink alcoholic beverages (beer, liquor or wine)? F2AQ18
___(1)Never ___(2)Ex-drinker ___(3)Currently

If NEVER, skip to Question 19.
If Ex-drinker or Current drinker,

a. How many days per week, on the average, do/did you drink alcoholic beverages? ....F2AQ18A.... ___.___

b. On days that you do/did drink alcohol, how many drinks do/did you have on the average? ....F2AQ18B.... ___ ___

c. Are you a recovering alcoholic or ex-alcoholic?....F2AQ18C.... ___(1)Yes ___(2)No
If NO, skip to Question 19.

If YES to Question 18c, complete the following:
d. How long has it been since you last had an alcoholic drink? F2AQ18D
___(1)More than 1 year ___(3)Less than 6 months

___(2)6 months to one year

SMOKING HISTORY

Tobacco Smoking:

19. a. Have you ever smoked **cigarettes**? ....F2AQ19A.... ___(1)Yes ___(2)No

("No" means less than 20 packs of cigarettes or 12 oz of tobacco in a lifetime or less than one cigarette a day for one year)

If YES to Question 19a:
b. Do you now smoke cigarettes (as of 1 month ago)? ....F2AQ19B.... ___(1)Yes ___(2)No

c. How old were you when you first started regular cigarette smoking?....F2AQ19C.... ___ ___ Age in years

d. If you have stopped smoking cigarettes completely, how old were you when you stopped? ....F2AQ19D.... ___ ___ Age in years

e. How many cigarettes do you smoke per day now?....F2AQ19E.... ___ ___ ___cigarettes per day

f. On the average of the entire time you smoked, how many cigarettes did you smoke per day?....F2AQ19F.... ___cigarettes per day

g. Do or did you inhale the cigarette smoke?....F2AQ19G.... ___(1)Not at all
___(2)Slightly
___(3)Moderately
___(4)Deeply

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

Smoking History, continued:

20. a. Have you ever smoked a **pipe** regularly? F2AQ20A ___(1)Yes ___(2)No

("Yes" means more than 12 oz of tobacco in a lifetime)

If YES to Question 20a. (For persons who have ever smoked a pipe):

b. 1. How old were you when you started to smoke a pipe regularly? F2AQ20B1 ___ ___ Age in years

b. 2. Are you still smoking a pipe? F2AQ20B2 ___(1)Yes ___(2)No

b. 3. If you have stopped smoking a pipe completely, how old were you when you stopped? F2AQ20B3 ___ ___ Age in years

c. On the average over the entire time you smoked a pipe, how much pipe tobacco did you smoke per week? F2AQ20C ___ ___ oz per week

(A standard pouch of tobacco contains 1 1/2 oz)

d. How much pipe tobacco are you smoking now? F2AQ20D ___ ___ oz per week

e. Do or did you inhale the pipe smoke? F2AQ20E
___(1)Not at all
___(2)Slightly
___(3)Moderately
___(4)Deeply

21. a. Have you ever smoked **cigars** regularly? F2AQ21A ___(1)Yes ___(2)No

("Yes" means more than 1 cigar a week for a year)

If YES to Question 21a. (For persons who have ever smoked cigars):

b. 1. How old were you when you started to smoke cigars regularly? F2AQ21B1 ___ ___ Age in years

b. 2. Are you currently smoking cigars? F2AQ21B2 ___(1)Yes ___(2)No

b. 3. If you have stopped smoking cigars completely, how old were you when you stopped? F2AQ21B3 ___ ___ Age in years

c. On the average over the entire time you smoked cigars, how many cigars did you smoke per week? F2AQ21C ___ ___ cigars per week

d. How many cigars are you smoking now? F2AQ21D ___ ___ cigars per week

e. Do you or did you inhale the cigar smoke? F2AQ21E
___(1)Not at all
___(2)Slightly
___(3)Moderately
___(4)Deeply

22. Other **(non-tobacco) smoking:** F2AQ22
___(0)Never ___(2)Current
___(1)Ex-smoker ___(9)Unknown

(Specify, if available): never entered

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

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

MEDICAL HISTORY

It is recommended that a physician review/complete the medical history and medication sections of this form.

23. Have you and/or any of your family members ever had a disease of the lung? .....F2AQ23.....___(1)Yes ___(2)No

If YES, Check If:

For each letter there are 5 variables. The variable name starts with the base letters below. Replace the "x" with the number in the coorespondding blank.

	Diagnosed By Doctor	Hospitalized For This Condition Within the Last Year	Condition is Present in Another Member of Your Family F	M	O*
a. Emphysema: F2AQ23Ax	1	2	4	5	3
b. Pneumothorax: F2AQ23Bx	1	2	4	5	3
c. Bullous Lung Disease: F2AQ23Cx	1	2	4	5	3
d. Chronic Bronchitis: F2AQ23Dx	1	2	4	5	3
e. Asthma: F2AQ23Ex	1	2	4	5	3
f. Infant Respiratory Distress Syndrome: F2AQ23Fx	1		4	5	3
g. COPD: F2AQ23Gx	1	2	4	5	3
(Specify): never entered					
h. Bronchiectasis: F2AQ23Hx	1	2	4	5	3
i. Pulmonary Fibrosis: F2AQ23Ix	1	2	4	5	3
j. Lung Cancer: F2AQ23Jx	1	2	4	5	3
k. Pulmonary Embolism: F2AQ23Kx	1	2	4	5	3
l. Pneumonia: F2AQ23Lx	1	2	4	5	3
m. Pleural Disease: F2AQ23Mx	1	2	4	5	3
n. Tuberculosis: F2AQ23Nx	1	2	4	5	3
o. Primary Pulmonary Hypertension: F2AQ23Ox	1	2	4	5	3
p. Allergies affecting Respiratory Tract (Hay Fever): F2AQ23Px	1	2	4	5	3
q. Other diseases of the lung: F2AQ23Qx	1	2	4	5	3
(Specify): never entered					

***For Family History: F = Father, M = Mother, O = Other blood relative**

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

Medical History, continued:

24. Have you and/or any of your family members ever had **liver** disease?.....F2AQ24.....___(1)Yes ___(2)No

If YES, Check If:

For explanation on variable names, see Q.23. (Replace "x" with cooresponding number)

	Diagnosed By Doctor	Hospitalized For This Condition Within the Last Year	Condition is Present in Another Member of Your Family F	M	O*
a. Hepatitis: F2A24Ax	1	2	4	5	3
b. Childhood Onset, Acute Hepatitis: F2A24Bx	1	2	4	5	3
c. Childhood Onset, Chronic Hepatitis: F2A24Cx	1	2	4	5	3
d. Adult Onset, Hepatitis: F2A24Dx	1	2	4	5	3
e. Jaundice within 1st month of life: F2A24Ex	1		4	5	3
f. Cirrhosis: F2A24Fx	1	2	4	5	3
g. Liver Tumor: F2A24Gx	1	2	4	5	3
h. Other liver disease: F2A24Hx	1	2	4	5	3

(Specify): never entered

***For Family History:** F = Father, M = Mother, O = Other blood relative

25. Have you ever had **heart** disease?....F2AQ25.....___(1)Yes ___(2)No

If YES, Check If:

For explanation of variable names, see Q.23. (Replace "x" with cooresponding number).

	Diagnosed By Doctor	Hospitalized For Condition Within the the Last Year
a. Coronary Artery Disease: F2AQ25Ax	1	2
b. Heart Attack: F2AQ25Bx	1	2
c. Congestive Heart Failure: F2AQ25Cx	1	2
d. Chest Pain - Angina: F2AQ25Dx	1	2
e. Hypertension: F2AQ26Ex	1	2
f. Other heart disease: F2AQ26Fx	1	2

(Specify): never entered

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

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

Medical History, continued:

26. Have you ever had a disease of the **joints** or involving the **immune** system? F2AQ26 ____(1)Yes ____(2)No

If YES, Check If:

For explanation on variable names, see Q.23 (Replace "x" with corresponding number.)

		Diagnosed By Doctor	Hospitalized For This Condition Within the Last Year
a.	Adult Rheumatoid Arthritis: F2AQ26Ax	1	2
b.	Juvenile Chronic Polyarthritis: F2AQ26Bx	1	2
c.	Weber-Christian Disease (Necrotizing Panniculitis): F2AQ26Cx	1	2
d.	Other joint/auto-immune disease: F2AQ26Dx	1	2

(Specify): never entered

27. Have you ever had a disease of the **blood** system? F2AQ27 ____(1)Yes ____(2)No

If YES, specify: never entered

28. Have you ever had a disease of the **kidney**? F2AQ28 ____(1)Yes ____(2)No

If YES, specify: never entered

29. Have you ever had a disease of the **stomach, intestines,** or **pancreas**? F2AQ29 ____(1)Yes ____(2)No

If YES, specify: never entered

30. Have you ever had any **neurologic** disease? F2AQ30 ____(1)Yes ____(2)No

If YES, specify: never entered

31. Have you ever had a disease of the **glands** or **hormones** (i.e., sugar diabetes, thyroid disease, etc.)? F2AQ31 ____(1)Yes ____(2)No

If YES, specify: never entered

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

Medical History, continued:

32. Have you had any **other illnesses** not already mentioned? .....F2AQ32.....___(1)Yes ___(2)No

If YES, specify: never entered

SURGICAL HISTORY

33. Have you ever had **surgery**? .....F2AQ33.....___(1)Yes ___(2)No
If YES,

	Check if You Ever Had Surgery	Date of Most Recent Surgery (mm/yy) → all dates are "fuzzed." (Rule 1)
a. Lung (Other than transplant): F2AQ33A1	___(1)Yes ___(2)No	F2AQ33A2-fzd ___ ___/___ ___
(Specify type and site of surgery): never entered		
1. Lung Transplant? F2A33A1	___(1)Yes ___(2)No	
2. Date of Lung Transplant: F2A33A2-fzd		___ ___/ ___ ___/ ___ ___ month day year
b. Chest (Other Than Lung): F2AQ33B1	___(1)Yes ___(2)No	F2AQ33B2-fzd ___ ___/___ ___
(Specify type and site of surgery): never entered		
c. Abdominal: F2AQ33C1	___(1)Yes ___(2)No	F2AQ33C2-fzd ___ ___/___ ___
(Specify type and site of surgery): never entered		
d. Liver (Other than transplant): F2AQ33D1	___(1)Yes ___(2)No	F2AQ33D2-fzd ___ ___/___ ___
(Specify type and site of surgery): never entered		
1. Liver Transplant? F2A33D1	___(1)Yes ___(2)No	
2. Date of Liver Transplant: F2A33D2-fzd		___ ___/ ___ ___/ ___ ___ month day year
e. Other Surgery: F2AQ33E1	___(1)Yes ___(2)No	F2AQ33E2-fzd ___ ___/___ ___
(Specify type and site of surgery): never entered		

Medical and Surgical History Sections Completed By (Name):

never entered

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

MEDICATIONS ne = never entered

34. In the past month, have you used any prescription drugs? F2AQ34 ___(1)Yes ___(2)No

If YES, specify drugs taken. YES or NO must be indicated for each drug category.

a. Inhaled Bronchodilators: F2AQ34A ___(1)Yes ___(2)No
(Specify): ne

b. Oral Bronchodilators: F2AQ34B ___(1)Yes ___(2)No
(Specify): ne

c. Theophylline: F2AQ34C ___(1)Yes ___(2)No
(Specify): ne

d. Cromolyn: F2AQ34D ___(1)Yes ___(2)No
(Specify): ne

e. Systemic Corticosteroids: F2AQ34E ___(1)Yes ___(2)No
(Specify): ne

f. Inhaled Corticosteroids: F2AQ34F ___(1)Yes ___(2)No
(Specify): ne

g. Other Bronchodilators: F2AQ34G ___(1)Yes ___(2)No
(Specify): ne

h. Beta-Blockers: F2AQ34H ___(1)Yes ___(2)No
(Specify): ne

i. Insulin: F2AQ34I ___(1)Yes ___(2)No
(Specify): ne

j. Nitroglycerin or Other Nitrates: F2AQ34J ___(1)Yes ___(2)No
(Specify): ne

k. Digitalis: F2AQ34K ___(1)Yes ___(2)No
(Specify): ne

l. Anticoagulants: F2AQ34L ___(1)Yes ___(2)No
(Specify): ne

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

Medications, continued: ne - never entered

m. Antiarrhythmics.....F2AQ34M.....__(1)Yes __(2)No

(Specify): ne

n. Oral Contraceptives: .....F2AQ34N.....__(1)Yes __(2)No

(Specify): ne

o. Tranquilizers:.....F2AQ34O.....__(1)Yes __(2)No

(Specify): ne

p. Other prescription drugs: .....F2AQ34P.....__(1)Yes __(2)No

(Specify): ne

q. Supplemental Oxygen Questions

1. Do you receive supplemental oxygen?.....F2AQ34Q1...__(1)Yes __(2)No
If YES, complete items q.2-4 below.
If NO, skip to Question 35.

2. Type of oxygen delivery device: F2AQ34Q2
__(1) Nasal Cannula
__(2) Transtracheal Oxygen
__(3) Face mask, type:_____
__(4) Other, specify: ne

3. Oxygen Flow:

a. Liters/minute:.....F2A34Q3A.....__ __ . __

b. FIO_2 (if Venturi mask) (%).....F2A34Q3B..... __ __ __

4. Number of hours/24 hour period of oxygen use....F2AQ34Q4.....__ __ . __

Medications Section Completed By: ne
(Name)

ALPHA 1-ANTITRYPSIN AUGMENTATION THERAPY

35. Have you ever been on alpha 1-antitrypsin augmentation therapy (Prolastin)? .....F2AQ35.....__(1)Yes __(2)No

a1. If NO, identify reason why not (then skip to end of form): F2AQ35A1

__(1)Not recommended by physician

__(2)Financial reasons

__(3)Medical contra-indications (specify): ne

__(4)Other (specify): ne

__(9)Unknown

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

Augmentation Therapy, continued:

If YES to question 35, continue.

a. Are you presently on augmentation therapy? F2AQ35A ___(1)Yes ___(2)No

36. a. Have you discontinued therapy permanently? F2AQ36A ___(1)Yes ___(2)No
("Permanently" means no intention of continuing therapy)

If NO, skip to Question 37.

b. If YES, for what reason(s) have you discontinued therapy: F2AQ36B

___(1)Financial ___(4)Other (Specify) never entered

___(2)Adverse Reaction _____

___(3)Medical ___(9)Unknown/Unspecified

c. If therapy has been discontinued, date of last therapy received F2AQ36C-fzd (fuzzed) ___ ___/ ___ ___/ ___ ___
month day year

If you are presently on augmentation therapy, complete the following:

37. a. Date current therapy began: F2AQ37A-fzd (fuzzed) ___ ___/ ___ ___/ ___ ___
month day year

b. Date of most recent augmentation therapy F2AQ37B-fzd ___ ___/ ___ ___/ ___ ___
month day year

c. Dose (grams): F2AQ37C ___ ___.___

38. With what frequency are you given therapy? F2AQ38
(in number of days)
___(1)Weekly ___(2)Monthly ___(3)Other (specify): _____

Note: Coded by CCC as infusion interval (days): 7, 10, 14, 21, or 30.

39. Is therapy being given by a method other than infusion?

___(1)Yes (specify) F2AQ39 ___(2)No

Physician Signature: never entered

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