

ALPHA-1 RESEARCH REGISTRY

QUESTIONNAIRE

Please answer the below questions to the best of your ability. You may want to ask your doctor or family members for help in answering some of the medical history questions.

If you have any questions, please contact the Alpha-1 Foundation at Tel# _____

Participant Information

First Name _____

Last Name _____

Maiden Name _____

Date of Birth _____

Age _____

Street Address (Line 1) _____

Street Address (Line 2) _____

City _____

State Zip _____

Code _____

Country USA Other _____

Home Phone Number _____

Cell Phone Number _____

Work Phone Number _____

Email Address _____

Preferred Method of Contact

Phone

Email

Mail

Demographics

Race

- White
- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- Other _____
- Prefer not to say

Ethnicity

- Hispanic or Latino
- Not Hispanic or Latino
- Prefer not to say

Gender

- Female
- Male
- Other _____
- Prefer not to say

Marital Status

- Single
- Married
- Separated
- Divorced
- Widowed
- Prefer not to say

Geographic History

Do you currently reside in the same City, State, and Country where you were born?

- Yes
- No

City where you were born.

State where you were born.

Country where you were born.

- Australia
- Canada
- USA
- Other
- If other, list country _____

Current Home/Living Location

- Farm
- Rural Area
- Suburban Area
- Urban Area
- Unknown

Number of people living in your household, including yourself.

How long have you lived at this location? (years)

What is your annual gross household income?

- Less than \$10,000 (USD)
- \$ 10,000-\$ 24,999
- \$ 25,000-\$ 49,999
- \$ 50,000-\$ 74,999
- \$ 75,000-\$ 99,999
- \$ 100,000-\$ 149,999
- \$ 150,000-\$ 249,999
- \$ 250,000 and above
- Prefer not to say

Insurance

Are you covered by any kind of health insurance or some other kind of health care plan?

- Yes
- No

Primary Health Insurance Type

- Private Health Insurance
- Medicare
- Medi-gap
- Medicaid
- SCHIP (children's health insurance program)
- Military Health Care (Tricare/VA, Champ/VA)
- Indian Health Service
- State Sponsored Health Plan
- Other Government Program
- Single Service Plan (e.g. Dental, Vision, Prescription)
- No Coverage
- Unknown

Have you been denied

- Yes

health care for insurance reasons? No

Job History

Have you ever been employed for a wage or salary, either part-time or full-time? Yes No

Which of the following best describes your current employment status? Working On leave but still employed Temporary laid off Unemployed and looking for work Unable to work Attending school Homemaker Retired Other

What is your longest held job/occupation? _____

What (is) (was) the kind of business or industry? (If necessary) What (do) (did) they make or do at this business? _____

What (are) (were) the usual activities or duties? _____

At what age did you first begin this job? _____

How many years, altogether, (have) (did) you work(ed) at this job? _____

On average, how many weeks per year (does)(did) you work at this job? _____

In the weeks you worked, how many hours per week (does)(did) you usually work? _____

In response to this job, are/were you Yes

exposed to vapors, gas, dust
or fumes?

No
 Unknown

Which of these examples of vapors, gas, dust or fumes where you exposed to at work or other wise?

	Yes	No	Unknown
Irritant Gases (Such as Chlorine or Ammonia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fire, Smoke, or Other Combustion Products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incinerators, Boilers, or Oil Refineries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coal Dust or Powder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Silica, Sand, Concrete, or Cement Dust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Indoor Fuel Powered Motors, Compressors, or Engines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diesel Engine Exhaust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wheat Flour or Other Grain Dusts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Animal Feeds or Fodder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cotton Dust or Cotton Processing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wood or Saw Dust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cadmium Fumes, Batteries, or Silver Solder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Metal Dusts or Metal fumes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Welding or Flame Cutting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fiberglass or Other Man-made Mineral Fibers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Explosive or Blasting Fumes

Aside from this job, have you worked in any other jobs that exposed him/her to vapors, gas, dust or fumes?

Yes
 No
 Unknown

How many other jobs involved such exposures?

How many years, altogether, did you work in this/these job(s)?

At any of those jobs were you exposed to any of the following specific examples of vapors, gas, dust or fumes?

	Yes	No	Unknown
Irritant Gases (Such as Chlorine or Ammonia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fire, Smoke, or Other Combustion Products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incinerators, Boilers, or Oil Refineries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coal Dust or Powder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Silica, Sand, Concrete, or Cement Dust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Indoor Fuel Powered Motors, Compressors, or Engines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diesel Engine Exhaust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wheat Flour or Other Grain Dusts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Animal Feeds or Fodder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cotton Dust or Cotton Processing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Wood or Saw Dust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cadmium Fumes, Batteries, or Silver Solder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Metal Dusts or Metal fumes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Welding or Flame Cutting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fiberglass or Other Man- made Mineral Fibers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Explosive or Blasting Fumes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Considering all the jobs you have had, how many years of employment have they been regularly exposed to another person's cigarette smoke inside the workplace? Give the best estimate.

Education

If you are less than 18 years old, what is the highest grade you completed?

- No schooling completed
- Preschool or Nursery school, kindergarten
- 1st Grade
- 2nd Grade
- 3rd Grade
- 4th Grade
- 5th Grade
- 6th Grade
- 7th Grade
- 8th Grade
- 9th Grade
- 10th Grade
- 11th Grade
- 12th Grade
- GED
- College
- N/A- I am 18 years or older

If you are 18 years or older, what is the highest grade or level of school you have completed, or the highest degree you have received?

- 8th Grade or less
- More than 8th Grade, but did not graduate from high school
- Went to business, trade, or vocational school instead of high school
- High School Graduate
- Completed a GED
- Went to a business, trade, or vocational school after high school
- Went to a college but did not graduate
- Graduated from a college or university
- Professional training beyond a 4 year college or university
- Never went to school
- N/A- I am younger than 18 years

What is the highest level of education your mother completed?

- 8th Grade or less
- More than 8th Grade, but did not graduate from high school
- Went to business, trade, or vocational school instead of high school
- High School Graduate
- Completed a GED
- Went to a business, trade, or vocational school after high school
- Went to a college but did not graduate
- Graduated from a college or university
- Professional training beyond a 4 year college or university
- Never went to school
- Unknown

What is the highest level of education your father completed?

- 8th Grade or less
- More than 8th Grade, but did not graduate from high school
- Went to business, trade, or vocational school instead of high school
- High School Graduate
- Completed a GED
- Went to a business, trade, or vocational

- school after high school
- Went to a college but did not graduate
- Graduated from a college or university
- Professional training beyond a 4 year college or university
- Never went to school
- Unknown

Family History

Mother's First Name _____

Mother's Maiden Name _____

Mother's Last Name _____

Mother's Date of Birth _____

Father's First Name _____

Father's Last Name _____

Father's Date of Birth _____

Which family members also are known to have Alpha-1 Antitrypsin Deficiency? Please list only tested individuals who are severely deficient (PiZZ, PiZnull, PiSZ, PiSnull). Check all that apply.

- None
- Daughter
- Granddaughter
- Grandson
- Half-brother
- Half-sister
- Maternal Aunt
- Maternal Cousin
- Maternal Grandfather
- Maternal Grandmother
- Maternal Uncle
- Brother
- Father
- Mother
- Sister
- Nephew
- Niece
- Paternal Aunt Paternal
- Cousin Paternal

- Grandfather Paternal
- Grandmother
- Paternal Uncle
- Son
- Unknown
- Other _____

How many brothers do you have from the same parents?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 or more
- None

How many sisters do you have from the same parents?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 or more
- None

Medical History

Part 1: Alpha-1 Antitrypsin Deficiency (Alpha-1) History

What prompted you to have Alpha-1 testing done?

- Lung Symptoms
- Liver Symptoms
- Family Testing
- Other Screening
- Other _____

What is your Alpha-1 Genotype

- MS
- MZ
- MF
- SS
- SZ
- ZZ
- FZ
- FF
- Znull
- Mnull
- Snull
- Unknown
- Other _____

Do you have your Alpha-1 testing report?

- Yes
- No

At what age did you begin to notice symptoms of Alpha-1?

Alpha-1 Diagnosis Age?

Have you ever been admitted to a hospital due to Alpha-1?

- Yes
- No
- Unknown

How many times in the last 12 months have you been admitted to a hospital due to Alpha-1?

Have you had any surgeries as a result of Alpha-1?

- Yes
- No
- Unknown

Please list all surgeries that are applicable.

Have you been diagnosed with a fatty liver

- Yes

- No
- Unknown

Part 2: Lung History

◆ Section A: Asthma

Have you ever been diagnosed with Asthma? Yes
 No (if NO, please skip to next section)

Year of Asthma Diagnosis _____

Were you ever diagnosed with asthma as a child? Yes
 No
 Unknown
 Not Reported

At what age did you begin to notice childhood asthma symptoms? _____

Asthma as an adult Yes
 No
 Unknown
 Not Reported

◆ Section B: Bronchiectasis

Have you ever been diagnosed with Bronchiectasis? Yes
 No (if NO, please skip to next section)

Year of Bronchiectasis Diagnosis _____

Year of Chronic Bronchitis Diagnosis _____

◆ Section C: Chronic Obstructive Pulmonary Disease (COPD) and Emphysema

Have you ever been diagnosed with COPD? Yes
 No

Year of COPD Diagnosis _____ O N/A

Have you ever been diagnosed with Emphysema? Yes
 No

Year of Emphysema Diagnosis _____ O N/A

Number of exacerbations in the past year (defined by need for antibiotics or corticosteroids)? _____ O N/A

Number of exacerbations in the past year requiring ER or Hospital visits? _____ O N/A

◆ **Section D: Other Lung related diagnosis**

Have you ever had Hepatopulmonary Syndrome? Yes
 No

Year of Hepatopulmonary Syndrome Diagnosis _____

Have you ever been diagnosed with Lung Cancer? Yes
 No

Year of Lung Cancer Diagnosis _____

Have you ever been diagnosed with Portopulmonary Hypertension Diagnosis? Yes
 No

Year of Portopulmonary Hypertension Diagnosis _____

◆ **Section E: Lung Surgical History**

Have you ever had a Lung Transplant? Yes
 No

When was the date of the lung _____

transplant?

What hospital performed the lung transplant?

Have you ever had a Lung Volume Reduction?

- Yes
- No

What was the date of the lung volume reduction?

What hospital performed the lung volume reduction?

Was the lung reduction performed by bronchoscopy or surgically?

- Bronchoscopic
- Surgery
- Unknown
- N/A

How was the bronchoscopic procedure performed?

- Valve
- Steam
- Chemical
- Coil
- Unknown
- N/A – never had bronchoscopy

◆ **Section F: Lung Tests**

Have you ever had an X-ray or CT scan of the lung?

- Yes
- No

When was the date of the most recent lung imaging?

_____ N/A

Have you ever had a Pulmonary Function Test (PFT) done?

- Yes
- No

When was the date of the most recent PFT?

_____ N/A

Part 3: Liver History

◆ **Section A: Liver related Diagnosis**

Have you ever been diagnosed with Ascites? Yes
 No

Year of Ascites Diagnosis _____ N/A

Have you ever been diagnosed with Cirrhosis? Yes
 No

Year of Cirrhosis Diagnosis _____ N/A

Have you ever experienced symptoms of liver disease? Yes
 No

If YES, at what age did you begin to experience symptoms of liver disease? _____ N/A

At what age were you clinically diagnosed with liver disease? _____ N/A

Have you ever been diagnosed by a physician with any abnormal liver function tests? Yes
 No
 Not Tested
 Unknown

Were you ever diagnosed with childhood jaundice? If Yes, when did you begin to notice symptoms? 1st week of life
 2nd week of life
 3rd week of life
 1 month
 After 1 month
 I did not have childhood jaundice
 I do not know if I had childhood jaundice
 Unknown

Have you ever been diagnosed with Cholestasis? Yes
 No

Year of Neonatal Cholestasis Diagnosis _____ O N/A

Have you ever been diagnosed with Non-alcoholic Steatohepatitis (NASH)?
 Yes
 No

Year of Non-alcoholic Steatohepatitis _____ O N/A

Have you ever been diagnosed with Panniculitis?
 Yes
 No

Year of Panniculitis Diagnosis _____ O N/A

Have you ever been diagnosed with Splenomegaly?
 Yes
 No

Year of Splenomegaly Diagnosis _____ O N/A

Have you ever been diagnosed with Spontaneous Bacterial Peritonitis Diagnosis?
 Yes
 No

Year of Spontaneous Bacterial Peritonitis Diagnosis _____ O N/A

Do you have a history of variceal bleeding?
 Yes
 No

Year of variceal bleeding diagnosis _____ O N/A

◆ **Section B: Vaccinations**

Have you received a vaccination for Hepatitis A?
 Yes
 No
 Unknown

Hepatitis A Vaccination Date _____ O N/A

Have you received a _____ O Yes

vaccination for Hepatitis B? No
 Unknown

Hepatitis B Vaccination Date _____ N/A

Have you received a vaccination for Hepatitis C? Yes
 No

Hepatitis C Vaccination Date _____ N/A

Have you been tested for HIV? Positive
 Negative
 Not Tested
 Unknown

HIV Test Date _____ N/A

Have you ever been diagnosed with Hepatocellular Carcinoma (HCC)? Yes
 No

Year of Hepatocellular Carcinoma Diagnosis _____ N/A

◆ **Section C: Liver Surgical History**

Have you ever had a Liver biopsy? Yes
 No

When was the date of the liver biopsy procedure? _____ N/A

Have you had a Liver Transplant? Yes
 No

When was the date of the liver transplant procedure? _____ N/A

What hospital performed the liver transplant? _____ N/A

Have you had an endoscopy? Yes
 No

When was the date of the endoscopy? _____ . O N/A

◆ **Section E: Liver Imaging (radiology and ultrasound)**

Have you ever had an ultrasound or CT scan of the liver or abdomen? Yes No

When was the date of the most recent liver imaging? _____ O N/A

Part 4: Other Medical History

Have you been diagnosed with Diabetes? Yes No

Year of Diabetes Diagnosis _____ O N/A

Is Diabetes Insulin Requiring? Yes No

Have you had been diagnosed with? Gallstones? Yes No

Year of Gallstones Diagnosis _____ O N/A

Have you had bloodwork done? Yes No

What is the most recent date you had bloodwork done? _____ O N/A

Were you born at or close to your due date, how many weeks premature or after the due date were you? 2 weeks late 1 week late On time 1 week premature 2 weeks premature 3 weeks premature 4 weeks premature 5 weeks premature

- 6 weeks premature
- 7 weeks premature
- 8 weeks premature
- 9 weeks premature
- 10 weeks premature
- 11 weeks premature
- 12 weeks premature
- 13 weeks premature
- 14 weeks premature
- 15 weeks premature
- Unknown

Have you had any of the following:

- Myocardial infarct
- Congestive heart failure
- Peripheral vascular disease
- Cerebrovascular disease (except hemiplegia)
- Dementia
- Chronic pulmonary disease
- Connective tissue disease
- Ulcer disease (
- Mild liver disease
- Diabetes (without complications)
- N/A

Have you had any of the following:

- Diabetes with end organ damage
- Hemiplegia
- Moderate or severe renal disease
- Solid tumor (non metastatic)
- Leukemia
- Lymphoma, Multiple myeloma
- N/A

Have you had any of the following:

- Moderate or severe liver disease the
- Metastatic solid tumor
- AIDS
- N/A

Medication History

	Currently	In The Past	Never
Beta-Agonists (Ex. Albuterol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Oral Corticosteroids (Ex. Prednisone)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Inhaled Corticosteroids (Ex. Flovent, Advair, Symbicort)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aspirin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Statin – drugs to lower cholesterol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-Steroidal Anti-Inflammatory Drug (NSAID) (Ex. Celebrex, Ibuprofen)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Augmentation (Infusion) Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Oxygen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anticholinergics (Ex. Spiriva)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

List any other medications you are currently taking along with the dosage and frequency (e.g., Tylenol, 100mg, once a week)

Do you take any medical foods or follow a special diet for treatment of Alpha-1 Antitrypsin Deficiency? Yes No Not regularly

Hospitalization History

Please indicate if you were hospitalized in the last year Yes No (If NO, please skip to next section)

◆ First Hospitalization

Type of visit In-patient Emergency

Date of Hospitalization _____

Cause of Hospitalization _____

Please indicate if a second hospitalization occurred in the last year?

- Yes
- No (If NO, please skip to next section)

◆ Second Hospitalization

Type of visit

- In-patient
- Emergency

Date of Hospitalization _____

Cause of Hospitalization _____

Please indicate if a third hospitalization occurred in the last year?

- Yes
- No (If NO, please skip to next section)

◆ Third Hospitalization

Type of visit

- In-patient
- Emergency

Date of Hospitalization _____

Cause of Hospitalization _____

Please indicate if a fourth hospitalization occurred in the last year?

- Yes
- No (If NO, please skip to next section)

◆ Fourth Hospitalization

Type of visit

- In-patient
- Emergency

Date of Hospitalization _____

Cause of Hospitalization _____

Please indicate if a fifth hospitalization occurred in the last year?

- Yes
- No (If NO, please skip to next section)

◆ Fifth Hospitalization

Type of visit

- In-patient
- Emergency

Date of Hospitalization

Cause of Hospitalization

Smoking History

Have you ever smoked in your lifetime?

- Yes (continue with below section)
- No (skip to next section)

Current Smoking Status

- Non-smoker
 - Current smoker
 - Ex-smoker
- (Note: <100 cigarettes in a lifetime defines a non-smoker)

At what age did you start smoking?

At what age did you stop smoking?

Average cigarettes per day?

(Note: 1 pack = 20 cigarettes)

Were you exposed to second-hand smoke as a child (age 12 or younger) for at least one year?

- Yes
- No
- Unknown

Were you exposed to second-hand smoke after age 12 for at least one year?

- Yes
- No
- Unknown

Does anyone in your household currently smoke?

- Yes
- No
- Unknown

Alcohol History

I am

- Lifetime abstainer from alcohol
- Former alcohol consumer (no alcohol consumed in the past 12 months)
- Current alcohol consumer (consumed alcohol in the last 12 months, i.e., socially)
- Unknown

How many drinks containing alcohol do you consume each day? _____

The following are a set of validated questionnaires that will ask you about alcohol, COPD and quality of life.

Alcohol Use Disorder Identification Test (AUDIT-C) - Questionnaire

If you are a current alcohol consumer (consumed alcohol in the past 12 months), please answer the following questions. If not, please continue to the next section entitled Family History

How often do you have a drink containing alcohol?

- Never
- Monthly or less
- 2-4 times a month
- 2-3 times a week
- 4 or more times a week

How many standard drinks containing alcohol do you have on a typical day?

- 1 or 2
- 3 or 4

- 5 or 6
- 7 to 9
- 10 or more

How often do you have 6 or more drinks on one occasion?

- Never
- Less than monthly
- Monthly
- Weekly
- Daily or almost daily

St. Georges Respiratory Questionnaire (SGRQ)

ORIGINAL ENGLISH VERSION

This questionnaire is designed to help us learn much more about how your breathing is troubling you and how it affects your life. We are using it to find out which aspects of your illness cause you most problems, rather than what the doctors and nurses think your problems are. Please read the instructions carefully and contact us if you do not understand anything. Do not spend too long deciding about your answers.

The questions below are about how much chest trouble you have had over the past 3 months. Please tick one circle for each question:

Before completing the rest of the questionnaire:

Please choose one to show how you describe your current health:

- Very good
- Good
- Fair
- Poor
- Very Poor

St. George's Respiratory Questionnaire PART 1

1. Over the past 3 months, I have coughed:
Please select one:

- most days a week
- several days a week
- a few days a month
- only with chest infections
- not at all

2. Over the past 3 months, I have brought up phlegm (sputum):
Please select one:

- most days a week
- several days a week
- a few days a month
- only with chest infections

- not at all
3. Over the past 3 months, I have had shortness of breath:
Please select one:
- most days a week
 - several days a week
 - a few days a month
 - only with chest infections
 - not at all
4. Over the past 3 months, I have had attacks of wheezing:
Please select one:
- most days a week
 - several days a week
 - a few days a month
 - only with chest infections
 - not at all
5. Over the past 3 months how many severe or very unpleasant attacks of chest trouble have you had?
Please select one:
- more than 3 attacks
 - 3 attacks
 - 2 attacks
 - 1 attack
 - not at all
6. How long did the worst attack of chest trouble last?
(Go to question 7 if you had no severe attacks)
- a week or more
 - 3 or more days
 - 1 or 2 days
 - less than a day
- Please select one:
7. Over the past 3 months, in an average week, how many good days (with little chest trouble) have you had?
- No good days
 - 1 or 2 good days
 - 3 or 4 good days
 - nearly every day is good
 - every day is good
8. If you have a wheeze, is it worse in the morning?
- Yes
 - No

St. George's Respiratory Questionnaire PART 2

Section 1

9. How would you describe your chest condition?
Please select one:
- The most important problem I have
 - Causes me quite a lot of problems
 - Causes me a few problems
 - Causes no problem

10. If you have ever had paid employment.
Please select one:

- My chest trouble made me stop work altogether
- My chest trouble interferes with my work or made me change my work
- My chest trouble does not affect my work

Section 2

The following questions are about activities that may make you feel breathless these days. Please select True for any that make you feel breathless these days. Please select false for any statements that do not make you feel breathless these days:

- 11a. Sitting or lying still True False
- 11b. Getting washed or dressed True False
- 11c. Walking around the home True False
- 11d. Walking outside on the level True False
- 11e. Walking up a flight of stairs True False
- 11f. Walking up hills True False
- 11g. Playing sports or games True False

Section 3

The following questions are about your cough and breathlessness these days. Please select True for any statement that is accurate these days. Please select false for any statements that are inaccurate.

- 12a. My cough hurts True False
- 12b. My cough makes me tired True False
- 12c. I am breathless when I talk True False

- 12d. I am breathless when I bend over True
 False
- 12e. My cough or breathing disturbs my sleep True
 False
- 12f. I get exhausted easily True
 False

Section 4

The following questions are about other effects that your chest trouble may have on you these days. Please select True for any statement that applies. Please select False for any statement that does not apply.

- 13a. My cough or breathing is embarrassing in public True
 False
- 13b. My chest trouble is a nuisance to my family, friends or neighbors True
 False
- 13c. I get afraid or panic when I cannot get my breath True
 False
- 13d. I feel that I am not in control of my chest problem True
 False
- 13e. I do not expect my chest to get any better True
 False
- 13f. I have become frail or an invalid because of my chest True
 False
- 13g. Exercise is not safe for me True
 False
- 13h. Everything seems too much of an effort True
 False

14. Questions about your medication.

If no medications are being taken, answer "none" for 14a and then false for 14b-14e.

- 14a. I am not taking any medications None
- 14b. My medication does not help me very much True
 False

14c. I get embarrassed using my medication in public True
 False

14d. I have unpleasant side effects from my medication True
 False

14e. My medication interferes with my life a lot True
 False

Section 6

The following questions are about how your activities might be affected by your breathing. Please select True for any statement that applies to you because of your breathing. Please select False for any statement that applies to you because of your breathing.

15a. I take a long time to get washed or dressed True
 False

15b. I cannot take a bath or shower, or I take a long time True
 False

15c. I walk more slowly than other people, or stop for rests True
 False

15d. Jobs such as housework take a long time, or I have to stop for rests True
 False

15e. If I walk up one flight of stairs, I have to go slowly or stop True
 False

15f. If I hurry or walk fast, I have to stop or slow down True
 False

15g. My breathing makes it difficult to do things such as walk up hills, carry things up stairs, light gardening such as weeding, dance, play bowls or play golf True
 False

15h. My breathing makes it difficult to do things such as carry heavy loads, dig the garden or shovel snow, jog or walk at 5 miles per hour, play tennis or swim True
 False

15i. My breathing makes it difficult True

to do things such as very heavy manual work, run, cycle, swim fast or play competitive sports False

Section 7

The following questions pertain to how your chest usually affects your daily life. Please select True for any statement that applies to you because of your chest trouble:

16a. I cannot play sports or games True
 False

16b. I cannot go out for entertainment or recreation True
 False

16c. I cannot go out of the house to do the shopping True
 False

16d. I cannot do housework True
 False

16e. I cannot move far from my bed or chair True
 False

17. Which statement best describes how your chest affects you It does not stop me from doing anything I would like to do
 It stops me from doing one or two things I would like to do
 It stops me from doing most of the things I like to do
 It stops me from doing everything I would like to do

Here is list of other activities that your chest trouble may prevent you doing. (You do not have to select these, they are just to remind you of ways in which your breathlessness may affect you):

- Going for walks or walking the dog
- Doing things at home or in the garden
- Sexual intercourse
- Going out to church, pub, club or place of entertainment
- Going out in bad weather or into smoky rooms
- Visiting family or friends or playing with children

Please write in any important activities that your chest

trouble may stop you from doing:

COPD Assessment Test (CAT) - Questionnaire

	0	1	2	3	4	5
How often do you cough, with 0 being never and 5 coughing all the time?	0	0	0	0	0	0
How much phlegm (mucus) do you have in your chest, with 0 being that you have no phlegm (mucus) in your chest at all and 5 chest is completely full of phlegm (mucus)?	0	0	0	0	0	0
How tight does your chest feel, with 0 being not tight at all and 5 chest feels very tight?	0	0	0	0	0	0
Do you feel breathless when walking up a hill or one flight of stairs, with 0 being not breathless and 5 being very breathless?	0	0	0	0	0	0
How limited are you when doing activities at home, with 0 being not limited and 5 very limited?	0	0	0	0	0	0
How confident do you feel leaving your home with your lung condition, with 0 being not limited and 5 very limited?	0	0	0	0	0	0
How do you sleep, with 0 being that you sleep soundly and 5 you don't sleep soundly because of your lung condition?	0	0	0	0	0	0
How much energy do you have,	0	0	0	0	0	0

with 0 being lots of energy and
5 no energy at all.

General Health

In general, how would you
describe your
overall health?

- Excellent
- Very good
- Good
- Fair
- Poor

Does your health
now limit you in doing
vigorous activities?

- Not at all
- Very little
- Somewhat
- Quite a lot
- Cannot do

How much does pain interfere
with your enjoyment
of life?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

How often do you
feel tired?

- Never
- Rarely
- Sometimes
- Often
- Always

How often do you
feel depressed?

- Never
- Rarely
- Sometimes
- Often
- Always

Do you use any assistive devices?
(such as wheelchairs, hearing aids,
ramps, prosthetic devices)

- Yes
- No

If yes, can you specify the type _____
of assistive devices you use

Providers and Facilities

Once you have completed the questionnaire, we will ask you to provide the following labs and test results from your medical records. In the section below, please list where you have had the most recent following exams performed:

The last five 6 Minute Walk Test:

1. _____
2. _____
3. _____
4. _____
5. _____

The Last five Pulmonary Function Test:

1. _____
2. _____
3. _____
4. _____
5. _____

The Last five Bloodwork:

1. _____
2. _____
3. _____
4. _____
5. _____

The last five Lung and/ or Liver Ultrasound:

1. _____
2. _____
3. _____
4. _____
5. _____

The last 5 lung Fibro scan:

1. _____
2. _____
3. _____
4. _____
5. _____

Thank you for filling in this questionnaire. Before you finish would you please check to see that you have answered all the questions and list out the provider and facility information of where your medical tests and labs were performed.

Thank you for your participation!

We will make follow up calls everyone to two years to update any medical care changes and request any new relevant test results.