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# 877-228-7321 ext. 252

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: _____

Phone Number: _____

Email Address:

Demographics

Race	◯ White ◯ American Indian or Alaska Native ◯ Asian ◯ Black or African American ◯ Native Hawaiian or Other Pacific Islander ◯ Other ◯ Prefer not to say
Race	_____
Ethnicity	◯ Hispanic or Latino ◯ Not Hispanic or Latino ◯ Prefer not to say
Gender	◯ Female ◯ Male ◯ Other ◯ Prefer not to say
Gender	_____
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.	_____
Country where you were born.	◯ United States ◯ Other

State/Territory where you were born.

- ◯ Alabama (AL)
- ◯ Alaska (AK)
- ◯ American Samoa (AS)
- ◯ Arizona (AZ)
- ◯ Arkansas (AR)
- ◯ California (CA)
- ◯ Colorado (CO)
- ◯ Connecticut (CT)
- ◯ Delaware (DE)
- ◯ District of Columbia (DC)
- ◯ Florida (FL)
- ◯ Georgia (GA)
- ◯ Guam (GU)
- ◯ Hawaii (HI)
- ◯ Idaho (ID)
- ◯ Illinois (IL)
- ◯ Indiana (IN)
- ◯ Iowa (IA)
- ◯ Kansas (KS)
- ◯ Kentucky (KY)
- ◯ Louisiana (LA)
- ◯ Maine (ME)
- ◯ Northern Mariana Islands (MP)
- ◯ Maryland (MD)
- ◯ Massachusetts (MA)
- ◯ Michigan (MI)
- ◯ Minnesota (MN)
- ◯ Mississippi (MS)
- ◯ Missouri (MO)
- ◯ Montana (MT)
- ◯ Nebraska (NE)
- ◯ Nevada (NV)
- ◯ New Hampshire (NH)
- ◯ New Jersey (NJ)
- ◯ New Mexico (NM)
- ◯ New York (NY)
- ◯ North Carolina (NC)
- ◯ North Dakota (ND)
- ◯ Ohio (OH)
- ◯ Oklahoma (OK)
- ◯ Oregon (OR)
- ◯ Pennsylvania (PA)
- ◯ Puerto Rico (PR)
- ◯ Rhode Island (RI)
- ◯ South Carolina (SC)
- ◯ South Dakota (SD)
- ◯ Tennessee (TN)
- ◯ Texas (TX)
- ◯ Utah (UT)
- ◯ Vermont (VT)
- ◯ Virgin Islands (VI)
- ◯ Virginia (VA)
- ◯ Washington (WA)
- ◯ West Virginia (WV)
- ◯ Wisconsin (WI)
- ◯ Wyoming (WY)

Country where you were born.

_____

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 then $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 health care for insurance reasons?	◯ Yes ◯ 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?

_____
(Please write N/A if not applicable)

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

_____
(Please write N/A if not applicable)

What are/were the usual activities or duties?

_____
(Please write N/A if not applicable)

At what age did you first begin this job?

_____
(Please write N/A if not applicable)

How many years, altogether, have/did you work/worked at this job?

_____
(Please write N/A if not applicable)

On average, how many weeks per year have/did you work at this job?

_____
(Please write N/A if not applicable)

In the weeks you worked, how many hours per week did you usually work?

_____
(Please write N/A if not applicable)

In response to this job, are/were you exposed to vapors, gases, dusts, or fumes?

- ◯ Yes
- ◯ No
- ◯ Unknown

Which of these examples of vapors, gases, dusts, or fumes were you exposed to at your current work or otherwise?

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

Aside from this current job, have you worked in any other jobs that exposed you to vapors, gases, dusts or fumes?

◯ Yes
◯ No
◯ Unknown

How many other jobs involved such exposures? _____

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

Considering all the jobs you have had, how many years of employment have you 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?

- ◯ N/A - I am 18 years or older
- ◯ 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

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 recieved?

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

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

Do you have any family members who are known to have Alpha-1 Antitrypsin Deficiency?

- ◯ Yes
- ◯ No
- ◯ Unknown

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.

- ☐ Mother
- ☐ Father
- ☐ Sister
- ☐ Half-Sister
- ☐ Brother
- ☐ Half-Brother
- ☐ Daughter
- ☐ Son
- ☐ Maternal Grandmother
- ☐ Maternal Grandfather
- ☐ Paternal Grandmother
- ☐ Paternal Grandfather
- ☐ Maternal Aunt
- ☐ Maternal Uncle
- ☐ Paternal Aunt
- ☐ Paternal Uncle
- ☐ Maternal Cousin
- ☐ Paternal Cousin
- ☐ Niece
- ☐ Nephew
- ☐ Grandson
- ☐ Granddaughter

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 prompted you to have Alpha-1 testing done?

(**If other please list**)

_____

What is your Alpha-1 genotype?

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

What is your Alpha-1 genotype? (**If other please list**)

_____

Do you have your Alpha-1 testing report?

- ◯ Yes
- ◯ No

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

_____

What age were you diagnosed with Alpha-1?

_____

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?

_____

(If unsure, please type N/A)

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

Were you ever diagnosed with asthma as a child?
- ◯ Yes
- ◯ No
- ◯ Unknown

What age did you begin to notice childhood asthma symptoms?
_____

Were you ever diagnosed with asthma as an adult?
- ◯ Yes
- ◯ No
- ◯ Unknown

What age did you begin to notice adult asthma symptoms?
_____

Section B: Bronchiectasis

Have you ever been diagnosed with bronchiectasis?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of bronchiectasis diagnosis?
(if NO or Unknown, please skip to next section)
_____
(If unsure, please type N/A)

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

Have you ever been diagnosed with COPD?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of COPD diagnosis?
_____
(If unsure, please type N/A)

Have you ever been diagnosed with emphysema?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of emphysema diagnosis?
_____
(If unsure, please type N/A)

Number of exacerbations in the past year (defined by need for antibiotics or corticosteroids)?
_____
(If unsure, please type N/A)

Number of exacerbations in the past year requiring ER or hospital visits?
_____
(If unsure, please type N/A)

Section D: Other Lung Related Diagnosis

Have you ever been diagnosed with hepatopulmonary syndrome?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of hepatopulmonary syndrome diagnosis?

_____
(If unsure, please type N/A)

Have you ever been diagnosed with lung cancer?

◯ Yes
◯ No
◯ Unknown

Year of lung cancer diagnosis?

_____
(If unsure, please type N/A)

Have you ever been diagnosed with portopulmonary hypertension diagnosis?

◯ Yes
◯ No
◯ Unknown

Year of portopulmonary hypertension diagnosis?

_____
(If unsure, please type N/A)

Section E: Lung Surgical History

Have you ever had a lung transplant?

◯ Yes
◯ No
◯ Unknown

Year of the lung transplant?

_____
(If unsure, please type N/A)

What hospital performed the lung transplant?

_____
(If unsure, please type N/A)

Have you ever had a lung volume reduction?

◯ Yes
◯ No
◯ Unknown

Year of the lung volume reduction?

_____
(If unsure, please type N/A)

What hospital performed the lung volume reduction?

_____
(If unsure, please type N/A)

Was the lung volume reduction performed by bronchoscopy or surgically?

◯ Bronchoscopic
◯ Surgery
◯ Unknown

How was the bronchoscopic procedure performed?

◯ Valve
◯ Steam
◯ Chemical
◯ Coil
◯ Unknown

Section F: Lung Tests

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

◯ Yes
◯ No
◯ Unknown

Year of the most recent X-ray or CT scan of the lung?

_____
(If unsure, please type N/A)

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

- ◯ Yes
- ◯ No
- ◯ Unknown

Year of the most recent PFT?

_____
(If unsure, please type N/A)

Part 3: Liver History

Section A: Liver related Diagnosis

Have you ever been diagnosed with ascites?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of ascites diagnosis?

_____ (If unsure, please type N/A)

Have you ever been diagnosed with cirrhosis?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of cirrhosis diagnosis?

_____ (If unsure, please type N/A)

Have you ever experienced symptoms of liver disease?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, what age did you begin to experience symptoms of liver disease?

_____

What age were you clinically diagnosed with liver disease?

_____ (If unsure, please type 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
- ◯ Unknown

Year of cholestasis diagnosis?

_____ (If unsure, please type N/A)

Have you ever been diagnosed with neonatal cholestasis?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of neonatal cholestasis diagnosis

_____ (If unsure, please type N/A)

Have you ever been diagnosed with non-alcoholic steatohepatitis (NASH)?	◯ Yes ◯ No ◯ Unknown
Year of non-alcoholic steatohepatitis (NASH) diagnosis	_____ (If unsure, please type N/A)
Have you ever been diagnosed with panniculitis?	◯ Yes ◯ No ◯ Unknown
Year of panniculitis diagnosis?	_____ (If unsure, please type N/A)
Have you ever been diagnosed with splenomegaly?	◯ Yes ◯ No ◯ Unknown
Year of splenomegaly diagnosis?	_____ (If unsure, please type N/A)
Have you ever been diagnosed with spontaneous bacterial peritonitis?	◯ Yes ◯ No ◯ Unknown
Year of spontaneous bacterial peritonitis diagnosis	_____ (If unsure, please type N/A)
Have you ever been diagnosed with variceal bleeding?	◯ Yes ◯ No ◯ Unknown
Year of variceal bleeding diagnosis?	_____ (If unsure, please type N/A)

Section B: Vaccinations

Have you received a vaccination for hepatitis A?	◯ Yes ◯ No ◯ Unknown
Year of hepatitis A vaccination?	_____ (If unsure, please type N/A)
Have you received a vaccination for hepatitis B?	◯ Yes ◯ No ◯ Unknown
Year of hepatitis B vaccination?	_____ (If unsure, please type N/A)
Have you received a vaccine for hepatitis C?	◯ Yes ◯ No ◯ Unknown

Year of hepatitis C vaccination?

_____
(If unsure, please type N/A)

Have you been tested for HIV?

- ◯ Positive
- ◯ Negative
- ◯ Not tested
- ◯ Unknown

Year of HIV test?

_____
(If unsure, please type N/A)

Have you ever been diagnosed with hepatocellular carcinoma (HCC)?

- ◯ Yes
- ◯ No
- ◯ Unknown

Year of hepatocellular carcinoma diagnosis?

_____
(If unsure, please type N/A)

Section C: Liver Surgical History

Have you ever had a liver biopsy?

- ◯ Yes
- ◯ No
- ◯ Unknown

Year of the liver biopsy

_____
(If unsure, please type N/A)

Have you had a liver transplant?

- ◯ Yes
- ◯ No
- ◯ Unknown

Year of the liver transplant?

_____
(If unsure, please type N/A)

What hospital performed the liver transplant?

_____
(If unsure, please type N/A)

Have you had an endoscopy?

- ◯ Yes
- ◯ No
- ◯ Unknown

Year of the endoscopy?

_____
(If unsure, please type 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
- ◯ Unknown

Year of most recent ultrasound or CT scan of the liver or abdomen?

_____
(If unsure, please type N/A)

Part 4: Other Medical History

Have you been diagnosed with diabetes?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of diabetes diagnosis?

_____
(If unsure, please type N/A)

Does your diabetes require insulin?
- ◯ Yes
- ◯ No
- ◯ Unknown

Have you been diagnosed with gallstones?
- ◯ Yes
- ◯ No
- ◯ Unknown

Year of gallstones diagnosis?

_____
(If unsure, please type N/A)

Have you had bloodwork done?
(E.g. liver enzyme blood test, excessive bleeding or blood clotting test, Cholesterol)
- ◯ Yes
- ◯ No
- ◯ Unknown

What is the most recent date you had bloodwork done?
(E.g. liver enzyme blood test, excessive bleeding or blood clotting test, Cholesterol) (M-D-Y)

_____
(If unsure, please type 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 infarction
- ☐ Congestive heart failure
- ☐ Peripheral vascular disease
- ☐ Cerebrovascular disease (except hemiplegia)
- ☐ Dementia
- ☐ 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 ☐ Metastatic solid tumor ☐ AIDS ☐ N/A

Medication History

	Currently	In The Past	Never
Beta-Agonists (e.g. Albuterol)	◯	◯	◯
Oral Corticosteroids (e.g. Prednisone)	◯	◯	◯
Inhaled Corticosteroids (e.g. Flovent, Advair, Symbicort)	◯	◯	◯
Aspirin	◯	◯	◯
Statin - drugs to lower cholesterol	◯		◯
Non-Steroidal Anti-Inflammatory Drug (NSAID) (e.g. Celebrex, Ibuprofen)	◯	◯	◯
Augmentation (Infusion) Therapy	◯	◯	◯
Oxygen	◯	◯	◯
Anticholinergics (e.g. Spiriva)	◯	◯	◯

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

_____

_____

_____

Do you take any medical foods or follow a special diet for treatment of Alpha-1 Antitrypsin Deficiency?

◯ Yes
◯ No
◯ Not regularly

Hospitalization History

Were you hospitalized once in the past year?
(If NO, please skip to next section)
◯ Yes
◯ No

Type of visit
◯ In-patient
◯ Emergency

Date of hospitalization (M-D-Y)
_____

Cause of hospitalization
_____

Were you hospitalized a second time in the last year?
(If NO, please skip to next section)
◯ Yes
◯ No

Type of visit
◯ In-patient
◯ Emergency

Date of hospitalization (M-D-Y)
_____

Cause of hospitalization
_____

Were you hospitalized a third time in the last year?
(If NO, please skip to next section)
◯ Yes
◯ No

Type of visit
◯ In-patient
◯ Emergency

Date of hospitalization (M-D-Y)
_____

Cause of hospitalization
_____

Were you hospitalized a fourth time in the last year?
(If NO, please skip to next section)
◯ Yes
◯ No

Type of visit
◯ In-patient
◯ Emergency

Date of hospitalization (M-D-Y)
_____

Cause of hospitalization
_____

Were you hospitalized a fifth time in the last year?
(If NO, please skip to next section)
◯ Yes
◯ No

Type of visit
◯ In-patient
◯ Emergency

Date of hospitalization (M-D-Y)

_____

Cause of hospitalization

_____

Smoking History

Have you ever smoked in your lifetime?	◯ Yes ◯ No
Current smoking status	◯ Non-smoker ◯ Current smoker ◯ Ex-smoker (Note: < 100 cigarettes in a lifetime defines a non-smoker)
What age did you start smoking?	_____
What age did you stop smoking?	_____
Average cigarettes pack(s) per day?	_____ (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 past 12 months, i.e., socially)
How many drinks containing alcohol do you consume each day?	_____

The following are a set of validated questionnaires that may apply to you concerning alcohol, COPD, and quality of life.

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

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

How often do you have a drink containing alcohol?	◯ Never ◯ Monthly or less ◯ 2-4 times per month ◯ 2-3 times per week ◯ 4 or more times per week
How many standard drinks containing alcohol do you have on a typical day?	◯ 1 or 2 ◯ 3 or4 ◯ 5or 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)

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 select one option per 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
Section 1

1. Over the past three months, I have coughed:	◯ 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):	◯ 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:	◯ 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:	◯ 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?	◯ more than 3 attacks ◯ 3 attacks ◯ 2 attacks ◯ 1 attack ◯ not at all
6. How long did the worst attack of chest trouble last?	◯ a week or longer ◯ 3 or more days ◯ 1 or 2 days ◯ less than a day
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?	◯ 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.	◯ 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 activity that makes you feel breathless these days. Please select False for any statement that does not make you feel breathless these days.

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

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 statement that is inaccurate these days.

	True	False
12a. My cough hurts	◯	◯
12b. My cough makes me tired	◯	◯
12c. I am breathless when I talk	◯	◯
12d. I am breathless when I bend over	◯	◯
12e. My cough or breathing disturbs my sleep.	◯	◯
12f. I get exhausted easily	◯	◯

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.

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

The Following questions are about your medication.
If no medications are being taken, answer False for 14a-14d.

	True	False
14a. My medication does not help me very much	◯	◯
14b. I get embarrassed using my medication in public	◯	◯
14c. I have unpleasant side effects from my medication	◯	◯
14d. My medication interferes with my life a lot	◯	◯

Section 5

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.

	True	False
15a. I take a long time to get washed or dressed	○	○
15b. I cannot take a bath or shower, or I take a long time	○	○
15c. I walk more slowly than other people, or stop for rests	○	○
15d. Jobs such as housework take a long time, or I have to stop for rests	○	○
15e. If I walk up one flight of stairs, I have to go slowly or stop	○	○
15f. If I hurry or walk fast, I have to stop or slow down	○	○
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	○	○
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	○	○
15i. My breathing makes it difficult to do things such as very heavy manual work, run , cycle, swim fast, or play competitive sports	○	○

Section 6

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. Please select False for any statement that does not apply.

	True	False
16a. I cannot play sports or games	◯	◯
16b. I cannot go out for entertainment or recreation	◯	◯
16c. I cannot go out of the house to do the shopping	◯	◯
16d. I cannot do housework	◯	◯
16e. I cannot move far from my bed or chair	◯	◯

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 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 from 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.

_____

_____

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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?	○	○	○	○	○	○
How much phlegm (mucus) do you have in your chest, with **0** being that your have no phlegm (mucus) in your chest at all and **5** chest is completely full of phlegm (mucus)?	○	○	○	○	○	○
How tight does your chest feel, with **0** being not tight at all and **5** chest feels very tight?	○	○	○	○	○	○
Do you feel breathless when walking up a hill or one flight of stairs, with **0** being not breathless and **5** being very breathless?	○	○	○	○	○	○
How limited are you when doing activities at home, with **0** being not limited and **5** very limited?	○	○	○	○	○	○
How confident do you feel leaving your home with your lung condition, with **0** being not limited and **5** very limited?	○	○	○	○	○	○
How do you sleep, with **0** being that you sleep soundly and **5** you don't sleep soundly because of your lung condition?	○	○	○	○	○	○
How much energy do you have, 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
Please specify which assistive devices you use.	_____ _____

Physicians and Facilities

Please list the physicians and facilities where you've had up to 5 of the following most recent test and labs performed:

Have you ever had a 6 Minute Walk test?

_____
_____
_____
_____
_____

◯ Yes
◯ No
◯ Unknown

Have you ever had a Pulmonary Function Test?

_____
_____
_____
_____

◯ Yes
◯ No
◯ Unknown

Have you ever had bloodwork?
(e.g. liver enzyme blood test, blood clotting test, total cholesterol blood test)

_____
_____
_____
_____

◯ Yes
◯ No
◯ Unknown

Have you ever had Lung and/or Liver Ultrasounds?

_____
_____
_____
_____

◯ Yes
◯ No
◯ Unknown

Have you ever had lung fibroscans?

_____
_____
_____
_____

◯ Yes
◯ No
◯ Unknown