

Research Questionnaire

CONSENT TO PARTICIPATE IN THE PULMONARY FIBROSIS RESEARCH REGISTRY

We invite you to join the *Pulmonary Fibrosis Research Registry*, a program of the *Pulmonary Fibrosis Foundation*, whose mission is to help find a cure for Pulmonary Fibrosis.

Before you do, we want you to know that:

- Your participation is entirely voluntary.
- If you choose to join the Research Registry now, you may withdraw at any time for any reason.
- You may receive no benefit from taking part in the Research Registry. The only benefit that can be reasonably expected, at this time, is that research using information from the Research Registry may give us knowledge that may help persons with Pulmonary Fibrosis in the future.

CONFIDENTIALITY

No confidential personal information about Research Registry participants will be given to the *Pulmonary Fibrosis Foundation* or directly to any researcher(s). Only the agency managing the database will have access to confidential personal information. It will be up to you to choose whether or not to respond to or contact any researcher(s) seeking to recruit research volunteers from among participants in the *Pulmonary Fibrosis Research Registry*.

RISKS AND INCONVENIENCES

Risks:

The physical risks of participating in this Research Registry are anticipated to be minimal. All that is required is the time to fill out this survey and any future surveys. The risks that require more serious consideration relate to keeping your name in a database connected to your personal health information. Although every reasonable effort will be made to keep your information confidential, there can be no guarantees that errors in protecting this information will not be made. If it became known that you have Pulmonary Fibrosis, there may be risks to you related to your employment, or health or life insurance.

Inconveniences:

The burdens associated with participation in the Research Registry are:

1. Being contacted by the *Pulmonary Fibrosis Research Registry* about your willingness to participate in research projects approved by the Medical And Scientific Advisory Committee of the *Pulmonary Fibrosis Foundation*.
2. Being sent additional survey questionnaires and follow-up surveys on a continuing basis.

I agree to participate in the *Pulmonary Fibrosis Research Registry*.

Signature of Participant:

Date

Please return your survey to
(or for questions or help in
filling out this form), contact:

PULMONARY FIBROSIS RESEARCH
REGISTRY
1332 N. Halsted St. Suite 201
Chicago, IL 60622

Phone: 1-312-587-9272
Fax: 1-312-587-9273
Email: breathe@pulmonaryfibrosis.org

Please Note: This survey is being distributed through a number of different mailing lists and it is possible that you may receive more than one copy. If this happens, please respond to only one survey and give any duplicates you may receive to other diagnosed Pulmonary Fibrosis patients or your physician. To obtain additional copies of the questionnaire or other information about research activities, please contact the *Pulmonary Fibrosis Foundation* at: (312) 587-9272

PATIENT INFORMATION**Patient name and address:**

Name: Last First MI

Address: Street Apt.#

City State Zip Country

Social Security Number:

Phone: Area Code () -

Do you have a current physician who cares for your Pulmonary Fibrosis? Yes No

Who is your current physician?

Name: Last First MI

Address: Street Suite #

City State Zip Country

Phone: Area Code () -

DEMOGRAPHICS

1. What is your date of birth? Month Day Year

2. What is your gender? Male Female

3. Race/Ethnicity (check all that apply)? Native American African American Asian
 Hispanic Non-Hispanic White Other

4. Are you currently employed? Yes No
What is your current occupation? Length of Employment (yrs.)

5. Please list your former occupations: Length of Employment (yrs.)

6. Please identify your smoking behavior: Nonsmoker (Less than 100 cigarettes in whole life) Ex-Smoker
 Smoker

• At what age did you start smoking?

• At what age did you stop smoking?

• How many cigarettes did or do you smoke per day?

• Were you exposed to second hand smoke? Frequently Occasionally Rarely

PULMONARY FIBROSIS DIAGNOSTIC INFORMATION

7. Have you been diagnosed with Idiopathic Pulmonary Fibrosis? Yes No
Have you had a surgical lung biopsy? Yes No
Have you had a high resolution CT - Scan? Yes No
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8. How old were you when you were diagnosed with Idiopathic Pulmonary Fibrosis?

9. Does anyone else in your family have Pulmonary Fibrosis, Idiopathic Pulmonary Fibrosis or Interstitial Lung Disease?
 Yes No

10. Have you ever had pulmonary function (breathing) tests? Yes No I don't know
If yes, date of most recent FEV1: Month Day Year - or - I don't know

11. Please mark any of the other diseases/conditions that you have been diagnosed with:
 COPD Emphysema Bronchitis Asthma Rheumatoid Arthritis
 Scleroderma Polymyositis Lupus

12. Was your current lung disease discovered before or after the above diagnosis? Before After

13. Has anyone in your family been diagnosed with?:
 COPD Emphysema Bronchitis Asthma Rheumatoid Arthritis
 Scleroderma Polymyositis Lupus

TREATMENT

14. Are you currently receiving medications for your disease?
 I have never received any medication. I am currently receiving _____ (name of drug).
 I am NOT currently receiving any medications, but I did in the past. List prior medications:
Name of Drug(s) _____ Length of time _____ Doseage _____

15. Have you ever had a lung transplant? Yes No

16. Are you listed for a lung transplant? Yes No

FUTURE SURVEYS

17. Do you own a computer? Yes No

18. Would you be interested in responding to future surveys over the Internet? Yes No

19. If you answered "yes" to the previous question, what is your email address?

Final Check: I have signed and dated the consent form on the front of the application.
 I have filled the application out in full to the best of my knowledge.

If you have family members, friends or acquaintances who have Pulmonary Fibrosis and would like to join the Research Registry please encourage them to contact the **Pulmonary Fibrosis Research Registry** at our phone number 312-587-9272 or by email at: breathe@pulmonaryfibrosis.org. We will be happy to assist them.

