

## Interstitial Lung Disease (ILD) Registry Snapshot

**Study Title:** Pulmonary Fibrosis Foundation (PFF) Patient Registry Protocol

**Study Name:** PFF Registry

**Study Type:** Observational Study (Registry)

**Objective:** To develop and maintain a database of ILD patients that collects and stores de-identified patient medical information and other related information for use in research with a goal to improve care and treatment.

**Sponsor:** Pulmonary Fibrosis Foundation

- The PFF serves as the trusted resource for the pulmonary fibrosis (PF) community by raising awareness, providing disease education, and funding research.

**Location:** Inova Fairfax Medical Campus, Advanced Lung Disease & Transplant Clinic  
3300 Gallows Road, Falls Church, VA 22042

**Study Duration:**

- The PFF Registry is projected to be maintained for five (5) years, or until the sponsor discontinues.

**Visit frequency:**

- Completion of surveys will only occur at regularly scheduled clinic visits; no appointments outside of the standard of care are necessary.

**Relevant procedures required by study:**

*Please reference consent form for breakdown of all data that is collected for the duration of this registry.*

- As this is an observational study, no intervention or study medication is used.
- Four (4) Patient Reported Outcome (PRO) surveys will take approximately 15 minutes to finish, which will provide us with information about how you feel, your symptoms, and how pulmonary fibrosis impacts your life.

**For more information about the PFF**

- Call the Patient Communication Center at 844.TalkPFF (844.825.5733)
- Email - [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org), or visit [www.pulmonaryfibrosis.org](http://www.pulmonaryfibrosis.org)

*\* Please note this form does not constitute consent*

### **Contact Details**

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