

...a patient's journey

The Pulmonary Fibrosis Foundation

commissioned the Interstitial Lung Disease (ILD) Patient Diagnostic Journey (INTENSITY) survey with support from molecular diagnostics company Veracyte, Inc. to better understand the steps required for people with these potentially-fatal lung diseases to receive a diagnosis, the "road blocks" that delay diagnosis, and the impact of these diagnostic journeys on patients, their doctors and the healthcare system.

Each year, an estimated 175,000 to 200,000 patients in the United States and major European countries present with suspected ILDs. Among the known forms of ILD, idiopathic pulmonary fibrosis (IPF) is among the most common and the most deadly. Patients have a median survival time of just 3.8 years - worse than most forms of cancer.

Delayed and Wrong Diagnoses Are Common

- The most common ILD symptoms survey participants experienced were shortness of breath or breathlessness (77%), cough (53%) and fatigue and weakness (38%).
- 42% of survey respondents endured a year or more between the time they first experienced symptoms and the time they obtained a diagnosis; 25% endured two years or more; and an unlucky six percent endured six years or more
- 55% of respondents were misdiagnosed at least once and 38% were misdiagnosed at least twice over the course of diagnosing their disease
- The most common misdiagnoses were asthma (14%), pneumonia (13%) and bronchitis (12%)
- Among those who were misdiagnosed, the misdiagnoses persisted for nearly a year (average of 11 months)

Correct Diagnosis Requires Time and Many Healthcare Resources

- Survey participants saw an average of three physicians before receiving a diagnosis; more than one-quarter (26%) saw five or more doctors
- On average, respondents endured six pulmonary lung function tests, five chest X-rays, two bronchoscopies, and two to three CT scans before receiving a diagnosis
- Nearly half of survey participants (45%) underwent surgical lung biopsy - an invasive, expensive and painful procedure - as part of their diagnosis

The Diagnostic Journey is Hard on Patients Emotionally and Financially

Survey respondents reported feeling lonely, stressed and isolated

- 64% said they mostly agreed or agreed that it was "very stressful not to know what was wrong with me"
- 43% mostly agreed or agreed that they did not feel family/friends understood what they were going through in trying to get a diagnosis
- 85% mostly agreed or agreed that the process of trying to get their disease diagnosed took away from time with family/friends
- 22% mostly agreed or agreed that they had to go on disability or retire because of the time diagnosis was taking

Undiagnosed Patients Seek Information & Support

- Survey respondents reported that the Pulmonary Fibrosis Foundation (60%) and their personal physicians (52%) were the two most valuable sources of information about ILD during their diagnostic journey
- 49% of participants mostly agreed or agreed that they wished for a community of people who could relate to their experiences



For more information about the INTENSITY survey, interstitial lung diseases (ILDs) or idiopathic pulmonary fibrosis (IPF), contact the Pulmonary Fibrosis Foundation at www.pulmonaryfibrosis.org or **1-844-TalkPFF**