Registry for fatal lung disease aims to speed improvements in care

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Duke Clinical Research Institute (DCRI) has launched a patient registry to help researchers and clinicians identify, manage and study people who have a progressive lung disease called idiopathic pulmonary fibrosis.

The registry, a joint effort by DCRI and Boehringer Ingelheim Pharmaceuticals, Inc., is the first multi-center registry in the United States focused specifically on idiopathic pulmonary fibrosis. It will include 300 adults recently diagnosed with the disease at 14 participating care sites throughout the country.

"Most of our knowledge about idiopathic pulmonary fibrosis comes from single-center studies and clinical trials, so there has been a tremendous need for a multi-center registry to help doctors, patients and advocates understand how this disease develops and progresses," said Scott Palmer, M.D., MHS, director of pulmonary research at DCRI.

Idiopathic pulmonary fibrosis affects as many as 132,000 people in the United States. It is a progressive, fatal disease characterized by scarring deep in the lung tissue that leads to respiratory or heart failure, pneumonia, and pulmonary embolism. The causes are unknown, although there may be genetic roots; there are no cures and no treatments approved by the Food and Drug Administration.

Palmer said the multi-site registry will help doctors who treat patients with idiopathic pulmonary fibrosis better understand how to diagnose and manage the disease, while it will also help researchers uncover the

basic causes and mechanisms of the disease.

"Many factors, including limited understanding of IPF, have resulted in a poor outlook for most patients, with many patients living only three to five years after diagnosis," said Craig Conoscenti, M.D., Director and Idiopathic Pulmonary Fibrosis Program Lead, Clinical Development and Medical Affairs at Boehringer Ingelheim Pharmaceuticals, Inc.

"We are excited to be partnering with Duke Clinical Research Institute to bring important insights and new knowledge that we believe will provide a better understanding of how IPF both presents and progresses," Conoscenti said.

The registry will recruit patients over a two-year period from the 14 pulmonary care sites, providing a diverse geographic area and drawing upon leading scientific experts in the field. Patients will be followed for three to five years to provide time to better understand the factors associated with disease progression and natural history.

In addition, researchers will create a bio-repository that will include blood samples, including patient genetic material, to better understand the biomarkers or genetic factors impact on patient outcomes.

Provided by Duke University