Pulmonary Hypertension Association Registry

Status: RECRUITING

Eligibility Criteria

Sex: ALL
Age: Not specified
Healthy Volunteers: This study is NOT accepting healthy volunteers
Inclusion Criteria:

- All age groups
- Written informed consent
- Pulmonary arterial hypertension (PAH), chronic thromboembolic pulmonary hypertension (CTEPH), or pediatric PH due to developmental lung disease
- Within 6 months of first outpatient visit at a PH Care Center

Exclusion Criteria:

- Diagnosis of WSPH Group 2 pulmonary hypertension
- Diagnosis of WSPH Group 3 pulmonary hypertension, except PH due to developmental lung disease
- Diagnosis of WSPH Group 5 pulmonary hypertension

Conditions & Interventions

Conditions:
Pulmonary Arterial Hypertension, Chronic Thromboembolic Pulmonary Hypertension, Pulmonary Hypertension

More Information

Description:
The PHA Registry (PHAR) is a national study about people who have pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH). PHAR collects information from people with PAH and CTEPH who are cared for in participating PHA-accredited Pulmonary Hypertension Care Centers throughout the U.S. PHAR will determine how people with PAH and CTEPH are evaluated, tested, and treated, and will observe how well these participants do. The goal is to see if people with PH are treated according to recommended guidelines, and to see if there are certain factors that can lead to better or worse outcomes. PHAR will include information about people with PAH and CTEPH in the U.S. who are seen at participating PHA-accredited PH Care Centers. PHAR contains data about patient care and outcomes. Specifically, data in the PHAR includes information on diagnosis; clinical status; socioeconomic status; diagnosis test results; body size; treatment information; interest in participating in clinical trials; family health and social history; and information about smoking, alcohol, or drug use. Participants are followed over time, and provide updates such as changes in therapy, how often participants need to go to the hospital, and survival. Such information may help healthcare providers provide better care.

Contact(s): Jaynee Bartsch - jaynee.bartsch@cchmc.org
Principal Investigator:
Principal Investigator ID:
Phase:
IRB Number:
System ID: NCT04071327