



Spotlight on PH Research

2018 PHA on the Road – Long Beach, Calif.

Session Description

The treatment options for PH continue to expand as a result of advances in treatment, care and research. This presentation will explain the questions that scientists ask and how they evolve into clinical trials and registries that aim to advance the field of PH. Additionally, regional clinical trials that are in progress and the ways PH patients may be able to participate in current research studies will be covered.

Learning Objectives

At the end of the session attendees will be able to:

Objectives

- Understand the value of clinical trials and research in pulmonary hypertension (PH)
- Understand what questions guide researchers and clinicians in the field
- Learn how to find and participate in available, local clinical trials and registries

Definition of a clinical trial

- The World Health Organization (WHO) defines a clinical trial as, “any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes.”

Where to find out about clinical trials

- Pulmonary Hypertension Association PHA website: www.PHAssociation.org/ClinicalTrials
- National Library of Medicine website: www.ClinicalTrials.gov

Benefits of participating in a clinical trial

- Generate knowledge that will help us understand, diagnose and/or treat PH now and in the future
- Without clinical research, we are unable to improve our understanding of human disease
- Early access to new tests or treatments
- Frequent contact with health care providers

Risks of participating in a clinical trial

- Side effects from medications or adverse effects from study procedures
- Time investment
- The test or treatment may be ineffective or even harmful

Definition of a registry

- A registry is a collection of information about individuals, usually focused around a specific diagnosis or condition. Many registries collect information about people who have a specific disease or condition, while others seek participants of varying health status who may be willing to participate in research about a particular disease. In a biobank registry, patient biological samples (blood, urine, sputum, saliva, tissue, etc.) are collected and stored for later scientific research endeavors.

Where to find out about registries

- National Institutes of Health website: <https://www.nih.gov/health-information/nih-clinical-research-trials-you/list-registries>
- National Library of Medicine website: www.ClinicalTrials.gov

Registries differ from clinical trials

- Registries collect information voluntarily from participants but no intervention (tests or drugs) outside of standard clinical care is assigned
- Volunteering for a registry does not mean a person has signed up for a clinical trial
- Participating in a disease registry sometimes can become a first step toward participation in a clinical trial, but registries and specific trials are not directly linked

Benefits of participating in a registry

- Generate knowledge about patients with PH both individually and as a group, which can be used to track trends over time
- Knowledge gained from a registry may be used to design future PH studies, including development and testing of new treatments
- Some registries enable patients to indicate interest in participating in a clinical trial

Risks of participating in a registry

- May involve additional time investment
- Although personal health information sometimes is collected, there is a very small chance that identifiable information is shared