PHA 2022 Research Room Studies

- Study Title	Study Description	Criteria to Participate	Research Room Activities
A Natural History Study of Novel Biomarkers in Pulmonary Arterial Hypertension (PAH) Researcher: Grace Graninger *Attention: Researchers will be unavailable on June 9th from 3-6:30 pm.*	Researchers in the PHA Research Room will share information with patients about the study. Patients will enroll in the study at a later date if they meet the criteria and are interested. The purpose of the study is to: – Determine if changes in blood inflammatory proteins over time are clinically useful in PAH and/or are associated with right ventricular function as assessed by cardiac MRI. – Examine circulating immune cell gene expression differences in PAH patients that may improve diagnostic testing or clinical monitoring. – Expand an integrated NIH PAH research program that includes a compliment of laboratory and clinical investigations.	<u>Inclusion Criteria</u> – WHO Group 1 Pulmonary Hypertension (PAH) – Patients 18 years or older – Ability to provide informed written consent <u>Exclusion Criteria</u> – Pregnant or breastfeeding women – Age less than 18 years – Inability to provide informed written consent	– Researchers will discuss the study with potentially interested participants and share written information. – QR code will provided. – Contact information will be collected from interested participants for future involvement. – Estimated time commitment: 15 minutes per participant for an informal discussion.
Patient perspectives on pulmonary rehabilitation Researcher: Hilary DuBrock *Attention: Researcher will be unavailable June 11th after 5:00 pm.*	Pulmonary rehabilitation is a supervised exercise and educational program for patients with chronic lung conditions, including pulmonary hypertension. Among patients with pulmonary hypertension, pulmonary rehabilitation has been shown to improve quality of life and exercise capacity. The purpose of the study is to better understand patient perspectives and attitudes regarding pulmonary rehabilitation. Patients with and without prior knowledge or experience with pulmonary rehabilitation are invited to participate.	<u>Inclusion criteria</u> – Self-reported diagnosis of Pulmonary Hypertension – Age ≥ 18 years <u>Exclusion Criteria</u> – Inability to complete survey in English	– Participants will complete a survey. – A QR code and link will be available. – Researcher will provide a tablet for participants without access to a cell phone or their own electronic device. – Estimated time commitment: 5-10 minutes.
Survey assessing shared decision-making by patients with pulmonary hypertension and practitioners that treat patients with pulmonary hypertension Researcher: Paresh Giri	There are multiple medications available for treating pulmonary arterial hypertension. This survey will quiz both patients and healthcare providers about their current shared decision-making practices and the processes used in decision-making when initiating PAH therapy.	<u>Inclusion criteria</u> – Able to read English – Currently on PAH therapy <u>Exclusion criteria</u> – Unable to read English – Not on current PAH therapy	– Participants will complete a survey using laptops and tablets provided by the researchers – Paper copies of the survey will be available. – A QR code will be available. – Researchers will provide a tablet for participants who do not have access to a cell phone or an electronic device. – Estimated time commitment: 5 -7 minutes

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The MObile Health InterVEntion in Pulmonary Arterial Hypertension (MOVE PAH) Study Researcher – Evan Brittain	Patients with PAH who are more active report having better quality of life. Researchers in the PHA Research Room will share information with patients about the study and review eligibility criteria. Patients will enroll in the study at a later date. The purpose of this study to test whether encouraging text messages and personalized step count goals can lead to increased physical activity in patients with PAH. All participants who enroll in the study will be provided a new Fitbit device and divided into 2 groups: one group will receive text messages 3 times per day with personalized messages encouraging them to reach their specific daily step count goal; the other group will wear the device but will not receive text messages. All participants will be asked to wear the device for approximately 7 months and to complete a quality of life survey, home-based six minute walk test, and list of medications three times during the study. Participants enrolled in the study will be compensated, and research group will share the results at the end of the study. A smartphone will be provided to participants, if needed.	<u>Inclusion criteria</u> – Age 18 years or old – Patients with idiopathic, heritable, associated (connective tissue disease, drugs, or toxins) PAH or PAH due to simple congenital heart disease (i.e., atrial septal defect) who are functional class I-III. – Patients must be on a stable dose of PAH-specific medication for the previous three months. – Patients must not be active on another investigational intervention. <u>Exclusion Criteria</u> – Patients prohibited from normal activity due to wheelchair bound status, bed bound status, reliance on a cane/walker, activity-limiting angina or activity-limiting osteoarthritis. – Pregnancy – Forced vital capacity 2 diuretic adjustments in the prior three months.	– Researchers will review eligibility criteria and introduce possible participants to the device and text message examples. – Researchers will obtain a release of medical information to confirm a PAH diagnosis prior to performing informed consent.
Activity Monitoring in Pulmonary Hypertension Researcher – Evan Brittain	The purpose of the study is to understand if someone's daily activity level (measured in steps) can tell us who is more likely, or less likely, to get sick over time. Researchers in the PHA Research Room will share information about the study and eligibility criteria. Patients will be enrolled at a later date. Participants enrolled in the study will be asked to wear a device that tracks your movements and heart rate and we will ask you questions about your quality of life and health. The device is called a Fitbit, which will be referred to as the device. Patients will be involved in this study for 3 years. Participants will be asked to wear the device four times, for 12-weeks at a time. There will be a baseline monitoring period, followed by monitoring periods every year for 3 years. There will be no in-person study visits. A smartphone is required to send the data from the device to the study team. If you do not have a smartphone, one can be provided to you for use in this study.	<u>Inclusion criteria:</u> – Any patient in the United States with pulmonary hypertension confirmed by hemodynamics and expert clinical diagnosis <u>Exclusion criteria:</u> – Pregnancy – Hospitalization within the prior 3 months (please note that patients with a recent hospitalization will be contacted for possible enrollment after 3 months has elapsed from their last hospitalization)	– Researchers will explain the study and will familiarize potential participants with the device and how the device interacts with their smartphone. – Researchers will assess eligibility criteria and perform the consent process. Full eligibility will be confirmed after review of clinical records. – A signed release of information for clinical records will be collected in the Research Room.

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Health-Related Quality of Life: Patient-Focused Strategies for Measuring and Improving Sexual Health and Functioning Among Patients with Pulmonary Arterial Hypertension Researcher: Sara Vargas	Researchers are developing a survey that will help medical providers and researchers better understand sexual health and relationships among people living with pulmonary arterial hypertension. Researchers are also developing a guide to support the use of this survey during medical appointments with recommendations for how to address sexual health and relationships with patients.	<u>Inclusion criteria:</u> – Adults (>=18 years of age) who have: A. Self-reported diagnosis of PAH that is idiopathic, heritable, or associated with connective tissue disease, human immunodeficiency virus (HIV) infection, congenital systemic-to-pulmonary shunt, porto-pulmonary hypertension, or drug- or toxin-induced. B. Self-reported diagnosis of chronic thromboembolic pulmonary hypertension (CTEPH) that is non-operative or persistent/recurrent after endarterectomy or balloon pulmonary angioplasty. C. Provided A) or B) are met, treatment with targeted PAH therapy. <u>Exclusion criteria</u> – Self-reported history of congestive heart failure, chronic obstructive pulmonary disease, interstitial lung disease, or untreated obstructive sleep apnea.	– Researchers will provide interested participants with a QR code to access the self-guided screening questions and, if eligible, consent form. – Those who are eligible and sign the online consent form are invited to participate in a one-time online survey focused on general and sexual health-related quality of life. – All study activities can be completed online at the participant's convenience – Estimated time commitment: Approx. 30 minutes
Technology-Assisted Mindfulness for Symptom Management among Adults with COPD and PH Researcher: Tania Von Visger	Patients with PH experience a lot of psychological distress symptoms to which a complementary approach such as Mindfulness practice can help in PH self-management. Mindfulness-based stress reduction (MBSR) program effectively reduces depression and anxiety in persons with and without chronic conditions. However, in-person MBSR requires a lengthy time commitment and efforts to attend classes. The purpose of this survey is to determine whether patients with PH know about Mindfulness practice and its potential usefulness.	<u>Inclusion criteria</u> – >18 years of age – Diagnosed with COPD or PH, – Able to read and write in English – Having access to the internet and electronic device (laptop computer, smartphone, or iPad). <u>Exclusion criteria</u> – Individuals who cannot read or write English – Visually impaired individuals	– Participants will complete online survey questions and may access the REDCap link for data entry either via their own mobile phone or iPads. – A limited number of electronic devices will be available for participants without a device. – Estimated time commitment: 20 - 30 minutes.

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Pulmonary Arterial Hypertension (PAH) and Genetics Testing: A Patient Survey Researcher: Sandeep Sahay	The objective of this survey is to improve understanding of the patient perspective regarding genetic testing in the management of PAH.	Inclusion criteria – Adult patients ie >18 years – Diagnosis of PAH Exclusion criteria – PH patients from groups 2-5.	– Participants will complete a survey. – A QR code will be available. – Participation is anonymous, voluntary and there is no incentive – Participants may choose to decline at any time in the survey.