Pulmonary Hypertension Association, 2024 Conference, Research Room
Universal Data Collection Questionnaire: Demographics and Background Information

Today's Date: _____

Name:_____
(first) (middle) (last)

Date of Birth: _____ **Current Age:** _____

Address: _____

_____

_____

Phone: (home)_____

(cell)_____

Email:_____

Preferred method for us to contact you (check all that apply):

☐ Phone ☐ Email ☐ Regular Mail

Gender Identity:
☐ Female ☐ Male ☐ Non-Binary/Gender Non-conforming ☐ Transgender ☐ Prefer not to disclose

Ethnic Background:
☐ Hispanic or Latino
☐ Not Hispanic or Latino
☐ Both

Racial Background:
☐ American Indian/Alaska Native
☐ Asian/Asian American
☐ Black/African American
☐ Middle Eastern/North African
☐ Native Hawaiian or Pacific Islander
☐ White
☐ Unknown
☐ Other:
☐ Prefer not to answer

Do you have Pulmonary Hypertension (any type)? Yes ☐ No ☐

Do you have other family members with PH: Yes ☐ No ☐
If yes, how are they related to you?_____

If you do not have PH yourself, stop here. You do not need to complete the rest of the questionnaire.

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It is important for the researchers to have accurate information regarding the type of PH you have. If possible, please discuss the following questions with your doctor before the conference.

Please check one of these boxes:

- ☐ Yes, I have confirmed my diagnosis with my PH physician.
- ☐ No, I have not discussed this with my physician.
- ☐ I am unsure of my type of PH.

If you do have PH, please tell us more about the type of PH and your medical history below.

Do you have Pulmonary Arterial Hypertension (PAH/Group 1)? Yes ☐ No ☐

If yes, please check the type of PAH that you have:

A. ☐ Idiopathic
B. ☐ Familial/Heritable (family members also with PAH)
C. ☐ Associated with connective tissue disease
   - If yes, date of diagnosis with that connective tissue disease (Mo/Yr)_____
   - If yes, type of connective tissue disease:
     - ☐ Scleroderma/CREST
     - ☐ Lupus (SLE)
     - ☐ Rheumatoid Arthritis (type unknown)
     - ☐ Mixed connective tissue disease
     - ☐ Other connective tissue disease: _____
D. ☐ Congenital heart disease
E. ☐ Drugs and Toxins (e.g. a diet drug, or methamphetamine) Please specify:_____
F. ☐ HIV
G. ☐ Liver disease (portopulmonary hypertension)
H. ☐ Pulmonary veno-occlusive disease (PVOD) or pulmonary capillary hemangiomatosis (PCH)

Do you have Pulmonary Hypertension due to Left Heart Disease (Group 2) Yes ☐ No ☐

Do you have Pulmonary Hypertension due to Chronic Lung Disease (Group 3) Yes ☐ No ☐

- If yes, type of chronic lung disease:
  - ☐ PH-ILD/Pulmonary fibrosis
  - ☐ Chronic Obstructive Pulmonary Disease (COPD)
  - ☐ Mixed Obstructive/combined emphysema
  - ☐ Other: _____

Do you have Chronic Thromboembolic Pulmonary Hypertension (CTEPH/Group 4) Yes ☐ No ☐

Do you have Pulmonary Hypertension due to Another Cause (Group 5) Yes ☐ No ☐

If yes, please specify:_____

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MEDICAL HISTORY QUESTIONS

What was the approximate date of your PH diagnosis (confirmed by right heart catheterization)
Month, Year:_____
Age at time of diagnosis: _____
Age of first symptom onset: _____

Do you or have you had any of the following: (check if "Yes")

☐ Cancer	☐ Asthma	☐ Rheumatic Fever
☐ Leukemia	☐ Sleep Apnea	☐ Thyroid disease
☐ Epilepsy	☐ Colitis	☐ Diabetes
☐ Heart Disease	☐ Anemia	
☐ Stroke	☐ HIV	
☐ Psoriasis	☐ Liver disease	

Smoking History (Cigarette and/or Vape Use):

☐ Current/Daily Smoker ☐ Casual/Social Smoker ☐ Former Smoker
☐ Non-smoker

What is your weight?_____
What is your height?_____
Do you use oxygen? Yes ☐ No ☐

Please circle the description below that best describes your daily symptoms with PAH:

1. No symptoms and no limitation in ordinary physical activity. Example: shortness of breath when walking, climbing stairs etc.

2. Mild symptoms (mild shortness of breath and/or chest pains) and slight limitation during ordinary activity.

3. Significant limitation in activity due to symptoms, even during less-than-ordinary activity. Example: walking short distances. In fact, comfortable only at rest.

4. Severe limitations to activity with symptoms even while at rest.

Current PH Medications

Please check if you are currently being treated with any of the following PH medications:

- ☐ Ambrisentan (Letairis)
- ☐ Amlodipin
- ☐ Bosentan (Tracleer)
- ☐ Diltiazem
- ☐ Epoprostenol (Flolan or Veletri)
- ☐ Felodipin
- ☐ Iloprost
- ☐ Isradipin
- ☐ Lercanidipin
- ☐ Macitentan (Opsumit)
- ☐ Nifedipin
- ☐ Orenitram
- ☐ Remodulin
- ☐ Riociguat (Adempas)
- ☐ Selexipag (Uptravi)
- ☐ Sildenafil (Revatio)
- ☐ Sitaxentan
- ☐ Tadalafil (Adcirca)
- ☐ Treprostinil
- ☐ Tyvaso
- ☐ Verapamil
- ☐ None/No PH Specific Medications

☐ Are you currently receiving any PH drug(s) through a clinical trial? If so, which drug(s):_____

Current Medications

Please list all other non-PH medications you are currently taking.

Name of Drug	**Dose – Optional** (Include strength and number of pills per day)	**How long have you taken this medication?**

Is there a person close to you who we may contact if we are unable to reach you?

Name:_____

Phone: (home)_____ (cell)_____

Email: _____