**Pulmonary Hypertension Association, 2022 Conference, Research Room**
**Universal Data Collection Questionnaire: Demographics and Background Information**

**GENERAL QUESTIONS** **Today's Date: _____**

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

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

**Address:** _____

_____

_____

**Phone:** **(home)**_____

**(cell)**_____

**(work)**_____

**Email:** _____

**Preferred method for us to contact you (check):**

☐ **phone** ☐ **email** ☐ **regular mail**

**Gender:** ☐ **Female**
☐ **Male**

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

**Racial Background**
☐ **American Indian/Alaska Native**
☐ **Chinese**
☐ **Japanese**
☐ **Vietnamese**
☐ **Black/African American**
☐ **Native Hawaiian or other Pacific Islander (Native Hawaiian Guamanian, Chamorro, Samoan, Other Pacific Islander)**
☐ **Asian Indian**
☐ **Filipino**
☐ **Korean**
☐ **Other Asian**
☐ **White**
☐ **Unknown/Other**
☐ **Refuse 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, WSPH Group 1)? yes ☐ no ☐**
If yes, please check the type of PAH that you have:
A) Idiopathic ☐
B) Familial (family members also with PAH, also called Heritable) ☐
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) ☐
Arthritis (type unknown) ☐
Ankylosing Spondylitis ☐
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 (WSPH Group 2 PH) yes ☐ no ☐**

**Do you have Pulmonary Hypertension due to Chronic Lung Disease (WSPH Group 3 PH) yes ☐ no ☐**

**Do you have Chronic Thromboembolic Pulmonary Hypertension (WSPH Group 4 PH) yes ☐ no ☐**

**Do you have Pulmonary Hypertension due to Another Cause (WSPH Group 5 PH) yes ☐ no ☐**

**Other, specify:_____**

**If you have PH, what is the approximate date of your PH diagnosis (confirmed by right heart catheterization) (Mo/Yr):_____**
**Age at time of diagnosis: _____**
**Age of first symptom onset: _____**

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**BRIEF MEDICAL HISTORY QUESTIONS**

**Have you ever used a weight loss drug? yes ☐ no ☐**
**If yes, what is the name(s) of it (e.g., Phen/Fen)?_____**

**Do you or have you had: (check if "yes")**

| | | | | | |
|---|---|---|---|---|---|
| **Cancer** | ☐ | **Asthma** | ☐ | **Rheumatic Fever** | ☐ |
| **Leukemia** | ☐ | **Sleep Apnea** | ☐ | **Thyroid disease** | ☐ |
| **Epilepsy** | ☐ | **Colitis** | ☐ | | |
| **Heart disease** | ☐ | **Anemia** | ☐ | | |
| **Stroke** | ☐ | **HIV** | ☐ | | |
| **Psoriasis** | ☐ | **Liver disease** | ☐ | | |

**What is your weight?_____**
**What is your height?_____**
**Do you use oxygen? yes ☐ no ☐**

**<u>Please circle the description below that best describes your daily symptoms with PAH:</u>**

**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.**

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**Current Medications**

| Name of Drug | Dose (Include strength and number of pills per day) | How long have you taken this medication? |
|---|---|---|
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**Is there a person close to you who we may contact if we are unable to reach you?**

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

**Address:** _____

_____

_____

**Phone: (home)**_____**(cell)**_____

**(work)**_____**email:** _____