



## PVDOMICS STUDY

### Initial Enrollment Form #100

**Instructions:** Form 100 is completed and entered for each participant who consents to the PVDOMICS study. The alphacode is populated at the time this form is saved to the database. The identification number (PID) and alpha(numeric) code are unique to each participant and are used on all data collection forms.

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1. Identification Number

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2. Alphacode

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3. Date of initial enrollment (mm/dd/yyyy)

4. a. Date participant signed the consent form?(mm/dd/yyyy)..... \_\_\_\_/\_\_\_\_/\_\_\_\_
- b. Which consent was signed? (1=Main/Comparator, 2=Control)..... \_\_\_\_
- b1. If response to Q4b=1, what type of participant is this? (1=Main, 2=Comparator)..... \_\_\_\_
- c. Did participant agree to be contacted if clinically relevant genetic results become available? (0=No, 1=Yes)..... \_\_\_\_
- d. If yes to 4c (and participant is not a control), what did the participant agree to? ..... \_\_\_\_  
 1=ONLY results related to pulmonary hypertension risk  
 2=ONLY results related to risks for other serious health conditions  
 3=ANY results related to pulmonary hypertension or other diseases
5. a. Did participant sign Biobank consent form? (0=No, 1=Yes\*)..... \_\_\_\_  
 \*Participant agreed to allow samples/data to be sent to the Biobank at the end of the PVDOMICS study.
- b. Date participant signed the consent form for the Biobank?  
 (mm/dd/yyyy)..... \_\_\_\_/\_\_\_\_/\_\_\_\_
6. Sex of participant? (1=Male, 2=Female)..... \_\_\_\_
7. *For NIH:* Hispanic or Latino ethnicity? (0=No, 1=Yes, 9=Unknown or not reported)..... \_\_\_\_
8. Race? (*NIH format – Hispanics must choose a race*) ..... \_\_\_\_  
 1=American Indian/Alaska Native                      5=White  
 2=Asian    6=More than one race  
 3=Native Hawaiian or Other Pacific Islander      9=Unknown or not reported  
 4=Black or African American
9. Date of birth? (mm/dd/yyyy) ..... \_\_\_\_/\_\_\_\_/\_\_\_\_  
*Note, for eligibility, age must be 18 years at the time of enrollment.*

(continued on next page)

10. In the clinician's opinion, able to perform complete diagnostic testing according to protocol criteria? (0=No, 1=Yes) .....
11. In the clinician's opinion, too ill to perform the protocol testing? (0=No, 1=Yes).....
12. Dialysis dependent renal function? (0=No, 1=Yes) .....
13. Pregnant or nursing? (0=No, 1=Yes) .....

**Participant Source (not for eligibility)**

14. How did this participant first hear about the study?.....
- |   |  |
|---|--|
| 1=Personal physician or personal physician's office | 7=Received information in mail             |
| 2=PVDOMICS physician                                | 8=Health program or health fair            |
| 3=Other PVDOMICS study staff member                 | 9=Saw a newspaper article or advertisement |
| 4=Other physician or health professional            | 10=Learned of it from NHLBI or PHA website |
| 5=Relative/Friend                                   | 99=Unknown                                 |
| 6=Saw a poster or brochure                          |  |

200. Date form completed (mm/dd/yyyy)...../\_\_\_\_/\_\_\_\_
201. Username of person completing/reviewing completeness of this form .....

**Clinical Center Use Only**

Date form entered (mm/dd/yyyy) \_\_\_\_/\_\_\_\_/\_\_\_\_

Username of person entering this form\_\_\_\_\_