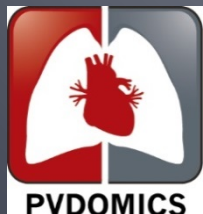


# GENERAL FORMS OVERVIEW



## **NHLBI Pulmonary Vascular Disease Phenomics Program**

*Funded by the National Heart, Lung, and Blood Institute of the  
National Institutes of Health with support from  
the Pulmonary Hypertension Association*

# Form 100 Initial Enrollment

- Date participant signed and what consent was signed
- Does the participant want to be contacted regarding genetic data?
- Biobank consent form and date
- Sex and Ethnicity
- Can the participant complete the testing, dialysis dependent or pregnant or breast feeding
- How did they hear about the study

# Form 104 Demographic Employment and Income

- Marital status, household, highest level of education, primary language, work status and household income, number of household and zip code-Form 104

# Form 105 Exposure History

- Industrial Solvents-Regular exposure through occupation or living environment to things such as gasoline and kerosene, toluene (used in paint thinner, contact cement and model glue), Dry cleaning agents, pesticides, explosives, fire works, dyes and detergents.
- Asbestos-fibrous silicate material (fire resistant and insulating materials)
- Mineral dust-Silica (mining quarrying, foundry), beryllium (nuclear power plants, aerospace), Coal dust
- High Altitude (>5000 ft)
- Animals and Birds (both inside and outside)
- Mold

# Form 105 Continued

- Diet and recreational Drugs
- Smoking (cigarettes, E-cigarettes, cigars, pipe and smokeless tobacco)
- Alcohol

# Form 106-Thrombophilia

- Does/Did the participant (and age they were during the event) have:
  - Any biological relatives (mother, father, child, sister, brother, grandparent or sister or brother, aunt or uncle) have:
    - DVT (deep vein thrombosis)
    - PE (pulmonary embolism)
    - MI (myocardial infarction/heart attack)
    - CVA (cerebrovascular accident/stroke)
    - Arterial Thrombus (clot within arterial system of the body)
    - Was anticoagulant being used during the event and provoked or unprovoked

# Form 106 Continued

- Any participant or family history of: clotting disorder, platelet abnormality, chronic hemolytic anemia, myelodysplastic syndrome?
- Any history of antiplatelet agent use (aspirin, Plavix, Effient, Brilinta, etc.?)
- Any history anticoagulant use (Coumadin, Xarelto, Eliquis, Lovenox, Heparin)?
- Does the participant have a intravenous catheter and was it ever associated with a DVT or PE?

# Form 107 Family History of Pulmonary Hypertension

- Mother's and Father's race
- Family history of pulmonary hypertension?
- Family member enrolled in PVDOMICS?
- If PH is present in the family then you are to ask by family member (mother, father, grandparent, aunt, uncle or child) 0-No, 1=Yes confirmed, 2=Yes, suspected 8=NA, adopted 9=Unknown
  - Have PH,
  - WHO group class,
  - Sudden death
  - Age at death

# Form 110-Medication Form

- All medications are captured on this form (OTC, prescribed, herbal supplements etc). This is obtained through the medical record and participant interview.
- In the last 3 months has the participant received:  
Blood or platelet transfusion, Intravenous immunoglobulin, chemotherapy or immunosuppressive medications
- Box to list Immunosuppressive and Chemotherapy
- Are they taking OTC or supplements
- List all medications
- Oxygen use at rest, at night, on exertion and amount used.

# Forms 170-172-Health Related Quality of Life Questionnaires

- Form 170 SF-36-participant fills out questionnaire related to their health and well-being
- Form 171-Minnesota Living with Heart Failure Questionnaire-participant circles 0-5 regarding 21 items during the past 4 weeks
- Form 172-EmPHasis-10 Quality of Life-10 questions that the participant answers 0-5
- Forms 171 and 172-have a form for the coordinator to fill out regarding how the questionnaire was completed