Heart Institute Biobank & Registry for Adult Congenital Heart Disease and Related Disorders

Status: RECRUITING

Eligibility Criteria

Sex: ALL
Age: 16 years and over
Healthy Volunteers: This study is also accepting healthy volunteers
Inclusion Criteria:

1. Any person ≥ 16 years-old suspected of having or diagnosed with congenital heart disease (CHD), other cardiovascular disease (CVD), pulmonary hypertension, connective tissue disease, or genetic syndrome/diagnosis.
2. Additionally, a cohort (Control group A) of control subjects will be enrolled, again ≥16 years-old, self-reported non-smokers without a known history of diabetes mellitus, myocardial infarction, stroke, heart failure, or chronic kidney disease. These controls will be either:
    1. A family member or other person accompanying a patient to a clinical encounter; or,
    2. A volunteer recruited via an advertisement; or,
    3. Another person who volunteers to enroll in HIBR-ACHD.
3. A cohort (Control group B) of comparison subjects who do not have CHD, but have a diagnosis of heart failure or pulmonary hypertension.

Exclusion Criteria:

- Unable to provide informed consent/assent personally or via a legal guardian.
- Considered unsafe to collect the biospecimen determined by either a clinical provider or an HIBR-ACHD investigator.
- Overnight hospitalization for non-obstetric reason with discharge in the prior 30 days.

Conditions & Interventions

Conditions:
Adult Congenital Heart Disease, Pulmonary Hypertension, Connective Tissue Disease, Other Cardiovascular Conditions
Keywords:
ACHD, Adult Congenital Heart Disease

More Information

Description:
A repository of biospecimens and detailed phenotypic information collected longitudinally from adults with congenital heart disease and related conditions, with an aim to facilitate future research on biologic mechanisms of underlying disease, compensation and deterioration; biologic correlates of patient experience and functional status; associations between clinical characteristics and various biomarkers; and predictors of clinical outcomes.

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