

---

**HEART-ACHD**  
**Health Education and Access**  
**Research Trial for Adult**  
**Congenital Heart Disease**

NIH R03-HL096135-01

# “Partners In Research” Program

---

- Part of Public Trust Initiative (PTI), an initiative of the National Institutes of Health (NIH)
  - Mission: enable the public to understand and have confidence in the research that NIH conducts and supports
- Engage scientists, community leaders, members of the public, and patient advocacy groups
- Develop partnerships between scientific or research institutions and community organizations
- Evaluate a variety of approaches in a range of target audiences or communities

# Partners In Research - RFA

---

- Fall 2007: release of a new Request for Applications (RFA) for the Partners in Research program
- The purpose of this RFA:
  - support studies designed to improve public understanding of health care research
  - promote collaboration between scientists and community organizations
  - help in the development of strategies to increase the public awareness and trust in the role of NIH and the importance of new directions of research for advancing the public health

# HEART-ACHD

---

- Response to Partners in Research RFA
- Effort of AARCC and ACHA
- Funding awarded 9/08 from NHLBI
- Grant writing committee:
  - Amy Verstappen – ACHA
  - Paul Khairy, Anne Valente, Joe Kay, Michelle Gurvitz - AARCC
- Co Principal Investigators:
  - Amy Verstappen – ACHA
  - Michelle Gurvitz – Seattle Children’s Hospital

# PARTICIPATING PROGRAMS

---

- UW / SCH – Michelle Gurvitz
- OHSU – Craig Broberg
- Univ Colorado – Joseph Kay
- OSU/Nationwide – Stephen Cook
- Wisconsin – Mike Earing
- Penn State – Jennifer Ting
- CNMC – Karen Kuehl
- HUP – Alexander Opotowsky / Gary Webb
- Columbia – Deborah Gersony
- UCLA – Jamil Aboulhosn
- BACH – Anne Marie Valente / Michael J. Landzberg

# HEART-ACHD

---

- Evaluation of New Patients to ACHD clinics
- AIMS:
  - To determine the prevalence of lapses in specialized CHD care and identify barriers to care
  - To assess the impact of a targeted educational intervention (ACHA passport and website) on disease knowledge and views regarding active participation in future ACHD-specific studies

# HEART-ACHD

- METHODS

- Baseline survey prior to seeing provider
- Subject given ACHA passport
- Directed to ACHA website (targeted based on first survey)
- Repeat survey at ~3 mos
- All data de-identified and sent to ACHA for data entry
- Expect ~1200 patients to complete both surveys

# HEART-ACHD

- TIMELINE
  - Months 1-3
    - (1) Finalize IRB approval (2) Finalize central database format and questionnaires (3) ACHA and research coordinator to coordinate with participating centers
  - Months 3-21
    - (1) Administer primary and follow up questionnaires and collect data (2) Begin data analysis
  - Months 18-24
    - (1) Data analysis (2) manuscript preparation (3) sharing of results with participating subjects and the community

# HEART-ACHD: UPDATE

---

- All programs have IRB approval
- 8 have started enrollment
- Total enrolled and first survey received:  
60 subjects
- First set of secondary surveys will go  
out: June 2009