

Alliance for Adult Research in Congenital Cardiology (AARCC): The First 4 years





2007

2006 – 2009 Accomplishments

2 new associates

1 new center

1 grant acceptance

5 ongoing research studies

4 abstract presentations

1 published manuscript

7 pages of bylaws

8 web pages

0 dollars in treasury

Centers



- University of Washington, Seattle, WA
- Oregon Health & Science Univ, Portland, OR
- University of California, Los Angeles, CA
- University of Colorado, Denver, CO
- Mayo Clinic, Rochester, MN
- Medical College of Wisconsin, Milwaukee, WI
- Ohio State University, Columbus, OH
- Pennsylvania State University, Hershey, PA
- University of Pennsylvania, Philadelphia, PA
- Columbia University, New York, NY
- Children's Hospital Boston, Boston, MA
- Montreal Heart Institute, Montreal, QC
- Emory University, Atlanta, GA

HEART ACHD

Identifying factors related to clinical follow-up and effects of
ACHD education

Joint collaboration with ACHA

NIH RO3 funded

Progress:

Enrollment began 1/2009

Next Step:

Continuing enrollment

Pregnancy Study

Predicting outcomes in pregnancy from exercise testing

$N = 75$ women/77 pregnancies

(in conjunction with C. Silversides, Toronto)

Data on cardiopulmonary exercise testing and pregnancy outcome

Progress:

Data collection and analysis complete

Next step:

Abstract submission (AHA)

Manuscript preparation

Tetralogy of Fallot Study

Descriptive study of TOF echo findings (LV dysfunction, diastolic parameters, and aortic root size)

$N = 563$ patients

Demographic and Echocardiographic Data

Progress:

3 abstracts presented at ACC

1 abstract at ACHA

Next step:

Final analysis

Manuscript submission

CALF Study

Venous stasis in Fontan patients

$N = 156$ Fontans, 40 controls

Data on lower extremity venous stasis changes
including photographic assessment

Progress:

Enrollment complete

Next Step:

Final data analysis

Manuscript submission for AHA

Coarctation Study

Incidence of cerebral aneurysm and CAD (by CT)

$N = 25 + 12$ controls

CT scans of head and coronary arteries

Progress:

Local funding (OSU)

Preliminary data/fine-tuning methodology

Next Step:

Multicenter expansion

TEAR-RV

Comparison of echo/mri findings in TOF

Preliminary stages

IRB approval

Manuscripts

Khairy, P et al. “Multicenter Research in Adult Congenital Heart Disease.” *Int J Cardiol.* 2008 Sep 25; 129(2):155-9.

Review; Explores multicenter efforts to date and lessons learned.

Goals

Publication of existing data

Establish common patient tracking tool (CONGENERATE)

Additional patient cohorts

Grant submission for funding

Prospective studies

Collaboration with other centers

