



Anomalous Aortic Origin of a Coronary Artery (AAOCA) Study

PATIENT ENROLLMENT FORM

OVERALL GOAL & OBJECTIVES:

- Develop a registry of children and young adults with Anomalous Aortic Origin of a Coronary Artery (AAOCA) with an interarterial, intraconal or intramural course
- Characterize the natural and unnatural history of AAOCA
- Characterize outcomes after interventions for AAOCA
- Develop models to identify patients in whom the risk of observation is greater than the risk of intervention and, conversely, patients in whom the risk of intervention is greater than the risk of observation

INCLUSION CRITERIA:

- Diagnosis of AAOCA at a CHSS member institution from January 1, 1998 forward
- Age \leq 0-30 years at time of diagnosis
- Diagnosis made:
 - i) From January 1, 1998 to study initiation for retrospective subjects
 - ii) From January 21, 2009 forward for prospectively identified subjects
- Structurally normal heart or heart with small, hemodynamically insignificant lesion, including: patent ductus arteriosus, atrial septal defect, restrictive ventricular septal defect, mild pulmonic valvar stenosis, or bicuspid aortic valve without aortic stenosis.
- Parental/guardian permission or subject consent if > 18 years of age

EXCLUSION CRITERIA:

- Anomalous coronary from the pulmonary artery, coronary artery atresia, or other coronary artery anomalies (e.g., coronary-cameral fistula, coronary aneurysms, myocardial bridging)
- Hemodynamically significant structural heart disease, except as outlined above.

To be completed by Enrollment Institution, for EACH patient being enrolled

Patient: _____ Date of Birth: _____
 Parent Name (if age<18): _____ Death Date (if applicable): _____
 Address: _____ Gender: Male Female
 _____ Date of diagnosis: _____
 Phone Number (Home/Cell): _____ Name of Alternate Contact for Patient: _____
 Email: _____ Phone Number of Alternate Contact: _____
 Institution: _____ Surgeon: _____
 Medical Record Number: _____ Surgeon's Phone Number: _____
 Cardiologist: _____ Primary M.D.: _____
 Cardiologist's Phone Number: _____ Primary M.D. Phone Number: _____

What needs to be sent for each patient?

- | | |
|--|--|
| <input type="checkbox"/> Copy of signed consent | <input type="checkbox"/> ALL echocardiogram reports (including TEE, echo, stress echo) |
| <input type="checkbox"/> Admission Slip or equivalent for demographic information | <input type="checkbox"/> ALL catheterization reports |
| <input type="checkbox"/> Admission history and physical | <input type="checkbox"/> ALL CT scan report s |
| <input type="checkbox"/> Operative report for coronary repair | <input type="checkbox"/> ALL MRI reports |
| <input type="checkbox"/> Perfusion record for coronary repair | <input type="checkbox"/> ALL Exercise Test reports |
| <input type="checkbox"/> Anesthetic record for coronary repair | <input type="checkbox"/> ALL Nuclear medicine reports |
| <input type="checkbox"/> Discharge summary | <input type="checkbox"/> ALL Holter reports |
| <input type="checkbox"/> Autopsy report / Death report | <input type="checkbox"/> ALL Cardiac Clinic letters |
| <input type="checkbox"/> For prospective patients: CD of all echocardiograms, catheterizations, CT scans, MRIs | <input type="checkbox"/> Initial ECG at time of diagnosis |
| <input type="checkbox"/> For retrospective patients: CD of complete echocardiogram, catheterization, CT scan and MRI only at time of diagnosis | |

For CHSS Data Center Use Only

Date placed on Registry: _____ Enrolled by: _____
 Study Number: _____



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