



# ATRIOVENTRICULAR SEPTAL DEFECT (AVSD) STUDY

## CHSS DATA CENTER REGISTRATION FORM

Date placed on Registry: \_\_\_\_\_ Enrolled by: \_\_\_\_\_

Study Number: \_\_\_\_\_

### OVERALL GOALS & OBJECTIVES

- Define the anatomic features of Unbalanced Atrioventricular Septal Defect (uAVSD)
- Determine patient and morphologic/physiologic factors that are associated with selection of surgical strategy and survival
- Determine relationships between patient and anatomic characteristics, selected surgical strategy, and outcome
- Develop and evaluate a clinically applicable prediction model to facilitate clinical decision making

### INCLUSION CRITERIA

**Check as applicable:**

- YES  NO Diagnosis of or referral with complete AVSD at a CHSS institution
- YES  NO Admitted to a CHSS institution for surgery after January 1, 2012
- YES  NO Age  $\leq$  365 days at admission for surgery
- YES  NO Atrioventricular and Ventriculoarterial concordance (includes Tetralogy of Fallot and Double Outlet Right Ventricle)

Must **MEET** all inclusion criteria (must all be **YES**)

### EXCLUSION CRITERIA

**Check as applicable:**

- YES  NO Partial or Transitional AVSD (separate AV valve orifices, restrictive VSD or intact ventricular septum)
- YES  NO Total or Partial Anomalous Pulmonary Venous Drainage (TAPVC or PAPVC)
- YES  NO Aortic Atresia
- YES  NO Heterotaxy
- YES  NO First intervention at a non-CHSS institution

Must **NOT** meet any exclusion criteria (must all be **NO**)

### RECEIVED DOCUMENTS

**Please check off all documents received:**

- |   |  |
|---|--|
| <input type="checkbox"/> Copy of signed consent and authorization (as applicable) (otherwise explain: _____)                      | <input type="checkbox"/> CT Cardiac imaging and report (if performed)                      |
| <input type="checkbox"/> Admission slip or equivalent for demographic information   | <input type="checkbox"/> MRI cardiac imaging and report (if performed)                     |
| <input type="checkbox"/> Admission history and physical (to include height, weight, oxygen saturation, signs and symptoms)        | <input type="checkbox"/> Any subsequent hospital admission (admit history and reports)     |
| <input type="checkbox"/> ALL Cardiac Cath report(s) (diagnostic and/or interventional)  | <input type="checkbox"/> Anesthetic and perfusion records                                  |
| <input type="checkbox"/> A copy of initial echo CD (most complete pre-intervention echo (TTE) in <b>DICOM</b> format) with report | <input type="checkbox"/> ALL Cardiac operative report(s) <b>AND</b> cardiac clinic note(s) |
| <input type="checkbox"/> Pre-discharge echo CD (post initial intervention (TTE) in <b>DICOM</b> format) with report               | <input type="checkbox"/> ALL Echo reports (include any TEE)                                |
| <input type="checkbox"/> Late post op echo CD (1 year up to 4 years post op (TTE) in <b>DICOM</b> format) with report             | <input type="checkbox"/> ALL Discharge summaries   |
|   | <input type="checkbox"/> Autopsy report / Death report (if applicable)                     |

Completed by: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**SickKids**<sup>®</sup>

555 University Ave  
Toronto, ON M5G 1X8, Canada  
1-866-477-CHSS (2477)  
Fax: 416-813-8776  
chss.dc@sickkids.ca  
www.chssdc.org

**EXECUTIVE DIRECTOR**  
Dr. William G. Williams

**MANAGING DIRECTOR**  
Dr. William M. DeCampi

**STATISTICAL CONSULTANTS**  
Dr. Brian McCrindle  
Dr. Eugene Blackstone

**DATABASE MANAGER**  
Sally Cai

**KIRKLIN/ASHBURN FELLOW**  
Dr. James Meza

**CLINICAL RESEARCH ASSOCIATE II**  
Kathryn Coulter

**CLINICAL RESEARCH NURSE COORDINATORS**  
Kristina Kovach  
Susan McIntyre

**CLINICAL RESEARCH PROJECT ASSISTANTS**  
Annette Flynn  
Iliana Ristevska