



# Tricuspid Atresia Study

## PATIENT ENROLLMENT FORM

### OVERALL GOAL & OBJECTIVES

- To assemble a multi-institutional inception cohort of patients with Tricuspid Atresia and normally related great arteries.
- To determine the impact of patient characteristics and management algorithms on outcomes of the Fontan track for infants with Tricuspid Atresia
- To examine the overall health status and quality of life of patients with Tricuspid Atresia

### INCLUSION CRITERIA

- Diagnosis of tricuspid atresia with normally related great arteries
- Age < 3 months at time of diagnosis
- Admitted to a CHSS institution after January 1, 1999; i.e. Date of Birth after October 1, 1998

### EXCLUSION CRITERIA

- Patients with AV discordance/Double outlet
- First intervention at non-CHSS institution
- Age > 3 months at time of diagnosis i.e. birth date before October 1, 1998

### For CHSS Data Center Use Only

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

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

Patient: \_\_\_\_\_ Phone: \_\_\_\_\_  
 Parents' Names: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Date of Birth: \_\_\_\_\_ Birth Weight: \_\_\_\_\_ Birth Height: \_\_\_\_\_  
 Gender: Male  Female  Race: \_\_\_\_\_ Language: \_\_\_\_\_  
 Hospital Number: \_\_\_\_\_ Date of first admission: \_\_\_\_\_  
 Date of discharge: \_\_\_\_\_ Death Date (if applicable): \_\_\_\_\_  
 Preliminary Diagnosis: \_\_\_\_\_  
 Operation: \_\_\_\_\_  
 Institution: \_\_\_\_\_ Pediatric Cardiologist: \_\_\_\_\_  
 Surgeon: \_\_\_\_\_ Local Physician: \_\_\_\_\_  
 Phone: \_\_\_\_\_ Contact Person: \_\_\_\_\_  
 Email address: \_\_\_\_\_  
 Notes: \_\_\_\_\_

### What needs to be sent for each patient?

- |  |  |
|--|--|
| <input type="checkbox"/> A copy of signed consent form   | <input type="checkbox"/> Operative report(s)                           |
| <input type="checkbox"/> Admission Slip or equivalent for demographic information  | <input type="checkbox"/> Discharge summaries                           |
| <input type="checkbox"/> Cath report(s) (diagnostic or interventional)   | <input type="checkbox"/> Autopsy report / Death report (if applicable) |
| <input type="checkbox"/> Echo report(s) (include any TEE)  | <input type="checkbox"/> MRI (if performed)                            |
| <input type="checkbox"/> Post-op cath report (if applicable)   | <input type="checkbox"/> Holter, exercise                              |
| <input type="checkbox"/> Admission history and physical (to include height, weight, oxygen saturation, signs and symptoms) | <input type="checkbox"/> Nuclear Medicine (MUGA, lung perfusion scans) |
| <input type="checkbox"/> Any subsequent hospital admission (admit history and reports)                                     | <input type="checkbox"/> Clinic letters                                |



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