

# Pediatric Heart Transplant Study

## FORM 0199: Initial Patient Entry at Listing: Page 1 of 2

ID# P 

--	--	--	--	--	--	--	--	--	--

<b>P</b> Institution Code	Sequential Patient Number	Patient Initials
---------------------------	---------------------------	------------------

<b>1. Institution:</b> _____	<b>2. Patient Number:</b> _____	<b>3. Patient Initials:</b> _____
------------------------------	---------------------------------	-----------------------------------

<b>4 Zip Code:</b> Home: _____ While Waiting for Tx: _____	<b>5. Date of Birth:</b> (mo-da-yr) <table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<b>6. Date Listed:</b> (mo-da-yr) <table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>				

<b>8. Gender:</b> <input type="checkbox"/> Male <input type="checkbox"/> Female	<b>9. Number of Pregnancies:</b> _____
--	--

**10. Race:**  White  Black  American Indian/Alaskan Native  Asian  Pacific Islander  Mid-east/Arabian  
(see manual)  Indian Subcontinent  Other(specify): \_\_\_\_\_ Hispanic Origin:  Yes  No

**11. Etiology:**  Ischemic  Idiopathic  Congenital (and congenital valvular)  Acquired Valvular  Myocarditis  
 Post Partum  Alcoholic  Restrictive  Hypertropic  Other (specify): \_\_\_\_\_  
Comments: \_\_\_\_\_

**11b. Congenital Diagnosis Code:**

--	--

**Associated Diagnoses:**

--	--	--	--	--	--

- |   |   |   |
|---|---|---|
| 01: Hypoplastic Left Ventricle<br>02: Aortic Atresia<br>03: Mitral Atresia<br>04: Hypoplastic Right Ventricle<br>05: Tricuspid Atresia<br>06: Pulmonary Atresia<br>07: Double Inlet Left Ventricle<br>08: Single Ventricle, RV Dominant (Not unbalanced AV septal defect)<br>09: Single Ventricle, LV Dominant (Not unbalanced AV septal defect)<br>10: Single Ventricle, Indeterminate<br>11: AV Discordance<br>12: "D" Transposition (VA Discordance)<br>13: "L" Transposition (VA Discordance)<br>14: Complete AV septal defect, normal situs, balanced (not single ventricle)<br>15: Complete AV septal defect, normal situs RV dominant (not single ventricle)<br>16: Partial AV septal defect (includes ostium) | 17: Complete AV septal defect normal situs, LV dominant (not single ventricle)<br>18: Pulmonary Stenosis<br>19: Pulmonary Atresia (with complex heart disease, not intact septum or Tetralogy of Fallot)<br>20: Dextrocardia<br>21: Situs Inversus<br>22: Right Isomerism<br>23: Left Isomerism<br>24: Situs Ambiguus<br>25: Tetralogy (includes pulmonary atresia with VSD)<br>26: Double Outlet Right Ventricle<br>27: Ebsteins Anomaly<br>28: Truncus Arteriosus<br>29: Right Aortic Arch<br>30: Critical Aortic Stenosis<br>31: Mitral Stenosis<br>32: Asplenia | 34: Bilateral SVC<br>35: Left SVC (no right SVC)<br>36: Interrupted IVC (congenital) Azygous continuation on right<br>37: Interrupted IVC (congenital) Azygous continuation on left<br>38: Total Anomalous Pulmonary Venous Return<br>39: Coarctation<br>40: Interrupted Aortic Arch<br>41: VSD<br>42: PDA (not on PGE)<br>43: ASD (isolated, not ostium primum)<br>44: Other (specify): _____<br>_____<br>_____<br>_____ |
|---|---|---|

**12. Status At Listing:**  1  1A  1B  2  Other, Specify: \_\_\_\_\_ (verify status with OPO)  
**Check All Status Details That Apply Per UNOS Policy 3.7 or 1/20/99:**  
 Status 1A, life expect < 7days (UNOS Policy 3.7.4.f)  
 In Hospital  Out Hospital  ICU  IV Inotropes, high  IV Inotropes, low  Hemo Monitoring  Ventilator  IABP  ECMO  
 <6 mon old, pulmonary hypertension >50% systemic pressure  <6 mon old, pulmonary hyperten <50% systemic pressure  
 Growth Failure due to acquired or congenital heart disease  
 VAD/TAH: Details: Date 1st Placed: \_\_\_ - \_\_\_ - \_\_\_  VAD > 30 Days with complication, specify: \_\_\_\_\_  
 Type:  Right  Left,  Both,  TAH Brand/Model: \_\_\_\_\_

<b>14a. Blood Type, Patient:</b> <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> AB <input type="checkbox"/> O	<b>14b Rh:</b> <input type="checkbox"/> Pos <input type="checkbox"/> Neg
<b>15a. Blood Type, Maternal:</b> <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> AB <input type="checkbox"/> O	<b>15b. Rh:</b> <input type="checkbox"/> Pos <input type="checkbox"/> Neg

<b>16. HLA Allotype</b> <input type="checkbox"/> N/A	A	A	B	B	DR	DR
--	---	---	---	---	----	----

**17. Insur. a. Primary (check one):** Medicare: ( State  HMO) Medicaid: ( State  HMO)  Other Gov  Private  Self  donation  Free  Other, on ance: back

**18. Percent or Panel Reactive Antibody Screening and method (closest to listing):**

18a. Cytotoxic PRA: _____% T _____% B _____% Date: ___-___-___	<input type="checkbox"/> Not Done
18b. Cytotoxic PRA, DTE/DTT: _____% T _____% B _____% Date: ___-___-___	<input type="checkbox"/> Not Done
18c. Flow Cytometry PRA: _____% T _____% B _____% Date: ___-___-___	<input type="checkbox"/> Not Done
18d. Other PRA, : _____% T _____% B _____% Date: ___-___-___	<input type="checkbox"/> Not Done

Person Completing this form: _____	Date Original Form Mailed (do not send copy): _____
------------------------------------	---

PRINT IN BLACK INK ONLY: USE THIS FORM FOR ALL PATIENTS OR EVENTS AFTER January 1, 1999. 2/14/99 RCB

# Pediatric Heart Transplant Study

## FORM 0199: Initial Patient Entry at Listing: Page 2 of 2

ID# P 

--	--	--	--	--	--	--	--	--	--

<b>P</b> Institution Code	Sequential Patient Number	Patient Initials
---------------------------	---------------------------	------------------

19. Infectious Dis. Screening Date:	General	HTLVIII: <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	IFA Toxo: <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	RPR: <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	Hepatitis	HBs Ag <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	HBs Ab <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	HB core Ab <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA
		CMV: <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	Herpes: <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	EBV: <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA		Hep A IgM <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	Hep A IGG <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA	Hep C Ab <input type="checkbox"/> Pos <input type="checkbox"/> Neg <input type="checkbox"/> NA

20. Immunizations:  DPT  IPV  Hib  Varicella  Influenza  OPV  MMR  HepB  Pneumococcal

21a: Creatinine at Listing: \_\_\_\_\_  mg/dl  IU/L

21b: Creatinine clearance at listing: \_\_\_\_\_ ml/min

**22. Med Hx (check all that apply)**

<input type="checkbox"/> Shock: Date Last: ____/____/____	<input type="checkbox"/> CVA: Dt Last: ____/____/____	<input type="checkbox"/> Pulmonary Emb.: Dt last: ____/____/____	<input type="checkbox"/> ETOH: <input type="checkbox"/> Use <input type="checkbox"/> Abuse
<input type="checkbox"/> CPR: Date Last: ____/____/____	<input type="checkbox"/> TIA: Dt Last: ____/____/____	<input type="checkbox"/> Malignancy, specify: _____	<input type="checkbox"/> Illicit Drug
<input type="checkbox"/> Hypertension Dt dx: ____/____/____	<input type="checkbox"/> Seizure disorder Dt last: ____/____/____	<input type="checkbox"/> Hyperlipidemia (any type) (specify): _____	<input type="checkbox"/> Arrhythmia (specify): <input type="checkbox"/> Afib/flutter
<input type="checkbox"/> Peripheral Edema at listing	<input type="checkbox"/> Failure to thrive (Pediatric pt)	<input type="checkbox"/> Prenatal Diagnosis	<input type="checkbox"/> V Tach <input type="checkbox"/> V Fib <input type="checkbox"/> Comp Ht Blk
<input type="checkbox"/> Hepatitis: Dt dx: ____/____/____	<input type="checkbox"/> Diabetes; Insl: <input type="checkbox"/> Y <input type="checkbox"/> N, Yr Dx: ____	<input type="checkbox"/> Varicella (zoster or "chicken pox")	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> Asthma/COPD/Emphysema	<input type="checkbox"/> Peripheral Myopathy	<input type="checkbox"/> Other (specify): _____	<input type="checkbox"/> Pacemaker: Dt 1st Placed
<input type="checkbox"/> Protein Losing Enteropathy	<input type="checkbox"/> Renal Insufficiency		

**23. Surgical History:**

Previous Sternotomy(s): Number: \_\_\_\_\_

Previous Thoracotomy(s): Number: \_\_\_\_\_

**Surgical Procedures:**

	Code	Date (at least year)	Mon	Day	Yr
See surgical codes to the right. See manual for additional codes. Please list in chronological order.	1.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	2.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	3.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	4.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	5.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	6.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	7.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Previous Palliative Surgical Codes:**

01: Classic Blalock Taussig \*

02: Modified Blalock Taussig \*

03: Waterston Shunt \*

04: Potts Shunt \*

05: Central Shunt \*

06: Classical Glenn Shunt

07: Bidirectional Caval Anastomosis \*\*

08: Fenestrated Fontan

09: Pulmonary Artery Band

10: Blalock-Hanlon Septectomy

11: Damus-Kaye-Stanzel (Aortopulmonary Anastomosis)

12: Stage I Norwood

13: Enlargement of VSD or Outlet Foramen

**Previous Surgical Repair Codes:**

14: Tetralogy Repair

15: Rastelli Repair, TOF, DORV, TGA, with VSD

16: Arterial Switch

17: Atrial Switch (Mustard or Senning)

18: VSD repair (except Rastelli and Tetralogy)

19: Aortic Valvotomy

20: Pulmonary Valvotomy (includes Brock procedure and RVOT procedure in Pulmonary Atresia with intact septum)

21: Aortic Valve Replacement (not Konno Procedure)

22: Pulmonary Valve Replacement

23: Mitral Valve Replacement

24: Konno Procedure

25: Repair of Ebstein's Anomaly- without valve replacement

26: Repair of Ebstein's Anomaly- with valve replacement

27: AV canal repair

28: Fontan (complete): includes total cardiopulmonary anastomosis and Stage III Norwood

29: Other (specify): \_\_\_\_\_

**24. Hemodynamics at listing:**

Height: \_\_\_\_\_ in/cm

Weight: \_\_\_\_\_ lb/kg (at initial)

	Initial	Best
RAm		
PAs		
PAd		
PAm		
PCW		
C.O.		
C.I.		
H.R.		
Aos		
Aod		
Aom		
Qp/Qs		
Rp		
Rs		
Date: ____-____-____		

**25. Development:**

Cerebral Outcomes Score: \_\_\_\_\_ (1-5)  
(see definition in manual)

**26. Schooling**

Age appropriate

Special School

**27. Exercise Capacity**

Normal

Impaired: ( mild  severe)

**28. Treadmill Test**

Resting BP: \_\_\_\_ / \_\_\_\_ HR: \_\_\_\_

Maximum: duration: \_\_\_\_\_ min

Max. BP: \_\_\_\_ / \_\_\_\_ HR: \_\_\_\_

% of Predicted for Age: \_\_\_\_\_

**29. O.F.C.** \_\_\_\_\_ cm (up to age 3 years)  
(occipital - frontal circumference)

**Indicate agents for best Hemodynamics:**

100% O2

Dopamine

Dobutamine

Amrinone (Inocor)

Milrinone (Primacor)

Isoproterenol (Isuprel)

PGE (Alprostadi)

PGI (Flolan)

Nitroglycerine

Nitroprusside (Nipride)

Nitric Oxide

Others, specify: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

30. Serum Albumin (closest to listing): \_\_\_\_\_ Dt: \_\_\_\_ - \_\_\_\_ - \_\_\_\_

31. Total Protein (closest to listing): \_\_\_\_\_ Dt: \_\_\_\_ - \_\_\_\_ - \_\_\_\_

Person Completing this form: \_\_\_\_\_ Date Original Form Mailed (do not send copy): \_\_\_\_\_

PRINT IN BLACK INK ONLY: USE THIS FORM FOR ALL PATIENTS OR EVENTS AFTER JANUARY 1, 1999.