Pediatric Heart Transplant Study
FORM 01r: Initial Patient Entry at Listing: Page 1of 2

ID# P [ ][ ][ ][ ][ ][ ][ ][ ][ ]

P | Institution Code | Sequential Patient Number | Patient Initials

1. Institution:

2. Patient Number:

3. Patient Initials:

4 Zip Code: Home: _____
While Waiting for Tx: _____

5. Date of Birth: (mo-da-yr) [ ][ ] [ ][ ] [ ][ ]

6. Date Listed: (mo-da-yr) [ ][ ] [ ][ ] [ ][ ]

8. Gender: ❑ Male ❑ Female

9. Number of Pregnancies: _____

10. Race: ❑ White ❑ Black ❑ American Indian/Alaskan Native ❑ Asian ❑ Pacific Islander ❑ Mid-east/Arabian
(see manual) ❑ Indian Subcontinant ❑ 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: (see codes below) [ ][ ] Associated Diagnoses: [ ][ ] [ ][ ] [ ][ ] [ ][ ]

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

12. Status at Listing: (Check all that apply for each status)

❑ STATUS 1: ❑ I.V. Inotropes ❑ IABP ❑ VAD(specify type_____ ❑R ❑L) ❑ TAH ❑ Ventilator
❑ ECMO ❑ PGE dependant ❑ Infant (<6 months of age)

❑ STATUS 2: ❑ In Hospital ❑ Out of Hospital ❑ On IV Inotropes

14a. Blood Type, Patient: ❑ A ❑ B ❑ AB ❑ O 14b Rh: ❑ Pos ❑ Neg

15a. Blood Type, Maternal: ❑ A ❑ B ❑ AB ❑ O 15b. Rh: ❑ Pos ❑ Neg

16. HLA Allotype ❑ N/A	A	A	B	B	DR	DR

17.Insur- a. Primary (one): ❑Medicare ❑Medicaid ❑Other Gov ❑Private ❑Self ❑donation ❑Free ❑Other, specify below*
ance: b. Second: (all that apply): ❑Medicare ❑Medicaid ❑Other Gov ❑Private ❑Self ❑donation ❑Free *_____

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

18a. Cytotoxic PRA: ____% T ____% B ____% Date ____-____-____ ❑ Not Done
18b. Cytotoxic PRA, DTE/DTT: ____% T ____% B ____% Date ____-____-____ ❑ Not Done
18c. Flow Cytometry PRA: ____% T ____% B ____% Date ____-____-____ ❑ Not Done
18d. Other PRA,:_____ ____% T ____% B ____% Date ____-____-____ ❑ 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 JULY 1, 1996.

8/1/96 RC

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19. Infectious Disease Screening Done:

General			Hepatitis		
HTLVIII: ❑Pos ❑Neg ❑NA	IFA Toxo: ❑Pos ❑Neg ❑NA	RPR: ❑Pos ❑Neg ❑NA	HBs Ag ❑Pos ❑Neg ❑NA	HBs Ab ❑Pos ❑Neg ❑NA	HB core Ab ❑Pos ❑Neg ❑NA
CMV: ❑Pos ❑Neg ❑NA	Herpes: ❑Pos ❑Neg ❑NA	EBV: ❑Pos ❑Neg ❑NA	HepA IgM ❑Pos ❑Neg ❑NA	HepA IGG ❑Pos ❑Neg ❑NA	Hep C Ab ❑Pos ❑Neg ❑NA

20. Immunizations: ❑ DPT ❑ IPV ❑ HIB ❑ Varicella ❑ Influenza ❑ OPV ❑ MMR ❑HepB ❑Pneumococca:

21a: Creatinine at Listing: _____ ❑ mg/dl ❑ IU/L

21b: Creatinine clearance at listing: _____ ml/min

22. Med Hx (check all that apply)

- ❑ Shock: Date Last: ____/____
- ❑ CPR: Date Last: ____/____
- ❑ Hypertension Dt dx:____/____
- ❑ Pancreatitis: Dt dx:____/____
- ❑ Hepatitis: Dt dx:____/____
- ❑ Asthma/COPD/Emphysema
- ❑ Peripheral Vascular Disease
- ❑ Prior Transfusions: #units ____
- ❑ CVA: Dt Last:____/____
- ❑ TIA: Dt Last:____/____
- ❑ Seizure disorder Dt last:____/____
- ❑ Failure to thrive (Pediatric pt)
- ❑ Diabetes; Insl: ❑Y ❑N, Yr Dx:____
- ❑ Renal Insufficiency
- ❑ Nephrolithiasis: Yr. last:____
- ❑ Peripheral Emb.: Dt last:____/____
- ❑ Pulmonary Emb.: Dt last:____/____
- ❑ Malignancy, specify:____
- ❑ Hyperlipidemia (any type)
- ❑ Prenatal Diagnosis
- ❑ Varicella (zoster or "chicken pox")
- ❑ Peripheral Myopathy
- ❑ Other(specify):____
- ❑ ETOH: ❑ Use ❑ Abuse
- ❑ Cigarette: ❑ Past ❑ Within 6 mon
- ❑ Illicit Drug (specify):____
- ❑ Arrhythmia (specify): ❑ Afib/flutter ❑ VTach ❑ VFib ❑ Comp Ht Blk
- ❑ Other(specify):____
- ❑ Pacemaker: Dt 1st Placed ____/____
- ❑ AICD: Dt 1st Placed ____/____

23. Surgical History:

❑ Previous Sternotomy(s): Number:____

❑ Previous Thoracotomy(s): Number:____

Surgical Procedures:

See surgical codes to the right. See manual for additional codes. Please list in chronological order.

	Code	Date (at least year) Mon	Day	Yr
1.				
2.				
3.				
4.				
5				
6.				
7.				

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):____

* Not Stage I Norwood
** Includes Stage II Norwood; not total cardiopulmonary anastomosis

24. Hemodynamics at listing:

Height: _____ in/cm
Weight:_____ lb/kg

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

Indicate agents for best Hemodynamics:

- ❑ 100% O2
- ❑ Dopamine
- ❑ Dobutamine
- ❑ Amrinone (Primacor)
- ❑ Milrinone (Inocor)
- ❑ Isuproterenol (Isuprel)
- ❑ PGE (Alprostadil)
- ❑ PGI (Flolan)
- ❑ Nitroglycerine
- ❑ Nitroprusside (Nipride)
- ❑ Nitric Oxide
- ❑ Others, specify:

_____
_____

25. Development:

- ❑ Normal
- ❑ Impaired: (❑ mild ❑ severe)

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)

Person Completing this form:_____

Date Original Form Mailed (do not send copy):_____