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Patient Enrollment Form

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Center Code

DCC

INSTITUT

Patient Eligibility

1

Is patient under the age of 18 at the time of listing?

☐ Yes

☐ No

If the patient is 18 years of age or older at the time of listing, they are not eligible for PHTS.

PTLT18

2

Was informed consent and HIPAA Authorization obtained?

☐ Yes/my center has a waiver

☐ No

PTIC

3

Was the patient listed for a heart/lung transplant?

☐ Yes

☐ No

Heart/lung listings are not currently eligible for PHTS. All other simultaneous organ listings are eligible.

NOHLTX

Patient Information

4

Patient Initials

If middle initial is not known, enter a hyphen (-)

Question Added: 01 JAN 1993
PATINIT

5

Date of Birth

MM/DD/YYYY

Question Added: 01 JAN 1993
BRTHDATE

6

Sex

☐ Female

☐ Male

Question Added: 01 JAN 1993
SEX

7

Race

Check all that apply.

☐ African-American or Black

☐ American Indian or Alaskan Native

☐ Asian

☐ Hawaiian or other Pacific Islander

☐ Unknown/Undisclosed

☐ White

☐ Other, specify

RRACE_B

RRACE_AI

RRACE_A

RRACE_PI

RRACE_UN

RRACE_W

RRACE_O

RACEOTH

Question Added: 01 JAN 1993
RACE

8

Hispanic or Latino

Yes if of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture of origin, regardless of race.

- ☐ Yes
☐ No
☐ Unknown

Question Added: 01 JAN 1993
HISP

Donor Blood Type	Recipient Blood Type			
	A	B	AB	O
A	<i>ABO compatible</i>	ABO incompatible	<i>ABO compatible</i>	ABO incompatible
B	ABO incompatible	<i>ABO compatible</i>	<i>ABO compatible</i>	ABO incompatible
AB	ABO incompatible	ABO incompatible	<i>ABO compatible</i>	ABO incompatible
O	<i>ABO compatible</i>	<i>ABO compatible</i>	<i>ABO compatible</i>	<i>ABO compatible</i>

9

Blood Type

- ☐ A
☐ AB
☐ B
☐ O
☐ Unknown

Question Added: 01 JAN 1993
RABOTYPE

9a

Blood A Subtype

- ☐ A1
☐ A2
☐ Unknown

Question Added: 01 January 2010
RABOAT

10

Rh

- ☐ Negative
☐ Positive
☐ Unknown

Question Added: 01 JAN 1993
RRHTYPE

Patient Listing

11

Is this the patient's first listing for a heart transplant?

- ☐ Yes
☐ No

PRIME1S

11a

Listing Date

MM/DD/YYYY

Question Added: 01 JAN 1993
LISTDATE

11b

Date of Relisting

Question Added: 01-JAN-1993
RELDATE

12

Is this a Japanese-American transfer patient?

- ☐ Yes
☐ No

Question Added: 09 AUG 2017
JATRAN

12a Are they coming from Japan or North America?

- ☐ Japan
☐ North America

Question Added: 09-AUG-2017
JASOURCE

12a.i Enter patient ID from North American Hospital

Question Added: 09-AUG-2017
USPTID

13

Primary Etiology

(For patients that have been transplanted prior to enrollment in PHTS, this should be the original diagnosis)

- ☐ Cardiac Tumor
☐ Cardiomyopathy
☐ Congenital Heart Disease
☐ Myocarditis
☐ Other, specify

ETIOOTH

Question Added: 01 JAN 1993
PRIM_DX

13a

Cardiomyopathy

- ☐ ARVD/C
☐ Dilated
☐ Hypertrophic
☐ MIXED
☐ Restrictive
☐ Unknown
☐ Other, specify

CMSECOH

Question Added: 01-JAN-1993
SEC_DX

13a.i

Cardiomyopathy: Dilated

- ☐ Chemotherapy-Induced
☐ Conduction Defect
☐ Familial
☐ Ischemic
☐ Isolated/Idiopathic
☐ LVNC
☐ Metabolic/Syndromic/Mitochondrial
☐ Neuromuscular
☐ s/p Myocarditis
☐ Unknown
☐ Other, specify

CMTEROTH

Question Added: 01-JAN-1993
TER_DX

13a.i.1

Cardiomyopathy: Dilated, Ischemic

- ☐ ALCAPA
☐ Kawasaki
☐ Unknown
☐ Other, specify

ISCOTHS

Question Added: 01-JAN-1993
ISC_OTH

13a.ii **Cardiomyopathy: Hypertrophic**

- ☐ Familial
- ☐ Isolated/Idiopathic
- ☐ Metabolic/Syndromic/Mitochondrial
- ☐ Neuromuscular
- ☐ Unknown
- ☐ Other, specify

CMTEROTH

Question Added: 01-JAN-1993
TER_DX

13a.iii **Cardiomyopathy: Restrictive**

- ☐ Chemotherapy-Induced
- ☐ Isolated/Idiopathic
- ☐ LVNC
- ☐ Metabolic/Syndromic/Mitochondrial
- ☐ s/p Radiation
- ☐ Unknown
- ☐ Other, specify

CMTEROTH

Question Added: 01 January 1993
TER_DX

13b Congenital Heart Disease

- | | |
|---|-------------|
| <input type="checkbox"/> ALCAPA | CHD_ALCAPA |
| <input type="checkbox"/> Aortic Atresia | CHD_AA |
| <input type="checkbox"/> Aortic Regurgitation | CHD_AR |
| <input type="checkbox"/> Arch Hypoplasia / Interruption / Hypoplasia / Coarctation | CHD_AHIH |
| <input type="checkbox"/> ASD/VSD | CHD_VSD |
| <input type="checkbox"/> AV Discordance | CHD_AVD |
| <input type="checkbox"/> Bilateral SVC | CHD_BIVC |
| <input type="checkbox"/> Complete AV Septal Defect/AV Canal | CHD_AVSEP |
| <input type="checkbox"/> Cong. Corrected Trans. (L-TGA) (CC-TGA) | CHD_CTGA |
| <input type="checkbox"/> Coronary Anomaly | CHD_ANOM |
| <input type="checkbox"/> Dextrocardia | CHD_DEX |
| <input type="checkbox"/> Double Inlet Left Ventricle | CHD_DILV |
| <input type="checkbox"/> DOLV | CHD_DOLV |
| <input type="checkbox"/> Ebstein's Anomaly | CHD_EBST |
| <input type="checkbox"/> Heart Block | CHD_HB |
| <input type="checkbox"/> Heterotaxy | CHD_HETER |
| <input type="checkbox"/> Hypoplastic Left Heart | CHD_HLH |
| <input type="checkbox"/> Hypoplastic Right Ventricle | CHD_HRH |
| <input type="checkbox"/> Interrupted IVC | CHD_IIVC |
| <input type="checkbox"/> Left SVC (no right SVC) | CHD_L SVC |
| <input type="checkbox"/> Left Ventricular Outflow Tract Obstruction / Aortic Stenosis | CHD_LVOTOAS |
| <input type="checkbox"/> Marfan's Syndrome | CHD_MART |
| <input type="checkbox"/> Mitral Atresia | CHD_MA |
| <input type="checkbox"/> Mitral Regurgitation | CHD_MR |
| <input type="checkbox"/> Mitral Stenosis | CHD_MSTN |
| <input type="checkbox"/> Right Aortic Arch | CHD_RAA |
| <input type="checkbox"/> PDA (not on PGE) | CHD_PDA |
| <input type="checkbox"/> Pulmonary Atresia (with complex heart disease, not intact septum or Tetralogy of Fallot) | CHD_PA |
| <input type="checkbox"/> Pulmonary Atresia with IVS | CHD_PATR |
| <input type="checkbox"/> Pulmonary Stenosis | CHD_PS |
| <input type="checkbox"/> Shone's Syndrome | CHD_SHONE |
| <input type="checkbox"/> Situs Inversus | CHD_SI |
| <input type="checkbox"/> TAPVR | CHD_TAPVR |
| <input type="checkbox"/> PAPVR | CHD_PAPVR |

☐ TOF/TOF Variant/DORV/RVOTO

☐ Transposition of the Great Arteries (d-TGA)

☐ Tricuspid Atresia

☐ Tricuspid Regurgitation

☐ Truncus Arteriosus

☐ Unknown

☐ Other, specify

CHD_TOF

CHD_TGA

CHD_TRIAT

CHD_TR

CHD_TART

CHD_UNK

CHD_OTH

CHD_OTHSP

13b.i Heterotaxy Details

☐ Asplenia or Right Isomerism

☐ Polysplenia or Left Isomerism

☐ Unknown

CHD_ASPL

CHD_PSPL

CHD_USPL

13b.ii Single Ventricle

☐ Yes

☐ No

CHD_SV

13b.iii If pulmonary atresia with IVS, RV dependent coronary circulation

☐ Yes

☐ No

☐ Unknown

CHD_PATRD