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# Patient Enrollment Form

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Not Started

**Center Code** 

## 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.

**1a** **Is Patient enrolled in Desensitization Study?**  Yes  No

Patient must be between the ages of 10-24 to take part in  
desensitization study.

Question Added: 30 SEPT 2024

**2** **Was informed consent and HIPAA Authorization obtained?**  Yes/my center has a waiver  No

**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.

## Patient Information

**4** **Patient Initials**

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

Question Added: 01 JAN 1993

**5** **Date of Birth**

MM/DD/YYYY

Question Added: 01 JAN 1993

**6** **Sex**  Female  Male

Question Added: 01 JAN 1993

**Race**  African-American or Black

7

- Check all that apply.
- American Indian or Alaskan Native
  - Asian
  - Hawaiian or other Pacific Islander
  - Unknown/Undisclosed
  - White
  - Other, specify

Question Added: 01 JAN 1993

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

Donor Blood Type	Recipient Blood Type			
	A	B	AB	O
A	ABO compatible	ABO incompatible	ABO compatible	ABO incompatible
B	ABO incompatible	ABO compatible	ABO compatible	ABO incompatible
AB	ABO incompatible	ABO incompatible	ABO compatible	ABO incompatible
O	ABO compatible	ABO compatible	ABO compatible	ABO compatible

9

**Blood Type**

- A
- AB
- B
- O
- Unknown

Question Added: 01 JAN 1993

9a

**Blood A Subtype**

- A1
- A2
- Unknown

Question Added: 01 January 2010

10

**Rh**

- Negative
- Positive
- Unknown

Question Added: 01 JAN 1993

**Patient Listing**

11

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

- Yes
- No

11a

**Listing Date**

MM/DD/YYYY

Question Added: 01 JAN 1993

11b

**Date of Relisting**

Question Added: 01-JAN-1993

**12** Is this a Japanese-American transfer patient?  Yes  
 No

Question Added: 09 AUG 2017

**12a** Are they coming from Japan or North America?  Japan  
 North America

Question Added: 09-AUG-2017

**12a.i** Enter patient ID from North American Hospital 

Question Added: 09-AUG-2017

**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 

Question Added: 01 JAN 1993

**13a** Cardiomyopathy  ARVD/C  
 Dilated  
 Hypertrophic  
 MIXED  
 Restrictive  
 Unknown  
 Other, specify 

Question Added: 01-JAN-1993

**13a.i** Cardiomyopathy: Dilated  Chemotherapy-Induced  
 Conduction Defect  
 Familial  
 Ischemic  
 Isolated/Idiopathic  
 LVNC  
 Metabolic/Syndromic/Mitochondrial  
 Neuromuscular  
 s/p Myocarditis  
 Unknown  
 Other, specify 

Question Added: 01-JAN-1993

**13a.i.1** Cardiomyopathy: Dilated, Ischemic  Kawasaki  
 Unknown  
 Other, specify 

Question Added: 01-JAN-1993

**13a.ii Cardiomyopathy: Hypertrophic**

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

Question Added: 01-JAN-1993

**13a.iii Cardiomyopathy: Restrictive**

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

Question Added: 01 January 1993

**13a Congenital Heart Disease**

The following diagnoses are almost exclusively single ventricle: Aortic Atresia, Double Inlet Left Ventricle, Mitral Atresia, and Tricuspid Atresia.

- ALCAPA
- Aortic Atresia
- Aortic Regurgitation
- Arch Hypoplasia / Interruption / Hypoplasia / Coarctation
- ASD/VSD
- AV Discordance
- Bilateral SVC
- Complete AV Septal Defect/AV Canal
- Cong. Corrected Trans. (L-TGA) (CC-TGA)
- Coronary Anomaly
- Dextrocardia
- Double Inlet Left Ventricle
- DOLV
- Ebstein's Anomaly
- Heart Block
- Heterotaxy
- Hypoplastic Left Heart
- Hypoplastic Right Ventricle
- Interrupted IVC
- Left SVC (no right SVC)
- Left Ventricular Outflow Tract Obstruction / Aortic Stenosis
- Marfan's Syndrome
- Mitral Atresia
- Mitral Regurgitation
- Mitral Stenosis
- Right Aortic Arch
- PDA (not on PGE)
- Pulmonary Atresia (with complex heart disease, not intact septum or Tetralogy of Fallot)
- Pulmonary Atresia with IVS
- Pulmonary Stenosis
- Shone's Syndrome
- Situs Inversus
- TAPVR
- PAPVR
- TOF/TOF Variant/DORV/RVOTO
- Transposition of the Great Arteries (d-TGA)

- Tricuspid Atresia
- Tricuspid Regurgitation
- Truncus Arteriosus
- Unknown
- Other, specify

**13b.i Heterotaxy Details**

- Asplenia or Right Isomerism
- Polysplenia or Left Isomerism
- Unknown

**13b Single Ventricle**

The following diagnoses are almost exclusively single ventricle: Aortic

Atresia, Double Inlet Left Ventricle, Mitral Atresia, and Tricuspid Atresia.

- Yes
- No

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

- Yes
- No
- Unknown

**Desensitization Study Form****14 Previous use of ECMO/VAD**

- Yes
- No
- Unknown

**15 Previous use of homograft material**

- Yes
- No
- Unknown

**16 Pregnancy**

- Yes
- No
- Unknown

**17 Prior transplant**

- Yes
- No
- Unknown

**17a Type of Transplant**

- Heart
- Non Heart

**17a.i****Date of Transplant****17a.ii****What type of Transplant****17a.ii****Date of Transplant****18****Prior desensitizing therapy**

- Yes
- No
- Unknown

**19****Any history of immune dysregulation?**

- Yes
- No
- Unknown

**19a****If yes**

- Autoimmune disease
- Immunodeficiency
- Other, Specify

**20****Concomitant medications,  
especially biologics****21****Any history of opportunistic infections or fungal infections particularly any requiring hospitalization and/or IV medications in the last year**

- Yes
- No
- Unknown

**22****Vaccinations: please list the ones received in the last 5 years with dates, emphasis on most recent, prior to desensitization therapy and ongoing**

Please follow this format: Month Day Year VACCINATION\_NAME  
Example- August 5 2023 VACCINATION NAME, July 2 2021

VACCINATION NAME

23

- Transfusions in the last year**
- Yes
  - No
  - Unknown

**Specify date and which blood products**

Please follow this format: Month Day Year Blood\_product\_name  
Example- August 5 2023 Abcd, July 2 2021 Abcd def

24

- Is patient listed for transplant as an adult?**
- Yes
  - No
  - Unknown

24a

- If yes**
- Adult status 1
  - Adult status 2
  - Adult status 3
  - Adult status 4
  - Adult status 5
  - Adult status 6

25

- Latent tuberculosis screening**
- Negative
  - Not done
  - Positive
  - Unknown