

[Home](#)[Dashboard](#)[Files](#)[Enroll New Patient](#)[Reports](#)[Data Transfer](#)[Search](#)[ccovington](#)
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[Change Password](#)[Logout](#)[Show/Hide Annotations](#) [Stickies: Toggle All](#) [Toggle Open](#) [Toggle Resolved](#)

Patient Enrollment Form

[Toggle Question Year/Info](#)[Print this Form](#)[Not Started](#)

Center Code

TCB

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

☐ No

☐ Unknown

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

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

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

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**☐ Yes☐ No

The following diagnoses are almost exclusively single ventricle: Aortic

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

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

Prior desensitizing therapy drug name

Please follow this format: Month Day Year Drug_Name Example- August
5 2023 Abc def, July 2 2021 abc def

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