Show/Hide Annotations Stickies: Toggle All Toggle Open Toggle Resolved

Patient Enrollment Form

Toggle Question Year/Info Print this Form Not Started

Center Code DCC

INSTITUT

Patient Eligibility

1 **Is patient under the age of 18 at the time of listing?**
If the patient is 18 years of age or older at the time of listing, they are not eligible for PHTS.
- ○ Yes
- ○ No

PTLT18

1a **Is Patient enrolled in Desensitization Study?**
Patient must be between the ages of 10-24 to take part in desensitization study.
- ○ Yes
- ○ No

Question Added: 30 SEPT 2024

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?**
Heart/lung listings are not currently eligible for PHTS. All other simultaneous organ listings are eligible.
- ○ Yes
- ○ No

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

Race ☐ African-American or Black RRACE_B

7 Check all that apply.

- ☐ American Indian or Alaskan Native — RRACE_AI
- ☐ Asian — RRACE_A
- ☐ Hawaiian or other Pacific Islander — RRACE_PI
- ☐ Unknown/Undisclosed — RRACE_UN
- ☐ White — RRACE_W
- ☐ Other, specify — RRACE_O
  - RACEOTH

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
HISP

	Recipient Blood Type			
Donor 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
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

PRIMELS

11a **Listing Date**
MM/DD/YYYY

Question Added: 01 JAN 1993
LISTDATE

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

CMSECOTH

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

- 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

13a Congenital Heart Disease

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

- [ ] ALCAPA — CHD_ALCAPA
- [ ] Aortic Atresia — CHD_AA
- [ ] Aortic Regurgitation — CHD_AR
- [ ] Arch Hypoplasia / Interruption / Hypoplasia / Coarctation — CHD_AHIH
- [ ] ASD/VSD — CHD_VSD
- [ ] AV Discordance — CHD_AVD
- [ ] Bilateral SVC — CHD_BIVC
- [ ] Complete AV Septal Defect/AV Canal — CHD_AVSEP
- [ ] Cong. Corrected Trans. (L-TGA) (CC-TGA) — CHD_CTGA
- [ ] Coronary Anomaly — CHD_ANOM
- [ ] Dextrocardia — CHD_DEX
- [ ] Double Inlet Left Ventricle — CHD_DILV
- [ ] DOLV — CHD_DOLV
- [ ] Ebstein's Anomaly — CHD_EBST
- [ ] Heart Block — CHD_HB
- [ ] Heterotaxy — CHD_HETER
- [ ] Hypoplastic Left Heart — CHD_HLH
- [ ] Hypoplastic Right Ventricle — CHD_HRH
- [ ] Interrupted IVC — CHD_IIVC
- [ ] Left SVC (no right SVC) — CHD_LSVC
- [ ] Left Ventricular Outflow Tract Obstruction / Aortic Stenosis — CHD_LVOTOAS
- [ ] Marfan's Syndrome — CHD_MART
- [ ] Mitral Atresia — CHD_MA
- [ ] Mitral Regurgitation — CHD_MR
- [ ] Mitral Stenosis — CHD_MSTN
- [ ] Right Aortic Arch — CHD_RAA
- [ ] PDA (not on PGE) — CHD_PDA

- [ ] Pulmonary Atresia (with complex heart disease, not intact septum or Tetralogy of Fallot) CHD_PA
- [ ] Pulmonary Atresia with IVS CHD_PATR
- [ ] Pulmonary Stenosis CHD_PS
- [ ] Shone's Syndrome CHD_SHONE
- [ ] Situs Inversus CHD_SI
- [ ] TAPVR CHD_TAPVR
- [ ] PAPVR CHD_PAPVR
- [ ] TOF/TOF Variant/DORV/RVOTO CHD_TOF
- [ ] Transposition of the Great Arteries (d-TGA) CHD_TGA
- [ ] Tricuspid Atresia CHD_TRIAT
- [ ] Tricuspid Regurgitation CHD_TR
- [ ] Truncus Arteriosus CHD_TART
- [ ] Unknown CHD_UNK
- [ ] Other, specify CHD_OTH

CHD_OTHSP

13b.i **Heterotaxy Details**

- [ ] Asplenia or Right Isomerism CHD_ASPL
- [ ] Polysplenia or Left Isomerism CHD_PSPL
- [ ] Unknown CHD_USPL

13b **Single Ventricle**

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

- ( ) Yes
- ( ) No

CHD_SV

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

- ( ) Yes
- ( ) No
- ( ) Unknown

CHD_PATRD

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**

SE_TxType

17a.ii **Date of Transplant**

SE_Dt

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**
- Yes
- No
- Unknown

hospitalization and/or IV medications in the last year

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

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