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Patient Enrollment Form

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Center Code

Question Added: 30 APR 2020

Patient Information

1 Patient Initials

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

Question Added: 30 APR 2020

2 Age at Infection < 1 month >= 1 month

Question Added: 30 APR 2020

2a Age at Infection (days)

Please enter either days or weeks, not both

Question Added: 30 APR 2020

2b Age at Infection (weeks)

Please enter either days or weeks, not both

Question Added: 30 APR 2020

2c Age at Infection (months)

Please enter either months or years, not both

Question Added: 30 APR 2020

2d Age at Infection (years)

Please enter either months or years, not both

Question Added: 30 APR 2020

3 Sex Female Male

Question Added: 30 APR 2020

4 Race African-American or Black American Indian or Alaskan Native Asian Hawaiian or other Pacific Islander Unknown/Undisclosed White Other, specify

Check all that apply.

Question Added: 30 APR 2020

5 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: 30 APR 2020

6 Patient Category Waitlist for heart transplant Heart transplant recipient Non-waitlist, non-transplant

Question Added: 30 APR 2020

6a Age at Transplant < 1 month >= 1 month

Question Added: 30 APR 2020

6a.i Age at Transplant (days)

Please enter either days or weeks, not both

Question Added: 30 APR 2020

6a.ii

Age at Transplant (weeks)
Please enter either days or weeks, not both

Question Added: 30 APR 2020

6a.iii

Age at Transplant (months)
Please enter either months or years, not both

Question Added: 30 APR 2020

6a.iv

Age at Transplant (years)
Please enter either months or years, not both

Question Added: 30 APR 2020

7

Primary Cardiac Etiology

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

Question Added: 30 APR 2020

7a

Cardiomyopathy

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

Question Added: 30 APR 2020

7a.i

Cardiomyopathy: Dilated

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

Question Added: 30 APR 2020

7a.i.1

Cardiomyopathy: Dilated, Ischemic

- Kawasaki
- Unknown
- Other, specify

Question Added: 30 APR 2020

7a.ii

Cardiomyopathy: Hypertrophic

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

Question Added: 30 APR 2020

7a.iii

Cardiomyopathy: Restrictive

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

Question Added: 30 APR 2020

7b

Congenital Heart Disease

- ALCAPA
- Aortic Atresia
- Aortic Regurgitation
- Arch Hypoplasia / Interruption / Hypoplasia / Coarctation
- ASD/VSD
- AV Discordance

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

- 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

Question Added: 30 APR 2020

7b.i

Heterotaxy Details

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

Question Added: 30 APR 2020

7b.ii

Single Ventricle

- Yes
- No

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

Question Added: 30 APR 2020

7b.iii **If pulmonary atresia with IVS,
RV dependent coronary circulation**

- Yes
- No
- Unknown

Question Added: 30 APR 2020