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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.

**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

**7** **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: 01 JAN 1993

8

**Hispanic or Latino**  Yes  
 Yes if of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture of origin, regardless of race.  
 No  
 Unknown

Question Added: 01 JAN 1993

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

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

Japan

**12a** Are they coming from Japan or North America?  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  
(For patients that have been transplanted prior to enrollment in PHTS, this should be the original diagnosis)  
 Cardiomyopathy  
 Congenital Heart Disease  
 Myocarditis  
 Other, specify

Question Added: 01 JAN 1993

**13** **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**  ALCAPA  
 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

- 13b Congenital Heart Disease**
- Arch Hypoplasia/Interruption/Hypoplasia
  - ASD/VSD
  - AV Discordance
  - Bilateral SVC
  - Complete AV Septal Defect/AV Canal
  - Cong. Corrected Trans. (I-TGA) (CC-TGA)
  - Coronary Anomaly
  - Dextrocardia
  - Double Inlet Left Ventricle
  - Ebstein's Anomaly
  - Heterotaxy
  - Hypoplastic Left Heart
  - Hypoplastic Right Ventricle NOS
  - Interrupted IVC
  - Left SVC (no right SVC)
  - Left Ventricular Outflow Tract Obstruction / Aortic Stenosis
  - 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
  - Situs Inversus
  - TAPVR
  - PAPVR
  - TOF/TOF Variant/DORV/RVOTO
  - Transposition of the Great Arteries (d-TGA)
  - Tricuspid Atresia
  - Truncus Arteriosus
  - Unknown
  - Other, specify

- 13b.i Heterotaxy Details**
- Asplenia
  - Polysplenia

Unknown

**13b.ii** Single Ventricle  Yes  
 No

**13b.iii** If pulmonary atresia with IVS, RV dependent coronary circulation  Yes  
 No  
 Unknown

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# Form 1: Listing

[Toggle Question Year/Info](#)

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Not Started

1

Listing Date   
MM/DD/YYYY

Question Added: 01 JAN 1993

## Height and Weight

2

Height   
 Centimeters  
 Inches

Question Added: 01  
JAN 1993

Missing Reason:  
 Not Done  
 Unknown

**Calculated**

BSA: n/a  
BMI: n/a

3

Weight   
 Kilograms  
 Pounds

Question Added: 01  
JAN 1993

Missing Reason:  
 Not Done  
 Unknown

4

**Main reason for listing**  CHD too high risk for palliative surgical options

Select only one primary reason for listing.

- Growth failure due to the heart disease
- Hypercyanosis without further palliative surgical options
- Malignant arrhythmia
- Medically refractory heart failure
- Plastic bronchitis
- Progressive liver disease
- Progressive pulmonary hypertension
- Protein losing enteropathy
- Unknown
- Other, specify

Question Added: 01 SEPT 2015

4a

**Medically refractory heart failure**  Both  
 Diastolic Failure  
 Systolic Failure  
 Unknown

Question Added: 01 SEPT 2015

## Surgeries Prior to Listing

**5** Did the patient have any cardiac surgery prior to listing?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**Surgery Details**

**5** If Congenital cardiac surgery, specify surgery:  AP Shunt (including BT Shunt, Modified BT Shunt, Waterson Shunt, Pott's Shunt, Central Shunt, and MEE procedure)  
 Arterial switch operation  
 ASD Repair  
 Atrial switch (Senning/Mustard)  
 CABG  
 Complete AV Septal Defect Repair  
 Congenitally Corrected Transposition Repair (classic)  
 Congenitally Corrected Transposition Repair (double switch)  
 Damus Kaye Stansel (DKS)  
 d-Transposition of the Great Vessels Repair  
 Ebstein's Anomaly Repair  
 Fontan Procedure  
 Glenn Procedure  
 Hybrid Palliation  
 Norwood Stage I: BT Shunt  
 Norwood Stage I: Sano/RV-PA conduit  
 PA Banding  
 TOF/DORV/RVOTO Repair  
 Truncus Arteriosus Repair  
 Valve Replacement  
 VSD Repair  
 Other, specify

**5** Date of Surgery

Missing Reason:  
 Unknown

**5** Congenital cardiac surgery, d- Transposition of the Great Vessels Repair  Arterial Switch Operation  
 Atrial Switch (Senning/Mustard)

**5** Congenital cardiac surgery, Valve Replacement  Aortic Valve Replacement  
 Mitral Valve Replacement  
 Pulmonary Valve Replacement  
 Tricuspid Valve Replacement  
 Other, specify



**5 Homograft Tissue in Aortic Valve Replacement?**  Yes  
 No  
 Unknown

**5 Pulmonary valve replacement?**  Yes  
 No  
 Unknown

**Status Details at Listing**

**6a Status at Listing**  Brazil  
 Canada  
 United Kingdom  
 United States

Question Added: 01 JAN 2010

**6a.i Brazil**  Non-Priority  
 Priority

**6a.ii Canada**  1  
 2  
 3  
 3.5  
 4  
 4S

Question Added: 01 JAN 2005

**6a.iii United Kingdom**  Routine  
 Urgent

Question Added: 01 JAN 2005

**6a.iv Status at Listing, US**  1 (this option is only for listings prior to 1999)  
 1A  
 1B  
 2  
 7

Question Added: 01 JAN 1993

**6b Was patient in or out of hospital at time of listing?**  In hospital  
 Out of hospital

Question Added: 01 JAN 1993

**6b.i** Was patient in the ICU at time of listing?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

**6b.ii** Did the patient require continuous invasive mechanical ventilation?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**6c** Did the patient require continuous inotropes at time of listing?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**6c.i** Inotropes Dose  Dose Unknown  
 High Dose or Multiple IV  
 Single Low Dose

Question Added: 01 JAN 2005

**6d** Did the patient have ductal dependent pulmonary or systemic circulation, with ductal patency maintained by stent or prostaglandin infusion?  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

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>

**6e** Was patient listed for an ABO Incompatible transplant?  Yes  
 No  
 Unknown

Question Added: 01 JAN 2010

**6f** Was patient on a VAD or ECMO at time of listing?  VAD  
 ECMO  
 Not on support at time of listing

Question Added: 01 JAN 1993

**6f.i** Specify initiation date (VAD)

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

6f.ii

Specify initiation date (ECMO)

Missing Reason:  
 Unknown

Question Added: 01 JAN 2005

6g

Was patient listed for DCD (Donation after Cardiac Death) organ?

- Yes
- No
- Unknown
- This is not current practice at our center
- Not Applicable

Question Added: 01 SEPT 2015

### Infectious Disease Screening

7a

**HIV Serology**  
AIDS testing

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7b

**CMV Serology**

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7c

**CMV PCR**

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 2010

7d

**EBV Serology**

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7e

**EBV PCR**

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 2010

7f

**IFA Toxo**  
Toxoplasma testing

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7g

**HBs Ag**  
Hepatitis B surface antigen

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7h

**HB core Ab**  
Hepatitis B core antibody

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7i

**HBs Ab**  
Hepatitis B surface antibody

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7j

**Hep C Ab**  
Hepatitis C antibody

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 1993

7k

**RPR/Syphilis**  
Syphilis testing

- Negative Unknown
- Not Done
- Positive
- 

Question Added: 01 JAN 2005

### Medical History at time of Listing

8

Medical History  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

8a

Type of medical history at Listing  Arrhythmia  
 Cardiac Arrest/CPR  
 Diabetes  
 GI/Nutrition  
 Heterotaxy/Isomerism  
 Malignancy  
 Metabolic/Disorder  
 Mitochondrial Disorder  
 Neurologic  
 Pacemaker  
 Peripheral Myopathy/Neuromuscular disease  
 Prenatal Diagnosis  
 Prior Transfusions  
 Renal Insufficiency  
 Respiratory  
 Shock  
 Syndrome  
 Other, specify

Question Added: 01 JAN 1993

8a.i

Arrhythmia  Afib/flutter  
 Complete heart block  
 V Fibrillation  
 V Tachycardia  
 Unknown  
 Other, specify

Question Added: 01 JAN 1993

8a.ii

Cardiac arrest/CPR   
 Date  
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 JAN 1996

8a.iii

Diabetes,   
 Date of last Hgb  
 A1c  
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

8a.iii

Diabetes,   
 Value of last  
 Hgb A1c

Missing Reason:  
 Unknown

Question Added: 01  
 SEPT 2015

8a.iii

**Diabetes,  
Treating with  
insulin**

Yes  
 No  
 Unknown

Question Added: 01 JAN 1993 to 31 DEC 2004 | 01 SEPT 2015

8a.iv

**Medical History,  
GI/Nutrition**

Failure to thrive/cachexia  
 Fontan associated liver disease  
 Infectious hepatitis  
 Protein losing Enteropathy  
 Other, specify

Question Added: 01 SEPT 2015

8a.iv.1

**GI/Nutrition,  
Infectious hepatitis type**

A  
 B  
 C  
 Unknown  
 Other, specify

Question Added: 01 SEPT 2015

8a.v

**Medical History,  
Heterotaxy/Isomerism**

Asplenia  
 Polysplenia  
 Unspecified  
 Other, specify

Question Added: 01 SEPT 2015

8a.vi

**Medical History,  
Malignancy**

Lymphoma, leukemia  
 s/p BMT  
 s/p Chest Radiation  
 Solid organ cancer  
 Unknown  
 Other, specify

Question Added: 01 JAN 1993

8a.vii

**Specify Metabolic  
Disorder**

Question Added: 01 SEPT 2015

8a.viii

**Medical History,  
Mitochondrial  
Disorder, specify**

Barth's  
 Unspecified  
 Other, specify

Question Added: 01 SEPT 2015

8a.ix

**Medical History,  
Neurologic**

Anoxic brain injury  
 Hemorrhagic and/or thromboembolic stroke  
 Other, specify

	<input type="text"/>	Question Added: 01 SEPT 2015
<p style="font-size: 24pt; margin: 0;"><b>8a.ix.1</b></p> <p style="margin: 0;"><b>Neurologic, Anoxic brain injury Last Date</b></p> <p style="font-size: 8pt; margin: 0;">MM/DD/YYYY</p>	<input type="text"/>	<p>Missing Reason: <input type="radio"/> Unknown</p> <p style="text-align: right; font-size: 8pt;">Question Added: 01 SEPT 2015</p>
<p style="font-size: 24pt; margin: 0;"><b>8a.ix.2</b></p> <p style="margin: 0;"><b>Neurologic, Hemorrhagic and/or thromboembolic stroke Date Last</b></p> <p style="font-size: 8pt; margin: 0;">MM/DD/YYYY</p>	<input type="text"/>	<p>Missing Reason: <input type="radio"/> Unknown</p> <p style="text-align: right; font-size: 8pt;">Question Added: 01 SEPT 2015</p>
<p style="font-size: 24pt; margin: 0;"><b>8a.x</b></p>	<p><b>Pacemaker</b></p> <p><input type="checkbox"/> Defibrillator/AICD</p> <p><input type="checkbox"/> Pacemaker, CRT/biventricular pacing</p> <p><input type="checkbox"/> Pacemaker, not CRT and not ICD</p>	Question Added: 01 JAN 1993
<p style="font-size: 24pt; margin: 0;"><b>8a.x.1</b></p> <p style="margin: 0;"><b>Pacemaker, Defibrillator/AICD Date Placed</b></p> <p style="font-size: 8pt; margin: 0;">MM/DD/YYYY</p>	<input type="text"/>	<p>Missing Reason: <input type="radio"/> Unknown</p> <p style="text-align: right; font-size: 8pt;">Question Added: 01 JAN 1993 to 31 DEC 2004   01 JAN 2010</p>
<p style="font-size: 24pt; margin: 0;"><b>8a.x.2</b></p> <p style="margin: 0;"><b>Pacemaker, CRT/biventricular pacing, Date Placed</b></p> <p style="font-size: 8pt; margin: 0;">MM/DD/YYYY</p>	<input type="text"/>	<p>Missing Reason: <input type="radio"/> Unknown</p> <p style="text-align: right; font-size: 8pt;">Question Added: 01 JAN 2010</p>
<p style="font-size: 24pt; margin: 0;"><b>8a.x.3</b></p> <p style="margin: 0;"><b>Pacemaker, not CRT and not ICD, Date Placed</b></p> <p style="font-size: 8pt; margin: 0;">MM/DD/YYYY</p>	<input type="text"/>	<p>Missing Reason: <input type="radio"/> Unknown</p> <p style="text-align: right; font-size: 8pt;">Question Added: 01 JAN 1993</p>
<p style="font-size: 24pt; margin: 0;"><b>8a.xi</b></p> <p style="margin: 0;"><b>Medical History, Peripheral myopathy/neuromuscular disease</b></p>	<p><input type="checkbox"/> Becker MuscularDystrophy</p> <p><input type="checkbox"/> Duschenne Muscular Dystrophy</p> <p><input type="checkbox"/> Freidrich's Ataxia</p> <p><input type="checkbox"/> Unspecified</p> <p><input type="checkbox"/> Other, specify</p> <p style="text-align: center;"><input type="text"/></p>	Question Added: 01 SEPT 2015

8a.xii

**History Dialysis**

- Dialysis, acute (within past 30 days)
- Dialysis, chronic (>1 month duration)
- Dysfunction, not dialysis
- Unknown
- Other, specify

Question Added: 01 JAN 2010

8a.xiii

**Medical History, Respiratory**

- Asthma
- Plastic Bronchitis
- Tracheostomy
- Unknown
- Other, specify

Question Added: 01 SEPT 2015

8a.xiv

**Shock, Date of last appropriate Shock**

MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 JAN 1996

8a.xv

**Medical History, Syndrome**

- Cardiofaciocutaneous Syndrome
- Costello Syndrome
- Digeorge (22q11 deletion)
- Down's/Trisomy 21
- Ehlers-Danlos Syndrome
- LEOPARD/Multiple Lentigenes
- Loeys-Dietz Syndrome
- Marfan Syndrome
- Noonan Syndrome
- Other Marfan-like Syndrome
- Turner Syndrome
- Unspecified
- Williams Syndrome
- Other, specify

Question Added: 01 SEPT 2015

**Insurance**

9

**Primary Insurance**

- Charitable Donation
- Free
- Government
- Private
- Self Pay
- Unknown
- Other, Specify

Question Added: 01 JAN 1996

- Charitable Donation – Indicates that a company, institution or individual(s) donated funds to pay for the care of the listed patient.
- Free – Indicates that the listing hospital will not charge the patient for the cost of the hospitalization
- Government – Other US or state government insurance. For Example, Medicaid, Medicare, CHIP (Children's Health Insurance Program), Department of VA refers to funds from the Veterans Administration or others.
- Private – Refers to funds from agencies such as Blue Cross/Blue Shield, etc.
- Self Pay – Indicates that the recipient will pay for the largest portion of the cost of the hospitalization.
- Other – For example, funds from a foreign government. Specify foreign country in the space provided.

**Percent or Panel Reactive Antibody (closest to listing)**

10a

**Cytotoxic PRA**  Done  
 Not Done

ie. Serum is tested against panel of lymphocytes

Question Added: 01 JAN 1993

10a.i

T Cell   
%

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

10a.ii

B Cell   
%

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

10a.iii

Date (Cytotoxic PRA)

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

10b

**Cytotoxic PRA, DTE/DTT**  Done  
 Not Done

Panel performed on serum treated with DTE or DTT (or equivalent)

to reduce the IgM antibodies and identify high PRA results presumably secondary to a drug or other causes.

Question Added: 01 JAN 1993

10b.i

T Cell   
%

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

10b.ii

B Cell   
%

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

10b.iii

Date (Cytotoxic PRA, DTE/DTT)

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

10c

**Flow Cytometry or Luminex PRA**  Done  
 Not Done

Question Added: 01 JAN 1996



<b>10c.i</b>	<b>Class I</b> <input style="width: 100%;" type="text"/> %	<b>Missing Reason:</b> <input type="radio"/> Unknown	Question Added: 01 JAN 1996
<b>10c.ii</b>	<b>Class II</b> <input style="width: 100%;" type="text"/> %	<b>Missing Reason:</b> <input type="radio"/> Unknown	Question Added: 01 JAN 1996
<b>10c.iii</b>	<b>Date</b> <input style="width: 100%;" type="text"/> <small>MM/DD/YYYY</small>	<b>Missing Reason:</b> <input type="radio"/> Unknown	Question Added: 01 JAN 1996

<b>10d</b>	<b>Listed for prospective crossmatch</b> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>10d.i</b>	<b>Prospective Crossmatch Results</b> <input type="radio"/> Donor Cells <input type="radio"/> Donor Cells and Virtual <input type="radio"/> Virtual <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>10d.i.1</b>	<b>Virtual Crossmatch</b> <input type="radio"/> Avoidance of donor antigens to all antibodies present <input type="radio"/> Avoidance of donor antigens to antibodies above pre-specified threshold <input type="radio"/> Avoidance of donor antigens to C1q fixing antibodies only <input type="radio"/> Unknown	Question Added: 01 SEPT 2015

### Hemodynamics Prior to Listing

Indicate the hemodynamics even if the patient is on pressors or inotropes. Best hemodynamics are those performed during the administration of agents given specifically to lower the pulmonary arterial pressure or the pulmonary vascular resistance. All pressures should be listed in mmHg. If unclear, please consult with your PI.

<b>11</b>	<b>Were hemodynamics done prior to listing?</b> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Question Added: 01 JAN 1993
<b>11a</b>	<b>Date</b> <input style="width: 100%;" type="text"/> <small>MM/DD/YYYY</small>	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>11b</b>	<b>Fontan Mean Pressure</b> <input style="width: 100%;" type="text"/>	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown
	<input style="width: 100%;" type="text"/>	Question Added: 01 JAN 1993

11c	<b>RAm (RAP or CVP)</b> Right Atrial Mean Pressure		Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	
11d	<b>PAm</b> Pulmonary Artery Mean	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
11e	<b>PCW</b> Mean Pulmonary Capillary Wedge Pressure	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
11f	<b>SVC Sat</b> Oxygen Saturation in the SVC	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
11g	<b>AO Sat</b> Aortic Saturation	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2005
11h	<b>Rp, PVRI</b> Pulmonary resistance indexed to body surface area (BSA) Woods Units x m <sup>2</sup>	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
11i	<b>Rs, SVRI</b> Systemic resistance indexed to body surface area (BSA) Woods Units x m <sup>2</sup>	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
11j	<b>EDP</b> End diastolic pressure of systemic ventricle	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
11k	<b>C.O.</b> Cardiac output (i.e. Qs) in L/min	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
11l	<b>C.I.</b> Cardiac index (i.e. C.O. divided by m <sup>2</sup> ) in L/min/m <sup>2</sup>	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
11m	<b>Was patient on mechanical support at time of Hemodynamics</b>	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Question Added: 01 SEPT 2015	
11n	<b>Hemodynamic Agents Used</b>	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Question Added: 01 JAN 1993	
11n.i	<b>Indicate agent for best hemodynamics</b> <input type="checkbox"/> 100% O2 <input type="checkbox"/> Dobutamine <input type="checkbox"/> Dopamine	<input type="button" value="↑"/> <input type="button" value="↓"/>		

- Unknown
- Epinephrine
- Isoproterenol (Isuprel)
- Milrinone (Primacor)
- Nesiritide
- Nitric Oxide
- Nitroglycerin
- Nitroprusside (Nipride)
- Norepinephrine
- PGE (Alprostadil)
- PGI (Flolan)
- Phenylephrine/ Neosynephrine
- Sildenafil
- Vasopressin
- Other, specify

Question Added: 01 JAN 1993

### Schooling

12

- Is the patient in school?
- Yes
  - No
  - Not Applicable, <6 years
  - Unknown

Question Added: 01 JAN 1996

12

- Are they at the age appropriate level
- Yes
  - No
  - Unknown

12b

- Are they in a special education class
- Yes
  - No
  - Unknown

Question Added: 01 JAN 1996

### Exercise Test

13

- Was exercise test performed?
- Yes
  - No
  - Unknown
  - Not Routinely Done

Question Added: 01 JAN 2005

13a

- If exercise test not performed, specify reason
- Age inappropriate
  - Too sick
  - Unknown

Other, specify

Question Added: 01 JAN 2015

**13b Max VO<sub>2</sub>% Predicted for Age**

Refers to predicted maximum VO<sub>2</sub> for patient (should be listed in exercise report; if not, exercise lab personnel should be able to provide this data)

Missing Reason:  
 Unknown  
 Not Done

Question Added: 01 JAN 2005

**13c Max VO<sub>2</sub>**

Maximum oxygen consumption ml/kg/min

Missing Reason:  
 Unknown  
 Not Done

Question Added: 01 JAN 1996

**13d Respiratory Value at Peak**

RER or Respiratory Quotient:R Value at peak is the respiratory quotient of carbon dioxide production divided by oxygen consumption, and is used as an index of how vigorously the patient exercised. A value above 1.05 is generally considered to represent an adequate effort.

Missing Reason:  
 Unknown  
 Not Done

Question Added: 01 SEPT 2015

**Laboratory Values closest to time of this report**

Note: labs may have been collected on different dates.

**14a Total Bilirubin**

  
 mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0.3 and 1.2  
 Question Zone: > 2.4  
 Red Flag Zone: > 10

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

**14b Direct Bilirubin**

  
 mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0 and 0.2  
 Question Zone: > 0.4  
 Red Flag Zone: > 5

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

**14c AST**

Aspartate transaminase (also SGOT) U/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 60  
 Question Zone: > 120  
 Red Flag Zone: > 1000

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

**14d ALT**

Alanine transaminase (also SGPT) U/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 7 and 45  
 Question Zone: > 90  
 Red Flag Zone: > 1000

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

**14e BNP**

B-type natriuretic peptide

  
 pg/mL or ng/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 100  
 Question Zone: > 1000  
 Red Flag Zone: > 10000

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

**14f Pro BNP**

Pro NT B-type natriuretic peptide

  
 pg/mL or ng/L  
 pmol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 300  
 Question Zone: > 3000  
 Red Flag Zone: > 30000

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

**Range Information**  
 Too Low: < 0

14g	<b>CRP</b> C reactive protein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mg/L	Normal: Between 0 and 0.5 Question Zone: > 5 Red Flag Zone: > 50	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
14h	<b>Creatinine</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.2 and 1.3 Question Zone: > 2.6 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 93 to 01 JAN 2004   01 JAN 2010 - CURRENT
14i	<b>BUN</b> Blood urea nitrogen	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> Urea mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 4 and 20 Question Zone: > 40 Red Flag Zone: > 120	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
14j	<b>Cystatin C</b>	<input type="text"/> mg/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.5 and 1.4 Question Zone: > 2.8 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 SEPT 2015
14k	<b>Total Protein</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 3.6 and 8.1 Question Zone: > 12 Red Flag Zone: > 16	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999
14l	<b>Pre Albumin</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 15 and 40 Question Zone: > 60 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2015
14m	<b>Serum Albumin</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999
14n	<b>Cholesterol</b> Total Cholesterol	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
14o	<b>TG</b> Triglycerides	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
14p	<b>LDL</b> Low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
14q	<b>HDL</b> High density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
14r	<b>VLDL</b> Very low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 2 and 30 Question Zone: > 60 Red Flag Zone: > 250	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010

**NYHA and Ross' Heart Failure**

15

- NYHA Class**  1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

**NYHA Classes**

- **Class I:** No symptoms at any level of exertion and no limitation in ordinary physical activity.
- **Class II:** Mild symptoms and slight limitation during regular activity. Comfortable at rest.
- **Class III:** Noticeable limitation due to symptoms, even during minimal activity. Comfortable only at rest.
- **Class IV:** Severe limitations. Experience symptoms even while at rest (sitting in a recliner or watching TV).

16

- Ross' Heart Failure Class**  1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

**Ross Heart Failure Classes**

- **Class I:** No limitations or symptoms
- **Class II:** Mild tachypnea and/or diaphoresis with feeds in infants; dyspnea on exercise in older children. No growth failure.
- **Class III:** Marked tachypnea and/or diaphoresis with feeds or exertion and prolonged feeding time with growth failure.
- **Class IV:** Symptomatic at rest with tachypnea, retractions, grunting or diaphoresis.

Patient Details Hidden [Show](#)

[Show/Hide Annotations](#) [Stickers: Toggle All](#) [Toggle Open](#) [Toggle Resolved](#)

# Form 1RL: Relisting

[Toggle Question Year/Info](#)

[Print this Form](#)

Not Started

1

Date of Relisting

## Height and Weight

2

Height

- Centimeters
- Inches

Missing Reason:

- Not Done
- Unknown

Calculated

BSA: n/a  
BMI: n/a

3

Weight

- Kilograms
- Pounds

Missing Reason:

- Not Done
- Unknown

4

Has this patient been transplanted  Yes

No

4a

Indicate total number of prior transplants

This includes transplants that were and were not done at your hospital.

Missing Reason:

- Unknown

4b

Date of most recent transplant

MM/DD/YYYY

5

Main reason for Re-Listing  Coronary artery disease, (infarction, arrhythmia, CHF post MI)

Graft dysfunction <30 days in the absence of rejection, pulmonary hypertension or surgical complications

Non-Specific Graft Failure (>30 days post transplant)

Other, specify

- Pulmonary Hypertension/RV Failure Rejection, acute
- Rejection Hyperacute (onset < 24 hours post transplant)
- Rejection, Acute
- Sudden Cardiac Death, no MI documented

### 6

#### Contributing reason for Re-Listing

- Coronary artery disease, (infarction, arrhythmia, CHF post MI)
- Graft dysfunction <30 days in the absence of rejection, pulmonary hypertension or surgical complications
- Non-compliance
- Non-specific graft failure (>30 days post transplant)
- No contributing cause
- Other, specify
- Pulmonary Hypertension/RV Failure
- Rejection, acute
- Rejection, hyperacute (onset < 24 hours post transplant)
- Sudden cardiac death, no MI documented

### Status Details at Re-Listing

#### 7a

##### Status at Re-Listing

- Brazil
- Canada
- United Kingdom
- United States

#### 7a.i

##### Status at Re-Listing, Brazil

- Non-Priority
- Priority

#### 7a.ii

##### Status at Re-Listing, Canada

- 0
- 1
- 2
- 3
- 3.5
- 4

#### 7a.iii

##### Status at Re-Listing, UK

- Routine
- Urgent

#### 7a.iv

##### Status at Re-Listing, US

- 1 (this option is only for listings prior to 1999)
- 1A
- 1B





- 
- 2
- 7

**7b** Was patient in or out of hospital at time of listing?  In hospital  Out of hospital

**7b.i** Was patient in the ICU at time of relisting?  Yes  No  Unknown

**7b.ii** Did the patient require continuous invasive mechanical ventilation?  Yes  No  Unknown

**7c** Did the patient require continuous inotropes at time of listing?  Yes  No  Unknown

**7c.i** Inotropes does  Dose Unknown  High Dose or Multiple IV  Single Low Dose

**7d** Did the patient have ductal dependent pulmonary or systemic circulation, with ductal patency maintained by stent or prostaglandin infusion?  Yes  No  Unknown

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

**7e** Was patient listed for an ABO Incompatible transplant?  Yes  No  Unknown

VAD

**7f** Was patient on a VAD or ECMO at time of relisting?  ECMO  
 Not on support at time of Relisting

**7f.i** Specify initiation date (VAD)

Missing Reason:  
 Unknown

**7f.ii** Specify initiation date (ECMO)

Missing Reason:  
 Unknown

**7g** Was patient listed for DCD (Donation after Cardiac Death) organ?  Yes  
 No  
 Unknown  
 This is not current practice at our center  
 Not Applicable

**Infectious Disease Screening**

**8a** **HIV Serology**  Negative  Not Done  Positive  Unknown  
AIDS testing

**8b** **CMV Serology**  Negative  Not Done  Positive  Unknown

**8c** **CMV PCR**  Negative  Not Done  Positive  Unknown

**8d** **EBV Serology**  Negative  Not Done  Positive  Unknown

**8e** **EBV PCR**  Negative  Not Done  Positive  Unknown

**8f** **IFA Toxo**  Negative  Not Done  Positive  Unknown  
Toxoplasma testing

**8g** **HBs Ag**  Negative  Not Done  Positive  Unknown  
Hepatitis B surface antigen

**8h** **HB core Ab**  Negative  Not Done  Positive  Unknown  
Hepatitis B core antibody

**8i** **HBs Ab**  Negative  Not Done  Positive  Unknown  
Hepatitis B surface antibody

8j

**Hep C Ab**  Negative  Not Done  Positive   
Hepatitis C antibody Unknown

8k

**RPR/Syphilis**  Negative  Not Done  Positive   
Syphilis testing Unknown

**Medical History at time of Re-Listing**

9

**Medical History**  Yes  
 No  
 Unknown

9a

**Medical History Details**

Select all medical history the patient had at the time of listing.

- Arrhythmia (current heart only)
- Cardiac arrest/CPR (current heart)
- Diabetes
- GI/Nutrition
- Heterotaxy/Isomerism
- Malignancy
- Metabolic Disorder
- Mitochondrial Disorder
- Neurological
- Pacemaker (current heart)
- Peripheral myopathy/neuromuscular disease
- Prenatal Diagnosis
- Prior transfusions
- Renal insufficiency
- Respiratory
- Shock (current heart)
- Syndrome
- Other, specify

9a.i

**Arrhythmia**  Afib/flutter  
 Complete heart block  
 V Fibrillation  
 V Tachycardia  
 Unknown  
 Other, specify

9a.ii

**Date of last cardiac arrest/CPR**  
MM/DD/YYYY

Missing Reason:  
 Unknown

**Date of Last Hgb A1c**  
MM/DD/YYYY

Missing Reason:  
 Unknown

9a.iii

9a.iv Value of Last Hgb   
A1c

Missing Reason:  
 Not Done  
 Unknown

9a.v Treating with Insulin  Yes  
 No  
 Unknown

9a.vi GI/Nutrition  Failure to thrive/cachexia  
 Fontan associated liver disease  
 Infectious hepatitis  
 Protein losing Enteropathy  
 Other, specify

9a.vi.1 Hepatitis History  A  
 B  
 C  
 Unknown  
 Other, specify

9a.vii Heterotaxy/Isomerism  Asplenia  
 Polysplenia  
 Situs inversus  
 Unspecified  
 Other, specify

9a.viii Malignancy  Lymphoma, leukemia  
 s/p BMT  
 s/p Chest Radiation  
 Solid organ cancer  
 Unknown  
 Other, specify

9a.ix Specify Metabolic Disorder

Barth's

<b>9a.x</b>	<b>Medical History, Mitochondrial Disorder, specify</b>	<input type="radio"/> <input type="radio"/> Unspecified <input type="radio"/> Other, specify <input style="width: 100%;" type="text"/>	
<b>9a.xi</b>	<b>Neurologic</b>	<input type="checkbox"/> Anoxic brain injury <input type="checkbox"/> Hemorrhagic and/or thromboembolic stroke <input type="checkbox"/> Other, specify <input style="width: 100%;" type="text"/>	
<b>9a.xi.1</b>	<b>Anoxic Brain Injury Date</b> <small>MM/DD/YYYY</small>	<input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
<b>9a.xi.2</b>	<b>Hemorrhagic and/or Thromboembolic Stroke, Date Last</b> <small>MM/DD/YYYY</small>	<input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
<b>9a.xii</b>	<b>Pacemaker</b>	<input type="checkbox"/> Defibrillator/AICD <input type="checkbox"/> Pacemaker, CRT/Biventricular pacing <input type="checkbox"/> Pacemaker, not CRT and not ICD	
<b>9a.xii.1</b>	<b>Defibrillator/AICD, Date Placed</b> <small>MM/DD/YYYY</small>	<input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
<b>9a.xii.2</b>	<b>Pacemaker, CRT/Biventricular pacing, Date placed</b> <small>MM/DD/YYYY</small>	<input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
<b>9a.xii.3</b>	<b>Pacemaker, not CRT and not ICD, Date placed</b> <small>MM/DD/YYYY</small>	<input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
<b>9a.xiii</b>	<b>Peripheral myopathy/ neuromuscular disease</b>	<input type="checkbox"/> Becker muscular dystrophy <input type="checkbox"/> Duchenne muscular dystrophy <input type="checkbox"/> Freidrich's ataxia	

- Unspecified
  - Other, specify
- 

9a.xiv

- Renal Insufficiency**
- Dialysis, acute (within past 30 days)
  - Dialysis, chronic (>1 month duration)
  - Dysfunction, not dialysis
  - Unknown
  - Other, specify
- 

9a.xv

- Respiratory**
- Asthma
  - Plastic Bronchitis
  - Tracheostomy
  - Unknown
  - Other, specify
- 

9a.xvi

**Date of last appropriate Shock**   
MM/DD/YYYY

**Missing Reason:**  
 Unknown

9a.xvii

- Syndrome**
- Cardiofaciocutaneous syndrome
  - Costello syndrome
  - DiGeorge (22q11 deletion)
  - Down's/Trisomy 21
  - Ehlers-Danlos Syndrome
  - LEOPARD/Multiple Lentigenes
  - Loeys-Dietz Syndrome
  - Marfan Syndrome
  - Noonan syndrome
  - Other Marfan-like syndrome
  - Turner Syndrome
  - Unspecified
  - Williams syndrome
  - Other, specify
- 

**Insurance**

10

- Primary Insuran#e**
- Charitable Donation
  - Free
  - Government
  - Private
  - Self Pay

Unknown  
 Other, specify

- Charitable Donation – Indicates that a company, institution or individual(s) donated funds to pay for the care of the listed patient.
- Free – Indicates that the listing hospital will not charge the patient for the cost of the hospitalization
- Government – Other US or state government insurance. For Example, Medicaid, Medicare, CHIP (Children’s Health Insurance Program), Department of VA refers to funds from the Veterans Administration or others.
- Private – Refers to funds from agencies such as Blue Cross/Blue Shield, etc.
- Self Pay – Indicates that the recipient will pay for the largest portion of the cost of the hospitalization.
- Other – For example, funds from a foreign government. Specify foreign country in the space provided.

**Percent or Panel Reactive Antibody (closest to relisting)**

**11a** **Cytotoxic PRA**  Done  
ie. Serum is tested against panel of lymphocytes  Not Done

**11a.i** **T Cell**  % **Missing Reason:**  
 Not Done  
 Unknown

**11a.ii** **B Cell**  % **Missing Reason:**  
 Not Done  
 Unknown

**11a.iii** **Date (Cytotoxic PRA)**  **Missing Reason:**  
 Not Done  
 Unknown

**11b** **Cytotoxic PRA, DTE/DTT**  Done  
Panel performed on serum treated with DTE or DTT (or equivalent)  Not Done  
to reduce the IgM antibodies and identify high PRA results presumably secondary to a drug or other causes.

**11b.i** **T Cell**  % **Missing Reason:**  
 Not Done  
 Unknown

**11b.ii** **B Cell**  % **Missing Reason:**  
 Not Done  
 Unknown

**11b.iii** **Date (Cytotoxic PRA, DTE/DTT)**  **Missing Reason:**  
 Unknown

**11c** Flow Cytometry or Luminex  Done  
 PRA  Not Done

**11c.i** Class I  % Missing Reason:  Unknown

**11c.ii** Class II  % Missing Reason:  Unknown

**11c.iii** Date  Missing Reason:  Unknown  
MM/DD/YYYY

**11d** Re-listed for prospective  Yes  
 crossmatch  No  
 Unknown

**11d.i** Prospective Crossmatch  Donor Cells  
 Type  Donor Cells and Virtual  
 Virtual  
 Unknown

**11d.i.1** Virtual  Avoidance of donor antigens to all antibodies  
 Crossmatch present  
 Avoidance of donor antigens to antibodies above  
 pre-specified threshold  
 Avoidance of donor antigens to C1q fixing  
 antibodies only  
 Unknown

### Hemodynamics Prior to Re-Listing

Indicate the hemodynamics even if the patient is on pressors or inotropes. Best hemodynamics are those performed during the administration of agents given specifically to lower the pulmonary arterial pressure or the pulmonary vascular resistance. All pressures should be listed in mmHg. If unclear, please consult with your PI.

**12** Were hemodynamics done  Yes  
 prior to relisting?  No  
 Unknown

**12a** Date  Missing Reason:  Unknown  
MM/DD/YYYY



12b	Fontan Mean Pressure	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12c	RAm (RAP or CVP) Right Atrial Mean Pressure	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12d	PAm Pulmonary Artery Mean	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12e	PCW Mean Pulmonary Capillary Wedge Pressure	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12f	SVC Sat Oxygen Saturation in the SVC	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12g	AO Sat Aortic Saturation	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12h	Rp, PVRI Pulmonary resistance indexed to body surface area (BSA) Woods Units x m <sup>2</sup>	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12i	Rs, SVRI Systemic resistance indexed to body surface area (BSA) Woods Units x m <sup>2</sup>	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12j	EDP End diastolic pressure of systemic ventricle	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12k	C.O. Cardiac output (i.e. Qs) in L/min	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12l	C.I. Cardiac index (i.e. C.O. divided by m <sup>2</sup> ) in L/min/m <sup>2</sup>	<input type="text"/>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12m	Was patient on mechanical support at time of Hemodynamics	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
12n	Hemodynamic Agents	<input type="radio"/> Yes <input type="radio"/> No	

Unknown

12n.i

Indicate agent for best hemodynamics

- 100% O2
- Dobutamine
- Dopamine
- Epinephrine
- Isoproterenol (Isuprel)
- Milrinone (Primacor)
- Nesiritide
- Nitric Oxide
- Nitroglycerin
- Nitroprusside (Nipride)
- Norepinephrine
- PGE (Alprostadi)
- PGI (Flolan)
- Phenylephrine/ Neosynephrine
- Sildenafil
- Vasopressin
- Other, specify

**Schooling**

13

Is patient in school?  Yes  
 No  
 Not Applicable  
 Unknown

13a

Are they at the age appropriate level  Yes  
 No  
 Unknown

13b

Are they in a special education class  Yes  
 No  
 Unknown

**Exercise Test**

14

Was exercise test performed?  Yes  
 No  
 Unknown  
 Not Routinely Done

**14a** If test no, specify reason  Age Inappropriate  
 Too Sick  
 Unknown  
 Other, specify

**14b** Max VO<sub>2</sub>% Predicted for Age  %

Refers to predicted maximum VO<sub>2</sub> for patient (should be listed in exercise report; if not, exercise lab personnel should be able to provide this data)

Missing Reason:  
 Not Done  
 Unknown

**14c** Respiratory Value at Peak

RER or Respiratory Quotient:R Value at peak is the respiratory quotient of carbon dioxide production divided by oxygen consumption, and is used as an index of how vigorously the patient exercised. A value above 1.05 is generally considered to represent an adequate effort.

Missing Reason:  
 Not Done  
 Unknown

**14d** Max VO<sub>2</sub>  ml/kg/min

Maximum oxygen consumption

Missing Reason:  
 Not Done  
 Unknown

**Laboratory Values closest to time of this report**

Note: labs may have been collected on different dates.

**15a** Total Bilirubin

mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0.3 and 1.2  
 Question Zone: > 2.4  
 Red Flag Zone: > 10

Missing Reason:  
 Not Done  
 Unknown

**15b** Direct Bilirubin

mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0 and 0.2  
 Question Zone: > 0.4  
 Red Flag Zone: > 5

Missing Reason:  
 Not Done  
 Unknown

**15c** AST  U/L

Aspartate transaminase (also SGOT)

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 60  
 Question Zone: > 120  
 Red Flag Zone: > 1000

Missing Reason:  
 Not Done  
 Unknown

**15d** ALT  U/L

Alanine transaminase (also SGPT)

**Range Information**  
 Top Low: < 0  
 Normal: Between 7 and 45  
 Question Zone: > 90  
 Red Flag Zone: > 1000

Missing Reason:  
 Not Done  
 Unknown

**15e** BNP  pg/mL or ng/L

B-type natriuretic peptide

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 100  
 Question Zone: > 1000  
 Red Flag Zone: > 10000

Missing Reason:  
 Not Done  
 Unknown

Range Information

<b>15f</b>	<b>Pro BNP</b> <small>Pro NT B-type natriuretic peptide</small>	<input type="text"/> <input type="radio"/> pg/mL or ng/L <input type="radio"/> pmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 10 and 300 Question Zone: > 3000 Red Flag Zone: > 30000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15g</b>	<b>CRP</b> <small>C reactive protein</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mg/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0 and 0.5 Question Zone: > 5 Red Flag Zone: > 50	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15h</b>	<b>Creatinine</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.2 and 1.3 Question Zone: > 2.6 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15i</b>	<b>BUN</b> <small>Blood urea nitrogen</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> Urea mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 4 and 20 Question Zone: > 40 Red Flag Zone: > 120	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15j</b>	<b>Cystatin C</b>	<input type="text"/> mg/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.5 and 1.4 Question Zone: > 2.8 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15k</b>	<b>Total Protein</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 3.6 and 8.1 Question Zone: > 12 Red Flag Zone: > 16	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15l</b>	<b>Pre Albumin</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 15 and 40 Question Zone: > 60 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15m</b>	<b>Serum Albumin</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15n</b>	<b>Cholesterol</b> <small>Total Cholesterol</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15o</b>	<b>TG</b> <small>Triglycerides</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15p</b>	<b>LDL</b> <small>Low density lipoprotein</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>15q</b>	<b>HDL</b> <small>High density lipoprotein</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 2 and 30	

15r

VLDL  mg/dL  
 Very low density lipoprotein  mmol/L

Question Zone: > 60  
 Red Flag Zone: > 250

Missing Reason:  
 Not Done  
 Unknown

## NYHA and Ross' Heart Failure

16

NYHA Class  1  
 2  
 3  
 4  
 Not Done  
 Unknown

### NYHA Classes

- **Class I:** No symptoms at any level of exertion and no limitation in ordinary physical activity.
- **Class II:** Mild symptoms and slight limitation during regular activity. Comfortable at rest.
- **Class III:** Noticeable limitation due to symptoms, even during minimal activity. Comfortable only at rest.
- **Class IV:** Severe limitations. Experience symptoms even while at rest (sitting in a recliner or watching TV).

17

Ross Heart Failure Class  1  
 2  
 3  
 4  
 Not Done  
 Unknown

### Ross Heart Failure Classes

- **Class I:** No limitations or symptoms
- **Class II:** Mild tachypnea and/or diaphoresis with feeds in infants; dyspnea on exercise in older children. No growth failure.
- **Class III:** Marked tachypnea and/or diaphoresis with feeds or exertion and prolonged feeding time with growth failure.
- **Class IV:** Symptomatic at rest with tachypnea, retractions, grunting or diaphoresis.



Patient Details Hidden [Show](#)

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# Form 1T: Transplant

[Toggle Question Year/Info](#)

[Print this Form](#)

Not Started

1

Date of Transplant

MM/DD/YYYY

Question Added: 01 JAN 1993

2

Simultaneous organ

Check all that apply.

- Kidney
- Liver
- None
- Unknown
- Other, specify

Question Added: 01 JAN 2010

3

Type of Transplant

Orthotopic: recipient heart is replaced by donor heart.  
Heterotopic: donor heart is transplant into recipient without the removal of the recipient's heart (also called piggy-back transplant)

- Heterotopic
- Orthotopic
- Unknown

Question Added: 01 JAN 1993

## Height and Weight

4

Height

- Centimeters
- Inches

Question Added: 01 JAN 1993

Missing Reason:

- Not Done
- Unknown

**Calculated**

BSA: n/a  
BMI: n/a

5

Weight

- Kilograms
- Pounds

Question Added: 01 JAN 1993

Missing Reason:

- Not Done
- Unknown

## Status Details at Transplant

6a

Status at Transplant

- Brazil
- Canada
- United Kingdom
- United States

Question Added: 01 JAN 1993

6a.i

**Brazil**  Non Priority  
 Priority

Question Added: 01 JAN 2010

6a.ii

**Canada**  1  
 2  
 3  
 3.5  
 4  
 4S

Question Added: 01 JAN 2005

6a.iii

**United Kingdom**  Routine  
 Urgent

Question Added: 01 JAN 2005

6a.iv

**United States**  1 (this option is only for listings prior to 1999)  
 1A  
 1B  
 2  
 4

Question Added: 01 JAN 1993

6b

**Was patient in or out of hospital at time of transplant?**  In hospital  
 Out of hospital

Question Added: 01 JAN 1993

6b.i

**Was patient in the ICU at time of transplant?**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

6b.ii

**Did the patient require continuous invasive mechanical ventilation?**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

6c

**Did the patient require continuous inotropes at time of transplant?**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

6c.i

**Inotropes Dose**  High Dose or Multiple IV  
 Single Low Dose  
 Unknown

Question Added: 01 JAN 1999

6d

**Did the patient have ductal dependent pulmonary or**  Yes  
 No



systemic circulation, with ductal patency maintained by stent or prostaglandin infusion?  Unknown

Question Added: 01 SEPT 2015

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>

6e Was the patient transplanted with an ABO incompatible transplant?  Yes  No  Unknown

Question Added: 01 JAN 2005

6f Was patient on a VAD or ECMO at time of transplant?  VAD  ECMO  Not on support at time of Transplant

Question Added: 01 JAN 1993

6f.i Specify initiation date (VAD)

Missing Reason:  Unknown

Question Added: 01 JAN 1999

6f.ii Specify initiation date (ECMO)

Missing Reason:  Unknown

Question Added: 01 JAN 2005

6g Was patient listed for DCD (Donation after Cardiac Death) organ?  Yes  No  Unknown  This is not current practice at our center  Not Applicable

Question Added: 01 SEPT 2015

**Percent or Panel Antibody (closest to Transplant)**

7a Cytotoxic PRA  Done  Not Done

Question Added: 01 JAN 1993

7a T Cell  %  
Values above 10 will require section 10: Per-operative management for PRA to be completed.

Missing Reason:  Unknown

Question Added: 01 JAN 1993

7a **B Cell**  %  
Values above 10 will require section 10:  
Per-operative management for PRA to be completed.

Missing Reason:  Unknown  
Question Added: 01 JAN 1993

7a.iii **Date**   
MM/DD/YYYY

Missing Reason:  Unknown  
Question Added: 01 JAN 1993

7b **Cytotoxic PRA DTE/DTT**  Done  
 Not Done

Question Added: 01 JAN 1993

7b **T Cell**  %  
Values above 10 will require section 10:  
Per-operative management for PRA to be completed.

Missing Reason:  Unknown  
Question Added: 01 JAN 1993

7b **B Cell**  %  
Values above 10 will require section 10:  
Per-operative management for PRA to be completed.

Missing Reason:  Unknown  
Question Added: 01 JAN 1993

7b.iii **Date**   
MM/DD/YYYY

Missing Reason:  Unknown  
Question Added: 01 JAN 1993

7c **Flow Cytometry or Luminex PRA**  Done  
 Not Done

Question Added: 01 JAN 1996

7c **Class I**   
Values above 10 will require section 10:  
Per-operative management for PRA to be completed.

Missing Reason:  Unknown  
Question Added: 01 JAN 1996

7c **Class II**   
Values above 10 will require section 10:  
Per-operative management for PRA to be completed.

Missing Reason:  Unknown  
Question Added: 01 JAN 1996

7c.ii **Date**

Missing Reason:  Unknown  
Question Added: 01 JAN 1996

8 **Did this patient have a virtual crossmatch?**  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

8a **Crossmatch Results**  Negative  
 Positive  
 Unknown



○

Question Added: 01 SEPT 2015

**9 Donor Specific or Retrospective Crossmatch performed?**  
 Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**9a Crossmatch Results**  
 Negative  
 Not Done  
 Positive  
 Unknown

Question Added: 01 JAN 1993

**9b Was the crossmatch performed prior to the decision to accept the donor?**  
 Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**10a Did the patient receive treatment to lower or manage an elevated PRA while awaiting transplantation?**  
 Yes  
 No  
 Unknown

Question Added: 01 JAN 2010

**10a.i Which therapy was administered?**  
 Check all that apply.  
 Azathioprine (Imuran)  
 Bortezomib (Velcade)  
 Cytoxan (cyclophosphamide)  
 Immunoglobulin (IVIG, IV IgG)  
 Mycophenylate, MMF (Cellcept, Myfortic)  
 Plasmapheresis/plasma exchange  
 Rituximab (Rituxan)  
 Unknown  
 Other, specify

Question Added: 01 JAN 2010

**10a.ii How long was therapy administered?**  
 Check all that apply.  
 Only for a pre-specified time/number of treatments: specify   
 Until Heart transplantation, regardless of subsequent PRA levels/sensitization profile  
 Until PRA level reduced to 0%/patient no longer sensitized  
 Until PRA/sensitization profile diminished to a pre-specified goal  
 Unknown

Question Added: 01 JAN 2010

**10b** Was prophylactic plasmapheresis/exchange performed in the peri-operative period  Yes  No  Unknown

Question Added: 01 JAN 2010

**10b.i** Was this performed during cardiopulmonary bypass?  Yes  No  Unknown

Question Added: 01 JAN 2010

**10b.ii** Was this performed during the immediate post-operative period?  Yes  No  Unknown

Question Added: 01 JAN 2010

**10b.ii.1** How many cycles?

Missing Reason:  Unknown

Question Added: 01 JAN 2010

**10c** Were there additional therapies, not routinely administered to post transplant patients in your center, given to this patient?  Yes  No  Unknown

Question Added: 01 JAN 2010

**10c.i** Therapies administered  Alemtuzumab (Campath)  Azathioprine (Imuran)  Basiliximab (Simulect)  Bortezomib (Velcade)  Cyclosporine (cyclophosphamide)  Eculizumab (Soliris)  Immunoglobulin (IVIG, IV IgG)  MMF (Cellcept, Myfortic)  Plasmapheresis/plasma exchange  Rituximab (Rituxan)  Steroids (methylprednisone, prednisone, orapred, prednisolone, solumedrol, Medrol, etc.)  Other, specify

Question Added: 01 JAN 2010

**B Cell and T Cell Results**

**11a** B cell flow DSXM  Negative  Not Done  Positive  Unknown

Question Added: 01 SEPT 2015

**11b B cell CDC/cytotoxicity DSXM**  Negative Unknown  Not Done  Positive

Question Added: 01 SEPT 2015

**11c T cell flow DSXM**  Negative Unknown  Not Done  Positive

Question Added: 01 SEPT 2015

**11d T cell CDC/cytotoxicity DSXM**  Negative Unknown  Not Done  Positive

Question Added: 01 SEPT 2015

**12 Donor Specific Antibodies (DSA)**  Yes  No  Unknown

Question Added: 01 SEPT 2015

**12a Donor Specific Antibodies (DSA) Results**  Class I  Class II  Unknown

Question Added: 01 SEPT 2015

**12b Was DSA complement fixing?**  Yes  No  Unknown  
(i.e. positive C1q assay)

Question Added: 01 SEPT 2015

**Laboratory Values (closest to time of transplant)**

Note: labs may have been collected on different dates.

**13a Total Bilirubin**  **Range Information**  
Top Low: < 0  
Normal: Between 0.3 and 1.2  
Question Zone: > 2.4  
Red Flag Zone: > 10

mg/dL  umol/L

**Missing Reason:**  Not Done  Unknown

Question Added: 01 JAN 2005

**13b Direct Bilirubin**  **Range Information**  
Top Low: < 0  
Normal: Between 0 and 0.2  
Question Zone: > 0.4  
Red Flag Zone: > 5

mg/dL  umol/L

**Missing Reason:**  Not Done  Unknown

Question Added: 01 JAN 2005

**13c AST**  **Range Information**  
Top Low: < 0  
Normal: Between 10 and 60  
Question Zone: > 120  
Red Flag Zone: > 1000

Aspartate transaminase (also SGOT) U/L

**Missing Reason:**  Not Done  Unknown

Question Added: 01 JAN 2005

**13d ALT**  **Range Information**  
Top Low: < 0  
Normal: Between 7 and 45  
Question Zone: > 90  
Red Flag Zone: > 1000

Alanine transaminase (also SGPT) U/L

**Missing Reason:**  Not Done  Unknown

Question Added: 01 JAN 2005

**13e BNP**  **Range Information**  
Top Low: < 0  
Normal: Between 10 and 100  
Question Zone: > 1000  
Red Flag Zone: > 10000

B-type natriuretic peptide pg/mL or ng/L

**Missing Reason:**  Not Done  Unknown

Question Added: 01 JAN 2010

**Range Information**  
Top Low: < 0  
Normal: Between 10 and 300

Question Added: 01 SEPT 2015

13f	<b>Pro BNP</b> Pro NT B-type natriuretic peptide	<input type="radio"/> pg/mL or ng/L <input type="radio"/> pmol/L	Question Zone: > 3000 Red Flag Zone: > 30000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	
13g	<b>CRP</b> C reactive protein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mg/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0 and 0.5 Question Zone: > 5 Red Flag Zone: > 50	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
13h	<b>Creatinine</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.2 and 1.3 Question Zone: > 2.6 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
13i	<b>BUN</b> Blood urea nitrogen	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> Urea mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 4 and 20 Question Zone: > 40 Red Flag Zone: > 120	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1993
13j	<b>Cystatin C</b>	<input type="text"/> mg/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.5 and 1.4 Question Zone: > 2.8 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 SEPT 2015
13k	<b>Total Protein</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 3.6 and 8.1 Question Zone: > 12 Red Flag Zone: > 16	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999
13l	<b>Pre Albumin</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 15 and 40 Question Zone: > 60 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2015
13m	<b>Serum Albumin</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999
13n	<b>Cholesterol</b> Total Cholesterol	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
13o	<b>TG</b> Triglycerides	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
13p	<b>LDL</b> Low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
13q	<b>HDL</b> High density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
13r	<b>VLDL</b> Very low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL	<b>Range Information</b> Top Low: < 0 Normal: Between 2 and 30		Question Added: 01 JAN 2010

mmol/L

Question Zone: > 60  
Red Flag Zone: > 250

Missing Reason:

- Not Done
- Unknown

### Hemodynamics (closest to transplant)

Indicate the hemodynamics even if the patient is on pressors or inotropes. Best hemodynamics are those performed during the administration of agents given specifically to lower the pulmonary arterial pressure or the pulmonary vascular resistance. All pressures should be listed in mm Hg. If unclear, please confirm with your PI.

14

**Hemodynamics**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

14a

Date   
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

14b

**Fontan Mean Pressure**

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

14c

**RAm (RAP or CVP)**   
Right atrial mean pressure

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14d

**PAm**   
Pulmonary artery mean

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14e

**PCW**   
Mean pulmonary capillary wedge pressure

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14f

**SVC Sat**   
Oxygen saturation in the SVC

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

14g

**AO Sat**   
Aortic saturation

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2005

14h

**Rp, PVRI**   
Pulmonary resistance indexed to body surface area (BSA) Woods Units x m<sup>2</sup>

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14i

**Rs, SVRI**   
Systemic resistance indexed to body surface area (BSA) Woods Units x m<sup>2</sup>

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14j

**EDP**   
End diastolic pressure of systemic ventricle

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

14k

C.O.   
 Cardiac output (i.e. Qs) in L/min L/min

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14l

C.I.   
 Cardiac index (i.e. C.O. divided by m<sup>2</sup>) in L/min/m<sup>2</sup> L/min/m<sup>2</sup>

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

14m

Hemodynamic Agents  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

14m.i

Indicate agent for best hemodynamics

Check all that apply.

- 100% O2
- Dobutamine
- Dopamine
- Epinephrine
- Isoproterenol (Isuprel)
- Milrinone
- Nesiritide
- Nitric Oxide
- Nitroglycerine
- Nitroprusside (Nipride)
- Norepinephrine
- PGE (Alprostadiol)
- PGI (Flolan)
- Phenylephrine/Neosynephrine
- Sildenafil
- Vasopressin
- Other, specify

Question Added: 01 JAN 1993

14n

Was patient on mechanical support at time of Hemodynamics?  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**Inotropes, Pressors, and Thyroid Hormones**

15

Was recipient on inotropes, pressors, or thyroid hormones at time of transplant?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

15a

Inotropes, Pressors, or Thyroid Hormones  100% O2  
 Dobutamine  
 Dopamine  
 Epinephrine



- Isoproterenol (Isuprel)
- Milrinone
- Neosynephrine
- Nesiritide
- Nitric Oxide
- Nitroglycerine
- Nitroprusside (Nipride)
- Norepinephrine (Levophed)
- PGE (Alprostadiil)
- PGI (Flolan)
- Phenylephrine/Neosynephrine
- Sildenafil
- T3 (Tri-iodothyronine)
- T4 (Levothyroxine)
- Vasopressin
- Other, specify

Question Added: 01 JAN 1993

### Cardiopulmonary bypass, donor ischemic, and technique of transplant

16

**Cardiopulmonary bypass time**

minutes

Report total number in minutes

Missing Reason:

Unknown

Question Added: 01 JAN 2005

17

**Total donor ischemic time**

minutes

Report minutes from recovery crossclamp to removal of crossclamp after transplant

Missing Reason:

Unknown

Question Added: 01 JAN 1993

18

**Technique of transplant**

- Atrial
- Bicaval
- Unknown

Question Added: 01 JAN 2005



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# Form 2: Donor

[Toggle Question Year/Info](#)

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Not Started

Transplant Date

Question Added: 01 JAN 1993

1

**Donor Age**

Indicate age in months, days, or years

- Days
- Months
- Years

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

2

**Donor Date of Birth**

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

## Height and Weight

3

**Donor Height**

- Centimeters
- Inches

Question Added: 01 JAN 1993

Missing Reason:  
 Not Done  
 Unknown

**Calculated**

BSA: n/a  
BMI: n/a

4

**Donor Weight**

- Kilograms
- Pounds

Question Added: 01 JAN 1993

Missing Reason:  
 Not Done  
 Unknown

5

**Donor Sex**  Female  
 Male  
 Unknown

Question Added: 01 JAN 1993

6

**Donor Race**  American Indian or Alaskan Native

Check all that apply.

- Asian
- Black
- Pacific Islander
- White
- Unknown
- Other, specify

Question Added: 01 JAN 1993

7

**Hispanic or Latino**  Yes

Yes if of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture of origin, regardless of race.  No  Unknown

Question Added: 01 JAN 1993

8a

**Donor Date of Death**

MM/DD/YYYY

**Missing Reason:**

Unknown

Question Added: 01 JAN 2005

8b

**Donor Cause of Death**  Anoxia

Check only one.

- Cerebrovascular/Stroke
- CNS Tumor
- Head Trauma
- Other, specify

Question Added: 01 JAN 1993

8c

**Donor Mechanism of death**  Asphyxiation

Check only one.

- Blunt Injury
- Cardiovascular
- Cerebral Embolism
- CNS Infection
- Drowning
- Drug Intoxication
- Electrical
- Gunshot Wound
- Intracranial Hemorrhage (ICH)
- Seizure
- Stab
- Sudden Infant Death
- Unknown
- Other, specify

Question Added: 01 JAN 1993

8d

**Donor Circumstances of death**  Alleged Child Abuse

- Alleged Homicide
- Alleged Suicide
- Motor Vehicle Accident
- Non-Motor Vehicle Accident
- Unknown
- Other, specify

Question Added: 01 JAN 1993

9

**Donor Downtime**  Yes

Previously called "Duration of Cardiac Arrest".  No  Unknown

Question Added: 01 JAN 2005

9a

**Duration of Donor Downtime**

Previously called "Duration of Cardiac Arrest".  
Enter duration in minutes.

Missing Reason:  
 Unknown

Question Added: 01 JAN 2005

10

**Chest Compressions (CPR)**

- Yes
- No
- Unknown

Question Added: 01 JAN 1993

10a

**If yes, CPR Time**

Enter duration in minutes  minutes

Missing Reason:  
 Unknown

Question Added: 01 JAN 2010

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

11

**Donor Blood Type**

- A
- AB
- B
- O

Question Added: 01 JAN 1993

11a

**Blood type A subtype**

- A1
- A2
- Unknown

Question Added: 01 JAN 2010

12

**Donor Rh**

- Negative
- Positive
- Unknown

Question Added: 01 JAN 1993

13

**Donor Past Medical History**

Check all that are known.

- Cancer at time of procurement
- Diabetes
- History of Cancer
- Hypertension
- Infection, specify
- Mitral Valve Prolapse
- None
- Unknown

Question Added: 01 JAN 1993

- Yes

**13a** If donor had diabetes, was patient on insulin?  No  Unknown

Question Added: 01 JAN 1993

**13** Cancer at Time of Procurement, Location

Question Added: 01 JAN 1993

**13** Cancer Type/Location

Question Added: 01 JAN 1993

**14** Did the donor have an increased risk for HIV, HBV, HCV?  Yes  No  Unknown

Question Added: 01 SEPT 2015

**14a** If yes, specify increased risk.  At risk medical history (i.e. hemodialysis, new diagnosis of or treatment for STD in past 12 months)  At risk social history (specify)  Hemodiluted sample

Question Added: 01 SEPT 2015

**14a.i** If at risk social history, specify.  Incarceration  Injected Drug Use  Mother with HIV  Sexual exposure  Unknown  Other, specify

Check all that apply

Question Added: 01 SEPT 2015

**Pre-transplant Donor Echocardiogram**

**15** Pre-Transplant Donor Echocardiogram (closest to time of procurement)  Yes  No  Unknown

Question Added: 01 JAN 1993

**15a** Result of Donor Echocardiogram  Abnormal  Normal  Unknown

Question Added: 01 JAN 1993

**15a.i** If abnormal, please specify  Abnormal Septal Motion  Diffuse Wall Motion Abnormality  Focal Wall Motion Abnormality  Mitral Regurgitation

Check all that apply.

- Tricuspid Regurgitation
- Unknown

Question Added: 01 JAN 1993

15b Donor Fractional Shortening

- Missing Reason:
- Not Done
  - Unknown

Question Added: 01 JAN 1993

15c Donor Estimated LV Eject Fraction

- Missing Reason:
- Not Done
  - Unknown

Question Added: 01 JAN 1993

### Pre-transplant Donor Angiogram

16 Pre-transplant Donor Angiogram  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

16a Angiogram results  Abnormal, Specify   
 Normal  
 Unknown

Question Added: 01 JAN 2005

### Donor Serologies

17a **HB core Ab**  Negative  Not Done  Positive  Unknown  
Hepatitis B core antibody

Question Added: 01 JAN 1993

17b **HBs Ag**  Negative  Not Done  Positive  Unknown  
Hepatitis B surface antigen

Question Added: 01 JAN 1993

17c **HBs Ab**  Negative  Not Done  Positive  Unknown  
Hepatitis B surface antibody

Question Added: 01 JAN 1993

17d **Hep C ab**  Negative  Not Done  Positive  Unknown  
Hepatitis C antibody

Question Added: 01 JAN 1993

17e **HIV Serology**  Negative  Not Done  Positive  Unknown  
AIDS testing

Question Added: 01 JAN 1993

17f **CMV IgG**  Negative  Not Done  Positive  Unknown  
Cytomegalovirus testing

Question Added: 01 JAN 1993

17g **RPR/Syphilis**  Negative  Not Done  Positive  Unknown  
Syphilis testing

Question Added: 01 JAN 1993

17h

**EBV IgG**  Negative  Not Done  Positive  Unknown  
Epstein Barr Virus

Question Added: 01 JAN 1993

17i

**IFA Toxo**  Negative  Not Done  Positive  Unknown  
Toxoplasma testing

Question Added: 01 JAN 1993

**Donor on Inotropes, Pressors, or Thyroid Hormones at time of recovery/harvest?**

18a

**T3**  Yes  No  Unknown  
Tri-iodothyronine (Thyroid hormone)

Question Added: 01 JAN 1993

18b

**T4**  Yes  No  Unknown  
Levothyroxine (Thyroid hormone)

Question Added: 01 JAN 1993

18c

**Epinephrine**  Yes  No  Unknown  
Adrenaline (Inotrope, pressor)

Question Added: 01 JAN 1993

18d

**Dopamine**  Yes  No  Unknown  
(Inotrope)

Question Added: 01 JAN 1993

18e

**Dobutamine**  Yes  No  Unknown  
Dobutrex (Inotrope)

Question Added: 01 JAN 1993

18f

**Vasopressin**  Yes  No  Unknown  
Pitressin (Pituitary hormone)

Question Added: 01 JAN 1993

18g

**Levophed**  Yes  No  Unknown  
Norepinephrine (Inotrope, Pressor)

Question Added: 01 JAN 1993

18h

**Milrinone**  Yes  No  Unknown  
Primacor (Inotrope)

Question Added: 01 JAN 1993

18i

**Neosynephrine**  Yes  No  Unknown  
Phenylephrine (Pressor)

Question Added: 01 JAN 1993

18j

**Other**  Yes  No  Unknown

Question Added: 01 JAN 1993

18j

Please specify

Question Added: 01 January 1993



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# Form 3: Initial Immunosuppression

Question Year/Info

[Print this Form](#)

Not Started

**Transplant Date**   
MM/DD/YYYY

Question Added: 01 JAN 1993

## Induction Therapy

Induction Therapy is defined as the prescribed use of lymphocyte cytolytic antibody or IL2-R antagonist therapy (e.g., ATGAM, Thymoglobulin, Basiliximab, Daclizumab) given soon after transplant (started within 3 days), not used to specifically treat a known or suspected rejection episode).

The use of non-cytolytic agents pre or intraoperatively is not considered to be induction therapy.

**1 Is Patient on Induction Therapy**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

## Induction Agents

### Induction Agent Details

**1a Induction Immunosuppression Agent**  Alemtuzumab (Campath)  
 Basiliximab (Simulect)  
 Bortezomib (Velcade)  
 Daclizumab (Zenapax)  
 OKT3  
 Rituximab (Rituxan)  
 Thymoglobulin (ATG)  
 Unknown  
 Other, specify

Question Added: 01 January 1993

**1b Start Date**   
MM/DD/YYYY

**Missing Reason:**  
 Unknown

Question Added: 01 January 1993

**1c End Date**   
MM/DD/YYYY

**Missing Reason:**  
 Unknown

Question Added: 01 January 1993

2

**Azathioprine (Imuran)**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

2a

Specify date of first post-op  
dose

MM/DD/YYYY

Question Added: 01 JAN 1999

2b

Was patient on medication at  
30 days?  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

2b.i

If patient is no longer  
on medication  
at 30 days, specify  
stop date.

MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

3

**Cyclosporine**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

3a

Specify date of first post-op  
dose

MM/DD/YYYY

Question Added: 01 JAN 1993

3b

Was patient on medication at  
30 days?  Yes  
 No  
 Unknown

Question Added: 01 JAN 2005

3b.i

If patient is no longer  
on medication  
at 30 days, specify  
stop date.

MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

4

**Mycophenolate (Cellcept, Myfortic)**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

**4a** Specify date of first post-op dose   
MM/DD/YYYY

Question Added: 01 JAN 1999

**4b** Was patient on medication at 30 days?  Yes  
 No  
 Unknown

Question Added: 01 JAN 2005

**4b.i** If patient is no longer on medication at 30 days, specify stop date.   
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

**5** Sirolimus (Rapamycin)  Yes  
 No  
 Unknown

Question Added: 01 JAN 2005

**5a** Specify date of first post-op dose   
MM/DD/YYYY

Question Added: 01 JAN 2005

**5b** Was patient on medication at 30 days?  Yes  
 No  
 Unknown

Question Added: 01 JAN 2005

**5b.i** If patient is no longer on medication at 30 days, specify stop date.   
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

**6** Tacrolimus (Prograf, FK506)  Yes  
 No  
 Unknown

Question Added: 01 JAN 1996

**6a** Specify date of first post-op dose   
MM/DD/YYYY

Question Added: 01 JAN 1996

**6b** Was patient on medication at 30 days?  Yes  
 No  
 Unknown

Question Added: 01 JAN 2005

**6b.i** If patient is no longer on medication at 30 days, specify stop date.  
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

**7**

**Everolimus**  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**7a** Specify date of first post-op dose  
MM/DD/YYYY

Question Added: 01 SEPT 2015

**7b** Was patient on medication at 30 days?  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**7b.i** If patient is no longer on medication at 30 days, specify stop date.  
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

**8**

**Cyclophosphamide (Cytoxan)**  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**8a** Specify date of first post-op dose  
MM/DD/YYYY

Question Added: 01 SEPT 2015

**8b** Was patient on medication at 30 days?  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**8b.i** If patient is no longer on medication at 30 days, specify stop date.  
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 SEPT 2015

**9a** Was patient given pre-operative steroids?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**9b** Was patient given intra-operative steroids?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**9c** Was patient given post-operative steroids?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**9c.i** Date of first post-op dose   
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

**9c.ii** Daily dose at 30 days  mg

Missing Reason:  
 No Steroids at 30 days  
 Unknown

Question Added: 01 JAN 1993

**9d** Planned Maintenance Steroids  Yes  
 No  
 Unknown

Question Added: 01 JAN 2005

**9d.i** If no, please specify End Date of steroid use   
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 JAN 2005

**10** Was patient given other immunosuppressants?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**Other immunosuppressant details**

**Other immunosuppressant details**

**10a** Specify other immunosuppressant

**10b** Specify date of first post op dose  
MM/DD/YYYY

Missing Reason:  
 Unknown

**10c** Patient on medication at 30 days  
 Yes  
 No  
 Unknown

**10c.i** If patient is no longer on medication at 30 days, specify stop date.  
MM/DD/YYYY

Missing Reason:  
 Unknown

**Prophylactic Antibiotics/Antivirals started Pre-op through 30 days post op**

Infection Prophylaxis: Started during the first 30 days post-transplant (not used to treat known infection).

**11** Prophylactic Antibiotics/Antivirals started Pre-op through 30 days post op  
Check all that apply

- Acyclovir
- Antifungal
- CMV Immunoglobulin (Cytogam)
- Dapsone
- Ganciclovir or Valganciclovir
- Immunoglobulin (IV Ig)
- Pentamidine
- Trimethaprim-Sulfamethoxazole
- Valacyclovir
- Unknown
- Other, specify

Question Added: 01 JAN 1993

**11a** If antifungal, please specify  
Check all that apply

- Fluconazole
- Nystatin
- Unspecified
- Other, specify

Question Added: 01 JAN 1993

**11b** If ganciclovir or valganciclovir, please specify  
Check all that apply

- IV
- PO

Question Added: 01 SEPT 2015



12

**Date of Hospital Discharge**

MM/DD/YYYY

Missing Reason:

- Still In Hospital
- Unknown

Question Added: 01 JAN 2005

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Patient Details Hidden [Show](#)[Show/Hide Annotations](#) [Stickies: Toggle All](#) [Toggle Open](#) [Toggle Resolved](#)**Form 4: Coronary Evaluation**[Toggle Question Year/Info](#)[Print this Form](#)

Not Started

1

Date of Coronary Evaluation

Question Added: 01 JAN 1993

**Coronary Evaluation**

2

**Indication for Coronary Evaluation**

Check only one.

- Angio NOT DONE: Non-invasive test performed
- Followup from PTCA / Revascularization (to check patency)
- Non-invasive test prior to this date indicated coronary disease
- Objective evidence of graft dysfunction/CAD
- Research Protocol
- Routine, per established protocol (i.e. yearly evaluation)
- Symptoms (suggesting CHF or angina equivalent)
- Unknown
- Other, specify

Question Added: 01 JAN 1993

2a

**Angio NOT DONE: Non-invasive test performed**

- Cardiac CT
- Dobutamine Stress Echo
- Exercise Stress Echo
- Exercise Test
- MRI
- Radionuclide Angiogram (MUGA)
- Resting Echo
- Stress Perfusion
- Unknown
- Other, specify

Question Added: 01 JAN 1999

2b

**Non-invasive test prior to this date indicated coronary disease, specify test**

Check only one.

- Cardiac CT
- Dobutamine Stress Echo
- Exercise Test
- MRI
- Radionuclide Angiogram (MUGA)
- Resting Echo
- Stress Perfusion
- Unknown
- Other, specify

Question Added: 01 JAN 1993

## Angiography

3a

**Injection sites**

Check all that apply.

- Aorta
- Left Ventricle
- Selective Left Coronary
- Selective Right Coronary
- Unknown

Question Added: 01 JAN 1993

3b

**Method of Interpretation**

(Pertains to the angiogram)

Check only one.

- Caliper
- Computer Assisted
- Visual Estimate
- Unknown

Question Added: 01 JAN 1993

3c

**Pre-angiogram nitroglycerin**

- Yes
- No
- Unknown

Question Added: 01 JAN 2005

## Angiography Results

4

**Angiography Results**

- Abnormal
- Normal
- Unknown

Question Added: 01 JAN 1993

4a

**If abnormal, indicate ISHLT CAV score**

(J Heart Lung Transplant July 2010;29(7):717-27)

- 0
- 1
- 2
- 3
- Not Graded
- Unknown

Question Added: 01 JAN 2015

- **ISHLT CAV 0 (Not significant):** No detectable angiographic lesion
- **ISHLT CAV 1 (Mild):** Angiographic left main (LM) <50%, or primary vessel with maximum lesion of <70%, or any branch stenosis <70% (including diffuse narrowing) without allograft dysfunction
- **ISHLT CAV 2 (Moderate):** Angiographic LM <50%; a single primary vessel >70%, or isolated branch stenosis >70% in branches of 2 systems, without allograft dysfunction
- **ISHLT CAV 3 (Severe):** Angiographic LM >50%, or two or more primary vessels >70% stenosis, or isolated branch stenosis >70% in all 3 systems; or ISHLT CAV 1 or CAV 2 with allograft dysfunction (defined as LVEF <45% usually in the presence of regional wall motion abnormalities)

L Main

LAD

LCx

4b

- Normal
- Not Visualized
- Unknown
- Absent (congenital)
- Mild Stenosis (0% to 50%)
- Moderate Stenosis (51% to 70%)
- Severe Stenosis (71% to 100%)
- Ectasia
- Severe Distal Pruning

**L Main** = Left Main Coronary Artery  
**LAD** = Left Anterior Descending  
**LCx** = Left Circumflex  
**RCA** = Right Coronary Artery  
**PDA** = Posterior Descending

Question Added: 01 JAN 1993    Question Added: 01 JAN 1993    Question Added: 01 JAN 1993

RCA

PDA

- 
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Question Added: 01 JAN 1993    Question Added: 01 JAN 1993

### Coronary Flow

Functional assessment of coronary flow performed using catheter-based methods  
 Abnormal Fractional Flow Reserve (FFR) is defined as <0.75  
 Abnormal Coronary Flow Reserve (CFR) is defined as <2.0 Maximal Flow: Resting Flow

- 5 Fractional Flow Reserve Performed**  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

5a

- Vessels Studied**  LAD  
 Check all that apply.  LCx  
 Left Main  
 RCA  
 Unknown

Question Added: 01 SEPT 2015

- 5a.i FFR Abnormal for Left Anterior Descending (LAD)**  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

Yes

**5a.ii** FFR Abnormal for Left Circumflex (LCx)  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**5a.iii** FFR Abnormal for Left Main Coronary Artery (L Main)  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**5a.iv** FFR Abnormal for Right Coronary Artery (RCA)  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**6** Coronary Flow Reserve (CFR) Performed  Yes  
 No  
 Unknown

Question Added: 01 SEPT 2015

**6a** If CFR Performed, CFR abnormal  Yes  
 No  
 Unknown  
(Abnormal is defined as:  $\leq 2.0$  Maximal Flow: Resting Flow)

Question Added: 01 SEPT 2015

### Intravascular Ultrasound

**7** Intravascular Ultrasound Performed  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

**7a** Vessels Studied  LAD  
 LCx  
 Left Main  
 RCA  
 Unknown

Question Added: 01 JAN 2005

**7a.i** If LAD, Maximal Intimal Thickness (MIT)  <0.3 mm  
  $\geq 0.3$ mm  
 Unknown

Question Added: 01 SEPT 2015

**7a.ii** If LAD, Stanford Score  0  
 1  
 2  
 3

- 
- 4
- Not Done
- Unknown

Question Added: 01 SEPT 2015

**7a.iii**      **If LCx, Maximal Intimal Thickness (MIT)**       <0.3 mm  
 >= 0.3mm  
 Unknown

Question Added: 01 SEPT 2015

**7a.iv**      **If LCx, Stanford Score**       0  
 1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

**7a.v**      **If Left Main, Maximal Intimal Thickness (MIT)**       <0.3 mm  
 >= 0.3mm  
 Unknown

Question Added: 01 SEPT 2015

**7a.vi**      **If Left Main, Stanford Score**       0  
 1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

**7a.vii**      **If RCA, Maximal Intimal Thickness (MIT)**       <0.3 mm  
 >= 0.3mm  
 Unknown

Question Added: 01 SEPT 2015

**7a.viii**      **If RCA, Stanford Score**       0  
 1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

### Left Ventricular Function Evaluation

**8 Left Ventricular Function Evaluation**  Yes  
Nearest to coronary angiogram  No  
 Unknown

Question Added: 01 JAN 1993

**8a Date of study**

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

**8b Method of Interpretation**  Contrast ventriculogram  
 Echocardiogram  
 MRI  
 Radionuclide angiogram (MUGA)  
 Unknown

Question Added: 01 JAN 1993

**8c Left Ventricular Ejection Fraction**

**Range Information**  
 Too Low: < 1 %  
 Normal: Between 1 and 100  
 Question Zone: > 101  
 Red Flag Zone: > 101

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1993

**8d Echo Shortening Fraction**

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1996

**8e Wall Motion**  Akinesis  
 Dyskinesis  
 Hypokinesis  
 Normal  
 Not interpreted for wall motion abnormalities  
 Unknown

Question Added: 01 JAN 1993

**8e.i Akinesis**  > 1 Segment  
 1 Segment  
 Diffuse  
 Unknown

Question Added: 01 JAN 1993

**8e.ii Dyskinesis**  > 1 Segment  
 1 Segment  
 Diffuse  
 Unknown

Question Added: 01 JAN 1993

**8e.iii Hypokinesis**  > 1 Segment  
 1 Segment  
 Diffuse



Unknown

Question Added: 01 JAN 1993

### Dobutamine or Exercise Stress Echo

**9** Was Dobutamine or Exercise Stress Echo performed?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

**9a** Date

Missing Reason:  
 Unknown

Question Added: 01 JAN 1999

**9b** Maximum Dobutamine Dose  mcg/kg/min

Missing Reason:  
 Not Done  
 Unknown

Question Added: 01 JAN 1999

**9c** Baseline  Akinesia/dyskinesia  
 Hypokinesia  
 Normal

Question Added: 01 JAN 1999

**9c.ii** Is there segmental hypokinesia and if so, how many segments?  > 1 Segment  
 1 Segment  
 Diffuse  
 Unknown

Question Added: 01 JAN 1999

**9c.i** Is there segmental Akinesia/dyskinesia and if so, how many segments?  > 1 Segment  
 1 Segment  
 Diffuse  
 less than 1  
 Unknown

Question Added: 01 JAN 1999

**9d** Stress  New Akinesia/dyskinesia  
 New Hypokinesia  
 Normal

Question Added: 01 JAN 1999

**9d.ii** If Stress is New Hypokinesia  > 1 Segment  
 1 Segment  
 Diffuse  
 Unknown

Question Added: 01 JAN 1999

> 1 Segment

9d.i

If Stress is  1 Segment  
New  Diffuse  
Akinesis/dyskinesis  Unknown

Question Added: 01 JAN 1999

9e

Maximum Heart Rate   
Achieved

Missing Reason:  
 Unknown

Question Added: 01 JAN 1999

9f

LV Dilatation with Stress  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

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# Form 5: Rejection

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Not Started

- 1** **Select the baseline immunosuppressive therapy at time of rejection**
- Azathioprine
  - Cyclosporine
  - Everolimus
  - Immune globulin
  - Methotrexate
  - Mycophenolate
  - Plasmapheresis
  - Prednisone
  - Rituximab
  - Sirolimus
  - Tacrolimus
  - Cytoxan (cyclophosphamide)
  - Unknown
  - Other, specify
- 

## Biopsy Prior to Rejection Event

- 2** **Biopsy Performed Prior to Rejection Event**  Yes  No
- If performed prior to this rejection diagnosis, indicate the score of the most recent biopsy performed that did not lead to rejection treatment.

**2a** **Biopsy Date Prior to Rejection**

MM/DD/YYYY

Missing Reason:  
 Unknown

- 2b** **ACR Grading**  0R  1R  2R  3R  Unknown
- 2004 revised ISHLT grading system for ACR: (J Heart Lung Transplant. 2005 Nov;24(11):1710-20.)  
ACR: acute cellular rejection (0, 1R, 2R, 3R)

- 2c** **AMR Grading**  Both histology and immunofluorescence/immunohistochemistry performed (ie. C4d or C3d)  Did not assess biopsy for evidence of AMR  Only assessed histology/ did not perform immunofluorescence/immunohistochemistry (ie. C4d or C3d)  Unknown
- 2013 revised ISHLT grading system for pAMR: J Heart Lung Transplant 2013 Dec 32(12):1147-62.)  
pAMR: pathologic antibody mediated rejection (0, 1h, 1i, 2, 3)

**2c.i pAMR Grading**

2013 revised ISHLT grading system for pAMR:  
 J Heart Lung Transplant 2013 Dec 32(12):1147-62.)  
 pAMR: pathologic antibody mediated rejection (0, 1h, 1i, 2, 3)

- 0 (negative)
- 1h
- 1i
- 2
- 3
- Positive for AMR but pAMR score not known

**2c.ii AMR Findings**

If only accessed histology/ did not perform immunofluorescence or immunohistochemistry (ie. C4d or C3d)

- No histologic features AMR
- Positive histologic features AMR (ie. Vasculitis/ pericapillaritis)

**Rejection Events**

Start with newly diagnosed rejection by biopsy (convert to ISHLT score) or other criteria leading to bolus immunotherapy. List all follow-up biopsies or changes in therapy. The last entry should be the first biopsy or echo not prompting additional therapy. Enter each subsequent rejection event until episode is resolved.

**3 Was donor specific Ab testing performed at the time of the rejection event**

- Yes
- No, Did not send testing for any circulating antibodies
- Unknown

**3a Which antibodies were tested and what were the results**

- HLA class I and/or class II DSA
- Isoagglutinin (A or B Ab) to ABO-i graft
- Non-HLA antibody (e.g. MICA, MICB, anti-endothelial, vimentin, anti-myosin, angiotensin receptor (AR1T), or other non-HLA
- Unknown

**3a.i HLA Class I and/or II DSA Result**

- Negative
- Positive
- Unknown

**3a.i.1 HLA class I and/or II DSA Result, Positive**

- Complement fixing (C1q positive)
- Increased from last date tested
- New
- Present but stable (no new abs and not increased from baseline)
- Unknown

**3a.ii Non-HLA Ab Result**

Non-HLA antibody (e.g. MICA, MICB, anti-endothelial, vimentin, anti-myosin, angiotensin receptor (AR1T), or other non-HLA Results

- Negative
- Positive
- Unknown

Increased from last date tested



**3a.ii.1 Non-HLA Ab Result, Positive**

Non-HLA antibody (e.g. MICA, MICB, anti-endothelial, vimentin, anti-myosin, angiotensin receptor (AR1T), or other non-HLA Results

- New
- Present but stable (no new abs and not increased from baseline)
- Unknown

**3a.iii Isoagglutinin (A or B Ab) to ABO-i graft**

Positive is defined as titer of 1:16 or higher

- Negative
- Positive
- Unknown

**Rejection Event**

**Date of rejection event**

Any episode leading to an increase in immunotherapy to treat a biopsy or clinically diagnosed episode of rejection  
MM/DD/YYYY

**4a**

**Basis for Diagnosis of Current Rejection Event**

- Biopsy
- Clinical
- ECHO
- New or increased Abs
- Unknown

**4b**

**Was biopsy performed?**

- Yes
- No

**4b.i**

**Indication for biopsy**

Check all that apply.

- Objective Evidence of Graft Dysfunction
- Research
- Routine (scheduled as part of protocol surveillance)
- Symptoms

**4b.ii**

**ACR Grading**

2004 revised ISHLT grading system for ACR: (J Heart Lung Transplant. 2005 Nov;24(11):1710-20.)  
ACR: acute cellular rejection (0, 1R, 2R, 3R)

- 0R
- 1R
- 2R
- 3R
- Unknown

**4b.iii**

**AMR Grading**

2013 revised ISHLT grading system for pAMR:

- Both histology and immunofluorescence/immunohistochemistry performed (ie. C4d or C3d)
- Did not assess biopsy for evidence of AMR

J Heart Lung Transplant 2013 Dec 32(12):1147-62.)  
 pAMR: pathologic antibody mediated rejection (0, 1h, 1i, 2, 3)

- Only assessed histology/ did not perform immunofluorescence/immunohistochemistry (ie. C4d or C3d)
- Unknown

**4b.iii.1** **If both histology and immunofluorescence/immunohistochemistry performed, indicate pAMR grading**

2013 revised ISHLT grading system for pAMR:  
 J Heart Lung Transplant 2013 Dec 32(12):1147-62.)  
 pAMR: pathologic antibody mediated rejection (0, 1h, 1i, 2, 3)

- 0
- 1h
- 1i
- 2
- 3
- Positive with Unknown Score

**4b.iii.2** **Histology results**

- No histologic features AMR
- Positive histologic features AMR

**4c** **Was there therapy used to treat this rejection episode?**

If no rejection therapy was used, no more rejection episodes should be entered for this event.

- Yes
- No

**4c.i** **Select the therapy used**

- ATG or ATGAM
- Bortezomib
- Eculizumab
- Immune Adsorption
- Immunoglobulin
- Methotrexate
- Photopheresis
- Plasmapheresis
- Rituximab
- Steroid Taper
- Steroids, IV
- Steroids, Oral
- Tacrolimus
- Cytoxan (cyclophosphamide)
- Other, specify

**4d** **Was episode of rejection associated with hemodynamic compromise?**

**None** - No significant change in cardiac function at the time of rejection  
**Mild** - Worsening of cardiac function detected (decreased ejection fraction, hypotension, EKG changes) not requiring inotropes.  
**Severe** Inotropic support added due to this rejection episode.

- Inotropic Support
- Mild
- None
- Unknown

5

Indicate date of the end of the rejection episode

MM/DD/YYYY

If rejection is ongoing at the time of death, the death date should be entered as the end date.

A death form should also be completed.

6

Was there baseline immunosuppressive therapy at time of resolution of rejection event

Yes

No

6a Baseline immunosuppressive therapy at time of resolution of rejection event

- Azathioprine (Imuran)
- Cyclosporine (Sandimmune, Neoral, Gengraf, CSA, CyA)
- Everolimus
- Immune globulin
- Methotrexate
- Mycophenolate (Cellcept, Myfortic)
- Prednisone
- Rituximab
- Sirolimus (Rapamycin, Rapamune)
- Tacrolimus (Prograf, FK506)
- Cytoxan (Cyclophosphamide)
- Unknown
- Other, Specify





Patient Details Hidden [Show](#)[Show/Hide Annotations](#) [Stickers: Toggle All](#) [Toggle Open](#) [Toggle Resolved](#)**Form 6: Infection**

Toggle Question Year/Info

Print this Form

Not Started

- 1** Is this infection a severe infection that requires IV therapy, hospitalization for infection >2 days, or escalation of care in an already hospitalized patient?
- Yes  
 No

If no to this question, this form is not required

- 2** **Date of Infection**
- Date of diagnosis or clinical presentation, whichever date is earliest.  
MM/DD/YYYY

Question Added: 01 JAN 1993

- 3** **Drug Therapy at Time of Infection**  Yes  
 No  
 Unknown

Indicate if there was an ongoing prophylactic drug therapy at time (date) of infection diagnosis (i.e. valganciclovir for CMV prophylaxis post-transplant).

Do not include drugs that have been prescribed to treat a specific previous infection unless that previous infection is considered to be resolved and the patient is now on long-term prophylaxis.

Do not include therapy for the current infection. Drug therapy for the current infection should be entered under 'intervention'.

Question Added: 01 JAN 1993

- 3a** **Specify drug therapy at time of infection.**
- Acyclovir
  - Alemtuzumab (Campath)
  - ATGAM
  - Azathioprine (Imuran)
  - Basiliximab (Simulect)
  - Bortezomib (Velcade)
  - CMV Immunoglobulin, Cytogam
  - Cyclosporine
  - Cytoxan (cyclophosphamide)
  - Dapsone
  - Everolimus (Certican)
  - Fluconazole
  - Ganciclovir or Valganciclovir
  - Immunoglobulin, IV Ig
  - Methotrexate
  - Mycophenylate, MMF (Cellcept, Myfortic)
  - Nystatin
  - Oseltamivir
  - Pentamidine
  - Prednisone
  - Rituximab (Rituxan)
  - Sirolimus (Rapamycin)
  - Tacrolimus (Prograf, FK506)
  - Thymoglobulin/ATG

- Trimethaprim-sulfamethoxazole, Septra
- Valacyclovir
- Other, specify

Question Added: 01 JAN 1993

3a

- Ganciclovir or Valganciclovir  IV
- PO

**(No type selected)**

Only organisms within a single category can be selected. For multiple types of infections, add additional Infection forms.

- No organism identified
- Unknown

**4 Bacterial Infection**

Select all that apply within this category

- Bordatella Pertussis
- Chlamydia
- Clostridium Difficile
- Enterobacter
- Enterococcus (including VRE)
- Escherichia Coli
- Haemophilus influenzae
- Haemophilus, NOS
- Klebsiella, NOS
- Moraxella
- Mycoplasma pneumonia
- Nocardia
- Pseudomonas
- Salmonella
- Serratia
- Staphylococcus Aureus, Methicillin/Oxacillin Resistant (MRSA)
- Staphylococcus Aureus, Methicillin/Oxacillin Sensitive (MSSA)
- Staphylococcus, Coagulase-Negative (Staph Epidermidis)
- Staphylococcus, Other
- Streptococcus Pneumoniae (Streptococcal Pneumonia)
- Streptococcus, Group A (S. pyogenes)
- Streptococcus, Viridians Group
- Streptococcus, NOS
- Streptococcus, Group B (S. agalactiae)
- Stenotrophomonas
- Mycobacterium tuberculosis (TB)
- Nontuberculous mycobacterium (NTM)

**4 Fungal Infection**

Select all that apply within this category

- Aspergillus
- Candida albicans
- Candida, Not Albicans/Other
- Coccidioidomycosis
- Cryptococcus
- Histoplasmosis
- Mucormycosis
- Pneumocystis (PCP/PJP)
- Fungal Organism(s) Unknown
- Other, specify

Question Added: 01 JAN 1993

**4 Protozoan Infection**

Select all that apply within this category

- Cryptosporidium
- Giardia
- Toxoplasma (Toxo)
- Protozoan/parasitic Organism(s) Unknown
- Other, specify

Question Added: 01 JAN 1993

**4 Viral Infection**

Select all that apply within this category

- Adenovirus
- Bk Virus
- Coronavirus
- Coxsackievirus (all serotypes)
- Cytomegalovirus, CMV
- Enterovirus
- Epstein Barr Virus, EBV (symptomatic)
- Hepatitis A
- Hepatitis B
- Hepatitis C
- Hepatitis D
- HIV
- Human Herpes Simplex Virus, Type 1/Type 2
- Influenzavirus A
- Influenzavirus B
- Influenzavirus H1N1
- Influenzavirus, NOS
- Metapneumovirus (HMPV)
- Norovirus (Norwalk Virus)
- Parainfluenza
- Parvovirus
- Respiratory Syncytial Virus (RSV)
- Rhinovirus
- Rhino/Enterovirus, NOS
- Rotavirus
- Varicella (Chicken Pox/Shingles)
- West Nile Virus
- Viral Organism(s) Unknown
- Other, specify

Question Added: 01 JAN 1993

- Bacterial Organism(s)  
Unknown
- Other, specify

Question Added: 01 JAN 1993

**5**

**Location of infection**

Check all that apply

- Blood: Culture positive
- Blood: PCR positive
- Bone: Osteomyelitis
- Central nervous system/ brain (ie. Meningitis /Encephalitis)
- Chest tube site infection
- Gastrointestinal infection (ie. Gastritis, colitis, infectious diarrhea)
- Heart (includes endocarditis)
- Hepatic/ liver: Infectious hepatitis
- Intrabdominal/ Peritoneal: Peritonitis
- Pericardium/ pericarditis
- Renal/ kidney/Urinary tract
- Respiratory (includes Pneumonia/ Bronchiolitis/Tracheitis/ Pleuritis)
- Skin or soft tissue: Cellulitis/fasciitis
- VAD infection
- Wound infection within 30 days, deep sternal: Deep sternal wound infection with positive culture or treated with prolonged antibiotics beyond perioperative prophylaxis when culture not obtained or pre-treated involving muscle, bone, and/or mediastinum requiring operative intervention
- Wound infection within 30 days, superficial sternal: Superficial, soft tissue
- Unknown
- Other, specify

Question Added: 01 JAN 1993

**5a**

**Was the blood infection directly attributed to the presence of a central line (ie. organism cultured from blood is not related to an infection at another site)?**

- Yes
- No
- Unknown

Question Added: 01 SEPT 2015

**5b**

**VAD Infection Location**

Check all that apply

- Cannulae
- Driveline
- Unknown

Question Added: 01 SEPT 2015

**6**

**Location of patient**

This is where the patient was at the time they developed the infection

- In Hospital
- Out of Hospital
- Unknown

Question Added: 01 SEPT 2015

- Drug therapy : Oral

7

**Intervention**

This is for treatments only, not diagnostic procedures.

- Drug therapy: IV or IM
- Mechanical Ventilation
- Surgical therapy, specify
- Unknown
- Supportive Care Only
- Other, specify

Question Added: 01 JAN 1993

7a

**Intervention - Surgical therapy, specify**

Question Added: 01 January 1993

8

**Outcome at 30 days post-date of infection**

Check only one.  
**Significant long term sequelae** means any residual medical problem persisting for > 30 days after the onset of the infection (e.g.) renal failure, respiratory failure.

- Death
- Resolution
- Significant Long Term Sequelae
- Unresolved at 30 days
- Unknown

Question Added: 01 JAN 1993

8a

**If death occurred, did the infection contribute to cause of death?**

- Yes
- No
- Unknown

Question Added: 01 September 2015

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# Form 7: Malignancy/Lymphoproliferative Disorder

Not Started

1

Date of Diagnosis   
MM/DD/YYYY

Question Added: 01 JAN 1993

## Height and Weight

2a

Height   
 cm  
 in

Question Added: 01 SEPT 2015

Missing Reason:  
 Not Done  
 Unknown

**Calculated**

BSA: n/a  
BMI: n/a

2b

Weight   
 kg  
 lb

Question Added: 01 JAN 2005

Missing Reason:  
 Not Done  
 Unknown

3

Patient Diagnosis  Initial Diagnosis  
 Recurrence of previously diagnosed malignancy thought to be "cured."  
 Unknown

Question Added: 01 JAN 1993

3a

If recurrence, date of previous diagnosis   
MM/DD/YYYY

Missing Reason:  
 Unknown

Question Added: 01 JAN 1993

4

Nature of Malignancy  Lymphoproliferative Disease/Lymphoma  
Check only one.  
 Sarcoma  
Complete additional form(s) for other malignancies.  
 Skin  
 Unknown  
 Other, specify

Question Added: 01 JAN 1993

5

Site(s) of involvement at initial diagnosis  Abdomen, not GI tract (retroperitoneum, intra-abdominal)  
Check all that apply.  Bone  
 Bone Marrow  
 Breast

- CNS
- GI, Large Bowel
- GI, Rectal
- GI, Small Bowel
- GI, Stomach
- Heart
- Hepatic
- Kidney/Renal
- Lymph Nodes, deep
- Lymph Nodes, subcutaneous
- Mucous Membranes, genital/anal
- Mucous Membranes, craniofacial
- Muscle
- Pulmonary (lungs)
- Skin, facial scalp
- Skin, non-facial
- Spleen
- Tonsils and/or adenoids
- Unknown
- Other, specify

Question Added: 01 JAN 1993

### Lymphoproliferative/Lymphoma

Details of EBV seroconversion. Question 6a relates to whether patient has EBV seroconverted since transplant. That is, if they were EBV negative pre-transplant and become positive post-transplant, we want to capture that event and question 6a should be completed.

**6a** **Ebstein-Barr Seroconversion (negative pre transplant to positive titer post-transplant)**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**6a.i** **If Ebstein-Barr Seroconversion is Yes, Date Last Negative EBV titer**

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 January 1993

**6a.ii** **If Ebstein-Barr Seroconversion is Yes, Date last Positive EBV titer**

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 January 1993

**6b** **Was clonal analysis performed?**  Yes  
 No  
 Unknown

Question Added: 01 JAN 1993

**6b.i** **Clonal analysis results**  Monoclonal  
 Polyclonal

- 
- Both
- Unknown

Question Added: 01 JAN 1993

- 6b.ii** Clonal analysis results  B Cell
- T Cell
- Both
- Unknown

Question Added: 01 JAN 2005

- 6c** EBV PCR  Negative
- Positive
- Unknown

Question Added: 01 JAN 2005

**6d** EBV PCR: DNA copies/ml

Missing Reason:  
 Unknown

Question Added: 01 JAN 2005

- 6e** Is tumor EBV positive?  Yes
- No
- Not Done
- Unknown

Question Added: 01 JAN 2005

## WHO Classification

- 7** WHO classification  Hodgkin's/Hodgkin's-like
- Monomorphic PTLD
- Polymorphic PTLD
- Unknown
- Other, specify

Question Added: 01 JAN 2005

- 7a** If Monomorphic PTLD, specify  Burkitts
- Diffuse large B cell
- Other
- Tcell lymphoma

Question Added: 01 JAN 2005

**Therapy at time of malignancy diagnosis and any changes made due to diagnosis within 30 days of diagnosis**

**Malignancy Lymph Disease Drug Details****8a****Therapy at time of malignancy diagnosis**

- Acyclovir
- Azathioprine (Imuran)
- Cyclophosphamide
- Cyclosporine
- Everolimus
- Ganciclovir/Valganciclovir
- Mycophenolate (Cellcept, Myfotic)
- None
- Rapamycin
- Rituxan
- Rituximab
- Sirolimus (Rapamycin)
- Steroids
- Tacrolimus (FK506)
- Unknown
- Other, specify

Question Added: 01 JAN 1993

**8a.i****If Therapy, Ganciclovir or Valganciclovir**

- IV
- PO

Question Added: 01 SEPT 2015

**8b****Changes made due to diagnosis within 30 days of diagnosis (specify)**

- Dose Decreased
- Drug Added
- Drug discontinued
- No Change
- Unknown

Question Added: 01 JAN 1993

**9****Additional therapeutic measures started within 30 days of diagnosis**

Check all that apply.

- Chemotherapy
- Radiation therapy
- Surgery (excision, not performed solely for diagnostic purposes)
- Unknown
- None
- Other, specify

Question Added: 01 JAN 1993

**Outcome at 30 days post diagnosis****10****Did malignancy/PTLD resolve?**

- Yes
- No
- Unknown



Question Added: 01 SEPT 2015

**10a** Was immune suppression  Yes  
decreased further from  No  
above?  Unknown

Question Added: 01 SEPT 2015

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# Form 8: Post Transplant Annual Followup

[Print this Form](#)

Not Started

- 1 Was patient seen for follow-up this year**
- Yes, patient was seen this year
  - No, patient was not seen this year or the patient follow-up falls outside the follow-up window (+/- 90 days of the transplant anniversary)
  - No, patient transferred care to another center (not at time of annual follow-up)

**7b Last Date of Followup at Your Center**

**2 Date of Follow-Up**

This is the date the patient was seen and the date for which the data on the form is current.  
It is not the date that the form is filled out.

## Height and Weight

**3 Height**

- Centimeters
- Inches

Missing Reason:

- Not Done
- Unknown

**Calculated**

BSA: n/a  
BMI: n/a

**4 Weight**

- Kilograms
- Pounds

Missing Reason:

- Not Done
- Unknown

**5 Were Hemodynamics Performed?**

- Yes
- No
- Unknown

**5a Hemodynamics**

If done during annual surveillance biopsy (if performed)  
or during coronary assessment.  
MM/DD/YYYY

Missing Reason:

- Unknown

<b>5b</b>	<b>AoM</b> <input style="width: 100%;" type="text"/> <small>Aortic mean</small>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>5c</b>	<b>RAm</b> <input style="width: 100%;" type="text"/> <small>Right atrial mean</small>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>5d</b>	<b>PAm</b> <input style="width: 100%;" type="text"/> <small>Pulmonary arterial mean</small>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>5e</b>	<b>PCW LV EDP</b> <input style="width: 100%;" type="text"/> <small>Pulmonary capillary wedge</small>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>5f</b>	<b>C.O.</b> <input style="width: 100%;" type="text"/> <small>Cardiac output L/min</small>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
<b>5g</b>	<b>C.I.</b> <input style="width: 100%;" type="text"/> <small>Cardiac Index L/min/m<sup>2</sup></small>	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown

<b>6</b>	<b>Current residence ZIP code/Postal Code</b> <input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
----------	---	--

<b>7</b>	<b>Is patient currently followed at your PHTS Transplant center?</b>	<input type="radio"/> Patient currently followed at our PHTS Transplant center <input type="radio"/> Patient followed exclusively at another center
----------	--	--

<b>7a</b>	<b>If currently followed</b>	<input type="radio"/> All care is provided at our center <input type="radio"/> Only yearly evaluation at our center
-----------	------------------------------	--

<b>7a.i</b>	<b>If only followed yearly, specify date PHTS event followup ceased</b> <input style="width: 100%;" type="text"/>	Missing Reason: <input type="radio"/> Unknown
-------------	---	--

<b>7b</b>	<b>Last Date of Followup at Your Center</b> <input style="width: 100%;" type="text"/>
-----------	---

**Followup Medications**

All medications that the patient was taking and prescribed at the time of the follow up date should be reported. Do not have to include PRN, topical, inhaled, or nebulizer medications.

**Medication Details**

8

Medications

Missing Reason:  
 None  
 Unknown

9

Schooling  Completed high school, >18 yo  
 Delayed grade level  
 Not applicable, <6 years  
 Special education  
 Status unknown  
 Within one grade level

10

Exercise Test  Yes  
 No  
 Unknown  
 Not Routinely Done

10a

If exercise test not performed, specify reason  Age inappropriate  
 Too sick  
 Unknown  
 Other, specify

10c

Max VO<sub>2</sub>% Predicted for Age  %

Refers to predicted maximum VO<sub>2</sub> for patient (should be listed in exercise report; if not, exercise lab personnel should be able to provide this data)

Missing Reason:  
 Not Done  
 Unknown

10c

VO<sub>2</sub> at follow-up   
 Maximum oxygen consumption ml/kg/min

Missing Reason:  
 Not Done  
 Unknown

10d

Respiratory Value at Peak

RER or Respiratory Quotient: R Value at peak is the respiratory quotient of carbon dioxide production divided by oxygen consumption, and is used as an index of how vigorously the patient exercised. A value above 1.05 is generally considered to represent an adequate effort.

Missing Reason:  
 Not Done  
 Unknown

11

Primary insurance at followup  Charitable Donation  
 Free  
 Government  
 Private

Self Pay  
 Unknown  
 Other, specify

- **Charitable Donation** – Indicates that a company, institution or individual(s) donated funds to pay for the care of the listed patient.
- **Free** – Indicates that the listing hospital will not charge the patient for the cost of the hospitalization
- **Government** – Other US or state government insurance. For Example, Medicaid, Medicare, CHIP (Children’s Health Insurance Program), Department of VA refers to funds from the Veterans Administration or others.
- **Private** – Refers to funds from agencies such as Blue Cross/Blue Shield, etc.
- **Self Pay** – Indicates that the recipient will pay for the largest portion of the cost of the hospitalization.
- **Other** – For example, funds from a foreign government. Specify foreign country in the space provided.

### Laboratory Values closest to time of this report

Note: labs may have been collected on different dates.

<b>12a</b>	<b>Total Bilirubin</b>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 0.3 and 1.2 Question Zone: > 2.4 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		<input type="radio"/> mg/dL <input type="radio"/> umol/L		
<b>12b</b>	<b>Direct Bilirubin</b>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 0 and 0.2 Question Zone: > 0.4 Red Flag Zone: > 5	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		<input type="radio"/> mg/dL <input type="radio"/> umol/L		
<b>12c</b>	<b>AST</b> <small>Aspartate transaminase (also SGOT)</small>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 10 and 60 Question Zone: > 120 Red Flag Zone: > 1000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		U/L		
<b>12d</b>	<b>ALT</b> <small>Alanine transaminase (also SGPT)</small>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 7 and 45 Question Zone: > 90 Red Flag Zone: > 1000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		U/L		
<b>12e</b>	<b>BNP</b> <small>B-type natriuretic peptide</small>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 10 and 100 Question Zone: > 1000 Red Flag Zone: > 10000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		pg/mL or ng/L		
<b>12f</b>	<b>Pro BNP</b> <small>Pro NT B-type natriuretic peptide</small>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 10 and 300 Question Zone: > 3000 Red Flag Zone: > 30000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		<input type="radio"/> pg/mL or ng/L <input type="radio"/> pmol/L		
<b>12g</b>	<b>CRP</b> <small>C reactive protein</small>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 0 and 0.5 Question Zone: > 5 Red Flag Zone: > 50	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
		<input type="radio"/> mg/dL <input type="radio"/> mg/L		
	<b>Creatinine</b>	<input type="text"/>	<b>Range Information</b> Top Low: < 0 Normal: Between 0.2 and 1.3	

12h	<input type="radio"/> mg/dL <input type="radio"/> umol/L	Question Zone: > 2.6 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12i	<b>BUN</b> Blood urea nitrogen <input type="radio"/> mg/dL <input type="radio"/> Urea mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 4 and 20 Question Zone: > 40 Red Flag Zone: > 120	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12j	<b>Cystatin C</b> mg/L	<b>Range Information</b> Top Low: < 0 Normal: Between 0.5 and 1.4 Question Zone: > 2.8 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12k	<b>Total Protein</b> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 3.6 and 8.1 Question Zone: > 12 Red Flag Zone: > 16	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12l	<b>Pre Albumin</b> <input type="radio"/> mg/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 15 and 40 Question Zone: > 60 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12m	<b>Serum Albumin</b> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12n	<b>Cholesterol</b> Total Cholesterol <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12o	<b>TG</b> Triglycerides <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12p	<b>LDL</b> Low density lipoprotein <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12q	<b>HDL</b> High density lipoprotein <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown
12r	<b>VLDL</b> Very low density lipoprotein <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 2 and 30 Question Zone: > 60 Red Flag Zone: > 250	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown

**Glomerular Filtration Rate (GFR)**

13a	GFR method <input type="radio"/> 12 or 24 hour urine collection <input type="radio"/> Calculated, specify method
-----	---

- Nuclear medicine scan
- Not Done
- Unknown

13b

Specify results

13b

Specify Units

**Viral Studies**

14a

**CMV serology**  Negative  Not Done  Positive  Unknown

14b

**CMV PCR**  Negative  Not Done  Positive  Unknown

14c

**EBV serology**  Negative  Not Done  Positive  Unknown

14d

**EBV PCR**  Negative  Not Done  Positive  Unknown

**Events since transplant or last Form 8**

15a

**Coronary Evaluation**  Yes  
If yes, complete form 4  No

15a.i

**Coronary Evaluation**   
Event Date:

15b

**Rejection**  Yes  
If yes, complete form 5  No

15b.i

**Rejection Event Date:**



15c **Infection**  Yes  
If yes, complete form 6  No

15c.i **Infection Event Date:**

15d **Malignancy/PTLD**  Yes  
If yes, complete form 7  No

15d.i **Malignancy Event Date:**

15e **Coronary Revascularization**  Yes  
If yes, complete form 9  No

15e.i **Coronary Revascularization Event Date:**

15f **Death**  Yes  
If yes, complete form 10  No

15f.i **Death Event Date:**

15g **Retransplantation**  Yes  
If yes, complete form 1RL, 1T, 2, and 3  No

15g.i **Retransplantation Event Date:**

15h **Renal Transplant**  Yes  
If yes, complete form 14  No

15h.i **Renal Transplant Event Date:**

15i

**Dialysis**  Yes  
If yes, complete form 14  No

15i.i

**Dialysis Event Date:**

15i.ii

**Acute Dialysis**  Yes  
 No

15i.iii

**Chronic Dialysis**  Yes  
 No

15j

**Diabetes requiring insulin**  Yes  
 No

15j.i

**Diabetes Event Date:**

15k

**Other major events**  Yes  
  
 No

15k.i

**Other major events**   
**Event Date:**

Patient Details Hidden [Show](#)[Show/Hide Annotations](#) [Stickers: Toggle All](#) [Toggle Open](#) [Toggle Resolved](#)**Form 9: Coronary Revascularization**[Add Question Year/Info](#)[Print this Form](#)

Not Started

1

Date of Procedure

MM/DD/YYYY

Question Added: 01 JAN 1999

**Functional Assessment of Coronary Flow Performed Using Catheter-Based Methods**Fractional Flow Reserve (FFR) Abnormal is defined as  $\leq 0.75$ 

2

Fractional Flow Reserve Performed?  Yes No Unknown

Question Added: 01 SEPT 2015

2a

Vessels Studied

Check all that apply

 LAD LCx Left Main RCA Unknown

Question Added: 01 SEPT 2015

2a.i

FFR Abnormal for Left Anterior Descending (LAD)  Yes No Unknown

Question Added: 01 SEPT 2015

2a.ii

FFR Abnormal for Left Circumflex (LCx)  Yes No Unknown

Question Added: 01 SEPT 2015

2a.iii

FFR Abnormal for Left Main Coronary Artery (L Main)  Yes No Unknown

Question Added: 01 SEPT 2015

2a.iv

FFR Abnormal for Right Coronary Artery (RCA)  Yes No Unknown

Question Added: 01 SEPT 2015

3

Coronary Flow Reserve (CFR) Performed  Yes No

Unknown

Question Added: 01 SEPT 2015

3a

**CFR abnormal**  Yes

Abnormal is defined as  $\leq 2.0$  Maximal Flow: Resting Flow)

No

Unknown

Question Added: 01 SEPT 2015

## Intravascular Ultrasound

4

**Intravascular Ultrasound Performed**  Yes

No

Unknown

Question Added: 01 JAN 1999

4a

**Vessels studied**  LAD

LCx

Left Main

RCA

Unknown

Question Added: 01 JAN 2005

4a.i

**If LAD, Median Intimal Thickness (MIT)**   $<0.3$  mm

$\geq 0.3$ mm

Unknown

Question Added: 01 SEPT 2015

4a.ii

**If LAD, Stanford Score**  0

1

2

3

4

Not Done

Unknown

Question Added: 01 SEPT 2015

4a.iii

**If LCx, Median Intimal Thickness (MIT)**   $<0.3$  mm

$\geq 0.3$ mm

Unknown

Question Added: 01 SEPT 2015

4a.iv

**If LCx, Stanford Score**  0

1

2

3

4

Not Done

Unknown

Question Added: 01 SEPT 2015

4a.v If Left Main, Median Intimal Thickness (MIT)  <0.3 mm  
 >= 0.3mm  
 Unknown

Question Added: 01 SEPT 2015

4a.vi If Left Main, Stanford Score  0  
 1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

4a.vii If RCA, Median Intimal Thickness (MIT)  <0.3 mm  
 >= 0.3mm  
 Unknown

Question Added: 01 SEPT 2015

4a.viii If RCA, Stanford Score  0  
 1  
 2  
 3  
 4  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

## Percutaneous Procedures

5 Did the patient have a PTCA/Stent/Atherectomy?  Yes  
 No  
 Unknown

Question Added: 01 JAN 1999

### Procedure Details

5a Procedure  AA (Angiojet Atherectomy)  
 DA (Directional Atherectomy)  
 PTCA (Angioplasty)  
 RA (Rotational Atherectomy)  
 Stent  
 Other, specify

5b

- Vessel**
- LAD (Left Anterior Descending)
  - LCx (Left Circumflex)
  - Left Main Coronary Artery
  - PDA (Posterior Descending)
  - RCA (Right Coronary Artery)
  - Unknown

5c

- Lesion Characteristic**
- Concentric
  - Eccentric
  - Tubular
  - Unknown

5d

- Location**
- Distal
  - Mid
  - Proximal
  - Unknown

5e

Pre Procedure Stenosis  %

Missing Reason:  
 Unknown

5f

Post Procedure Stenosis  %

Missing Reason:  
 Unknown

5g

Comments on Procedure(s) done

Missing Reason:  
 None

### Coronary Artery Bypass Grafting

6

- Coronary Artery Bypass Grafting**
- Yes
  - No
  - Unknown

Question Added: 01 JAN 1999

6a

- Vessel**
- LAD
  - LCx
  - Left Main
  - PDA
  - RCA
  - Unknown

Question Added: 01 SEPT 2015

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Toggle Question Year/Info

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Not Started

1

**Date of Death**

MM/DD/YYYY

Question Added: 01 JAN 1993

2

**Primary cause of death**

Check only one.

- Cardiac
- Hepatic Failure
- Infection
- Major bleeding
- Malignancy/Cancer
- Neurologic
- Poor donor preservation
- Primary graft failure (onset <24 hours post-transplant)
- Pulmonary embolism
- Pulmonary hypertension/RV failure
- Rejection
- Renal Failure
- Respiratory failure
- Suicide
- Trauma/Accidental, specify
- Unknown
- Other, specify

Question Added: 01 JAN 1993

\*American Heart Association definition of Sudden Cardiac Death (also called sudden arrest) is death resulting from an abrupt loss of heart function (cardiac arrest). The victim may or may not have diagnosed heart disease. The time and mode of death are unexpected. It occurs within minutes after symptoms appear. Do not list support withdrawal as COD. Identify underlying reason – i.e .cardiac failure, pulmonary hemorrhage, irreversible brain injury, etc...

2a

**If Cardiac, specify**

Check only one.

- Congestive heart failure
- Coronary artery disease, (infarction)
- Fatal arrhythmia
- Sudden cardiac death, no arrhythmia or MI documented

Question Added: 01 JAN 1993

2b

**If Major Bleeding, specify**

Check only one.

- Post-operative hemorrhage
- Pulmonary hemorrhage

Question Added: 01 JAN 2005

2c

**If Malignancy/Cancer, specify**

Check only one.

- Lymphoma/Lymphoproliferative disease
- Malignancy, non-lymphoma

Question Added: 01 JAN 1993

2d

**If Neurologic, specify**

Check only one.

- Anoxic insult
- Stroke/Cerebrovascular accident

○

Question Added: 01 JAN 1993

2e

If Rejection, specify

Check only one.

- Acute
- Chronic
- Hyper acute (onset <24 hours post-transplant)

Question Added: 01 JAN 1993

3

Did patient have a contributing cause of death?

- Yes
- No
- Unknown

Question Added: 01 JAN 1993

3a

- Cardiac
- Family decision to withdraw of support
- Hepatic Failure
- Infection
- Major bleeding
- Malignancy/Cancer
- Neurologic
- Non-compliance
- Poor donor preservation
- Primary graft failure (onset <24 hours post-transplant)
- Pulmonary embolism
- Pulmonary hypertension/RV failure
- Rejection
- Renal Failure
- Respiratory failure
- Suicide
- Trauma/Accidental, specify
- Other, specify
- 
- Unknown

Question Added: 01 JAN 1993

3a.i

If Cardiac, specify

- Congestive heart failure
- Coronary artery disease, (infarction)
- Fatal arrhythmia
- Sudden cardiac death, no arrhythmia or MI documented
- Other, specify

Question Added: 01 JAN 1993

3a.ii

If Major Bleeding, specify

- Post-operative hemorrhage
- Pulmonary hemorrhage
- Other, specify

Question Added: 01 JAN 2005

Lymphoma/Lymphoproliferative disease



**3a.iii** **Malignancy/Cancer, specify** **If**    
 Malignancy, non-lymphoma   
 Other, specify

Question Added: 01 JAN 1993

**3a.iv** **If Neurologic, specify**  Anoxic insult   
 Stroke/Cerebrovascular accident   
 Other, specify

Question Added: 01 JAN 2005

**3a.v** **If Rejection, specify**  Hyperacute (onset < 24 hours post transplant)   
 Acute   
 Chronic   
 Other, specify

Question Added: 01 JAN 1993

**3a.vi** **Trauma/Accidental, specify** **If**

Question Added: 01 JAN 1993

**4** **Patient supported by IABP/VAD/TAH/ECMO at time of death**  Yes   
 No   
 Unknown

Question Added: 01 JAN 1993

**5** **Was patient listed or relisted at time of death?**  Yes   
 No   
 Unknown

Question Added: 01 JAN 1993

**5a** **Status Details**  Has ductal dependent pulmonary or systemic circulation, with ductal patency maintained by stent of prostaglandin infusion   
Check all that Apply Per UNOS Policy 6.1 On 6/14/2015  In hospital   
 Out of hospital   
 Requires Inotropes

Question Added: 01 JAN 1993

**5a.i** **ICU**  Yes   
 No   
 Unknown

Question Added: 01 JAN 1999

**5a.ii** **Requires continuous mechanical ventilation**  Yes   
 No   
 Unknown

Question Added: 01 JAN 1993

5a.iii

- On inotropes**
- High dose or multiple IV
- Single low dose IV
- Unknown Dose

Question Added: 01 January 1999

5b

- ABO Incompatible**
- Yes
- No
- Unknown

Question Added: 01 JAN 2005

5c

- History of PRA > 10%**
- Yes
- No
- Unknown

Question Added: 01 JAN 2010

- 5c.i** Did the patient receive treatment to lower or manage an elevated PRA while awaiting transplantation?
- Yes
- No

Question Added: 01 January 1993

**5c.i.1** Which therapy was administered?

- Azathioprine (Imuran)
- Bortezomib (Velcade)
- Cytoxan (cyclophosphamide)
- Immunoglobulin (IVIG, IV IgG)
- Mycophenylate, MMF (Cellcept, Myfortic)
- Plasmapheresis/plasma exchange
- Rituximab (Rituxan)
- Other, specify

Question Added: 01 January 1993

**5c.i.2** How long was therapy administered?

- Only for a pre-specified time/number of treatments: specify
- Until Heart transplantation, regardless of subsequent PRA levels/sensitization profile
- Until PRA level reduced to 0%/patient no longer sensitized
- Until PRA/sensitization profile diminished to a pre-specified goal
- Unknown

Question Added: 01 January 1993

**6** Post Mortem Examination (autopsy)

Yes

No

Question Added: 01 JAN 1993

6a

- Cardiac pathology found**
- Check all that apply.
- Acute Rejection
- CAD, remote infarction (>1wk)

- Coronary artery disease, recent infarction (<= 1wk)
- Diffuse fibrosis, no acute rejection
- Graftatherosclerosis
- No cardiac pathology found
- Other, specify

Question Added: 01 JAN 1993

6a.i

- ACR Grading**
- 0
  - 1R
  - 2R
  - 3R
  - Unknown

Question Added: 01 JAN 1993

2004 revised ISHLT grading system for ACR:  
 (J Heart Lung Transplant. 2005 Nov;24(11):1710-20.)  
 ACR: acute cellular rejection (0, 1R, 2R, 3R)

6a.ii

- pAMR Grading**
- 0
  - 1h
  - 1i
  - 2
  - 3
  - Not evaluated
  - Positive, score not specified

Question Added: 01 JAN 2010

2013 revised ISHLT grading system for pAMR:  
 J Heart Lung Transplant 2013 Dec 32(12):1147-62.)  
 pAMR: pathologic antibody mediated rejection (0, 1h, 1i, 2, 3)

**7 Were there special circumstances surrounding the death?**

- Yes
- No

Question Added: 01 JAN 1993

7a

Comments

Question Added: 01 JAN 1993



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# Form 12: Pre Transplant Status Report

[Log Out](#) [Print this Form](#) [Not Started](#)

[Print this Form](#)

[Not Started](#)

1 Was patient seen for follow-up this year?  Yes  No

1 Date of Follow Up   
MM/DD/YYYY

Question Added: 01 JAN 1999

## Height and Weight

2 Height   
Indicate height at time of follow-up.  Centimeters  Inches

Question Added: 01 JAN 1999

Missing Reason:  
 Not Done  
 Unknown

**Calculated**

BSA: n/a  
BMI: n/a

3 Weight   
Indicate weight at time of follow-up.  Kilograms  Pounds

Question Added: 01 JAN 1999

Missing Reason:  
 Not Done  
 Unknown

## Status

4 Did the patient have any status changes since listing or the last form 12?  Yes  No  Unknown

Question Added: 01 JAN 1993

### Followup Status Change

4a Country  Brazil  Canada  United Kingdom  United States

Old Brazil Status Code

Non-Priority  
 Priority

New Brazil Status Code

Non-Priority  
 Priority

<p><b>Old Canada Status Code</b></p> <p><input type="radio"/> 0</p> <p><input type="radio"/> 1</p> <p><input type="radio"/> 2</p> <p><input type="radio"/> 3</p> <p><input type="radio"/> 3.5</p> <p><input type="radio"/> 4</p> <p><input type="radio"/> 4S</p>	<p><b>New Canada Status Code</b></p> <p><input type="radio"/> 0</p> <p><input type="radio"/> 1</p> <p><input type="radio"/> 2</p> <p><input type="radio"/> 3</p> <p><input type="radio"/> 3.5</p> <p><input type="radio"/> 4</p> <p><input type="radio"/> 4S</p>
--	--

<p><b>Old United Kingdom Status Code</b></p> <p><input type="radio"/> Routine</p> <p><input type="radio"/> Urgent</p> <p><input type="radio"/> Suspended</p>	<p><b>New United Kingdom Status Code</b></p> <p><input type="radio"/> Routine</p> <p><input type="radio"/> Urgent</p> <p><input type="radio"/> Suspended</p>
--	--

<p><b>Old US Status Code</b></p> <p><input type="radio"/> 1 (this option is only for listings prior to 1999)</p> <p><input type="radio"/> 1A</p> <p><input type="radio"/> 1B</p> <p><input type="radio"/> 2</p> <p><input type="radio"/> 7</p>	<p><b>New US Status Code</b></p> <p><input type="radio"/> 1 (this option is only for listings prior to 1999)</p> <p><input type="radio"/> 1A</p> <p><input type="radio"/> 1B</p> <p><input type="radio"/> 2</p> <p><input type="radio"/> 7</p>
--	--

<p><b>Reason for Status Change</b></p> <p><input type="text"/></p>	<p><b>Date of Status Code Change</b></p> <p>MM/DD/YYYY</p> <p><input type="text"/></p>
--	--

- Reasons for status change**
- Age now > 6 months
  - Alternate medical treatment
  - Alternate surgical treatment
  - Deterioration
  - Financial
  - Improved
  - Infection
  - Neurological
  - Parent/patient reluctance
  - Psychosocial
  - Too Sick
  - Other, specify

**5 Previous Cardiac Surgical History since listing or last follow-up?**  Yes  No  Unknown

Question Added: 01 JAN 1999

**Cardiac Surgery**



**Cardiac Surgery**

**5a**

**Surgical Intervention**

- AP Shunt (including BT Shunt, Modified BT Shunt, Waterson Shunt, Pott's Shunt, Central Shunt, and MEE procedure)
- ASD Repair
- CABG
- Complete AV Septal Defect Repair
- Congenitally Corrected Transposition Repair (classic)
- Congenitally Corrected Transposition Repair (double switch)
- Damus Kaye Stansel (DKS)
- d-Transposition of the Great Vessels Repair
- Ebstein's Anomaly Repair
- Fontan Procedure
- Glenn Procedure
- Hybrid Palliation (PA banding and PDA stent with or without septostomy)
- Norwood Procedure
- Norwood Stage I: BT Shunt
- Norwood Stage I: Sano/RV-PA conduit
- PA Banding
- Previous Heart Transplant
- TOF/DORV/RVOTO Repair
- Truncus Arteriosus Repair
- Valve Replacement
- VSD Repair
- Other, specify
- Unknown

**5b**

**Date of Surgical Intervention**

**Missing Reason:**

- Unknown

**5a.i**

**Arterial Switch Operation while Listed**

- Arterial switch operation
- Atrial switch (Senning/Mustard)
- Unknown

**5a.ii**

**Valve Replacement Details**

- Aortic valve replacement
- Mitral valve replacement
- Pulmonary valve replacement
- Tricuspid valve replacement
- Other, specify

**5a.ii.1**

**Aortic Valve, Homograft Tissue while Listed**

- Yes
- No
- Unknown

5a.ii.2 Pulmonary Valve, Homograft Tissue while Listed  Yes  No  Unknown

6 Catheter interventions/device placements  Atrial Septostomy/Balloon Dilation of IAS  Balloon Dilation  Cardiac Resynchronization Therapy  Defibrillator/AICD  None  Pacemaker  Stent  Other, specify

Question Added: 01 JAN 1999

6a Balloon Dilation, specify location

Question Added: 01 SEPT 2015

6b If stent, specify location  Arch  Atrial Septum  BT Shunt  Coronary artery  PDA  Pulmonary artery  Pulmonary vein  RV-PA conduit  Unknown  Other, specify

Question Added: 01 JAN 2005

**Patient Status**

7 Was patient permanently removed from Transplant Waiting List since listed or last Form 12?  Yes  No  Unknown  Not Applicable, patient died or transplanted

Note: If patient was completely removed from the waiting list and is later relisted, the new listing should be treated as a whole new patient.

Question Added: 01 JAN 1993

7a If yes, specify date removed   
MM/DD/YYYY

Question Added: 01 JAN 1993

7b

If yes, specify reason removed

- Alternate medical treatment
- Alternate surgical treatment
- Considered too well
- Contraindications/too sick
- Financial
- Neurological
- Parent/patient reluctance
- Psychosocial
- Other, specify

Question Added: 01 JAN 1993

8

Followed exclusively elsewhere  Yes

Note: If yes, no more data can be entered on this patient.  No

Question Added: 01 JAN 1993

8a

If yes, specify transfer date

MM/DD/YYYY

Question Added: 01 JAN 1993



Patient Details Hidden [Show](#)[Show/Hide Annotations](#) [Stickies: Toggle All](#) [Toggle Open](#) [Toggle Resolved](#)**Form 14: Dialysis or Renal Transplant**

Last Modified: 01 JAN 2010 Year/Info

[Print this Form](#)

Not Started

**Renal Transplant**

1

**Renal Transplant**  Yes  
 No  
 Unknown

Question Added: 01 JAN 2010

1a

**Date of renal transplant**   
MM/DD/YYYY

**Missing Reason:**  
 Unknown

Question Added: 01 JAN 2010

1b

**Type of donor**  Deceased  
 Living, Related  
 Living, Unrelated  
 Unknown

Question Added: 01 JAN 2010

**Dialysis**

Dialysis includes temporary CVVH in which BUN, Urea, Creatinine are being lowered.  
Dialysis does not include ultrafiltration, the removal of fluid only with preserved renal function.

2

**Dialysis**  Yes  
 No  
 Unknown

Question Added: 01 JAN 2010

2a

**Type of dialysis**  Acute  
 Both  
 Chronic  
 Unknown

Question Added: 01 JAN 2010

2b

**Date of first dialysis related  
to this event report**

**Missing Reason:**  
 Unknown

Question Added: 01 JAN 2010

2c

**Date of last dialysis  
related to this event**

**Missing Reason:**  
 Unknown  
 Ongoing

Question Added: 01 SEPT 2015

2d

**Type of dialysis**  Both  
 Hemodialysis  
 Peritoneal

Unknown

Question Added: 01 JAN 2010

### Laboratory Values Closet to Time of Dialysis or Renal Transplant

Note: labs may have been collected on different dates

3a

**Total Bilirubin**

mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0.3 and 1.2  
 Question Zone: > 2.4  
 Red Flag Zone: > 10

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3b

**Direct Bilirubin**

mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0 and 0.2  
 Question Zone: > 0.4  
 Red Flag Zone: > 5

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3c

**AST**

Aspartate transaminase (also SGOT) U/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 60  
 Question Zone: > 120  
 Red Flag Zone: > 1000

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3d

**ALT**

Alanine transaminase (also SGPT) U/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 7 and 45  
 Question Zone: > 90  
 Red Flag Zone: > 1000

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3e

**BNP**

B-type natriuretic peptide pg/mL or ng/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 100  
 Question Zone: > 1000  
 Red Flag Zone: > 10000

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3f

**Pro BNP**

Pro NT B-type natriuretic peptide  
 pg/mL or ng/L  
 pmol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 10 and 300  
 Question Zone: > 3000  
 Red Flag Zone: > 30000

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

3g

**CRP**

C reactive protein  
 mg/dL  
 mg/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0 and 0.5  
 Question Zone: > 5  
 Red Flag Zone: > 50

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3h

**Creatinine**

mg/dL  
 umol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0.2 and 1.3  
 Question Zone: > 2.6  
 Red Flag Zone: > 10

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3i

**BUN**

Blood urea nitrogen  
 mg/dL  
 Urea mmol/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 4 and 20  
 Question Zone: > 40  
 Red Flag Zone: > 120

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

3j

**Cystatin C**

mg/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 0.5 and 1.4  
 Question Zone: > 2.8  
 Red Flag Zone: > 10

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 SEPT 2015

3k

**Total Protein**

g/dL  
 g/L

**Range Information**  
 Top Low: < 0  
 Normal: Between 3.6 and 8.1  
 Question Zone: > 12  
 Red Flag Zone: > 16

**Missing Reason:**  
 Not Done  
 Unknown

Question Added: 01 JAN 2010

<b>3l</b>	<b>Pre Albumin</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 15 and 40 Question Zone: > 60 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 SEPT 2015
<b>3m</b>	<b>Serum Albumin</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Top Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>3n</b>	<b>Cholesterol</b> <small>Total Cholesterol</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>3o</b>	<b>TG</b> <small>Triglycerides</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>3p</b>	<b>LDL</b> <small>Low density lipoprotein</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>3q</b>	<b>HDL</b> <small>High density lipoprotein</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>3r</b>	<b>VLDL</b> <small>Very low density lipoprotein</small>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Top Low: < 0 Normal: Between 2 and 30 Question Zone: > 60 Red Flag Zone: > 250	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010

### Height and Weight

<b>4</b>	<b>Height</b>	<input type="text"/> <input type="radio"/> Centimeters <input type="radio"/> Inches	<b>Range Information</b> Top Low: < 0 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
<b>5</b>	<b>Weight</b>	<input type="text"/> <input type="radio"/> Kilograms <input type="radio"/> Pounds	<b>Range Information</b> Top Low: < 0 Normal: Between 2 and 30 Question Zone: > 60 Red Flag Zone: > 250	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010

**Calculated**

BSA: n/a  
BMI: n/a

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# Form 15: Mechanical Circulatory Support Events

[Toggle Questions and Info](#) [Print this Form](#)

Not Started

1

**Date of Initiation**

MM/DD/YYYY

Question Added: 01 JAN 1993 (VAD) | 01 JAN 2005 (ECMO)

2

**Date of Discontinuation**

MM/DD/YYYY

If patient is still on MCS support, check the "still in place" box. Then, you may edit this form with the discontinuation date once the support has been removed.

**Missing Reason:**

Still in place

Question Added: 01 JAN 1993 (VAD) | 01 JAN 2010 (ECMO)

3

**Type of Support**

- ECMO
- VAD
- Other, specify

Question Added: 01 JAN 1993

3a

**Type of ECMO**

- Both
- V-A
- V-V

Question Added: 01 JAN 2010

3b

**VAD Type**

BiVADs should be entered as two separate forms, one for the left VAD and one for the right VAD

- LVAD alone
- RVAD alone
- Systemic VAD (for single ventricle patients only)
- TAH

Question Added: 01 JAN 1993

3c

**Other temporary device brand**

- IABP
- Impella
- Other

Question Added: 01 January 1993

3b.i

**VAD Brands**

LVAD

- Abiomed AB5000
- Abiomed BVS 5000
- Abiomed Impella 2.5
- Abiomed Impella 5.0
- Berlin Heart EXCOR
- Biomedicus
- HeartMate II LVAS
- HeartMate IP
- HeartMate VE
- HeartMate XVE
- HeartWare HVAD
- Impella CP
- Maquet Rotaflow

- Micromed DeBakey VAD - Child
- Novacor PC
- Novacor PCq
- Sorin Revolution
- Tandem Heart
- Thoratec Centrimag (Levitronix)
- Thoratec IVAD
- Thoratec Pedimag
- Thoratec PVAD
- Other, specify

Question Added: 01 JAN 1993

### 3b.ii

#### VAD Brands

RVAD

- Abiomed AB5000
- Abiomed BVS 5000
- Abiomed Impella 2.5
- Abiomed Impella 5.0
- Berlin Heart EXCOR
- Biomedicus
- HeartWare HVAD
- Maquet Rotaflow
- Sorin Revolution
- Tandem Heart
- Thoratec Centrimag (Levitronix)
- Thoratec IVAD
- Thoratec Pedimag
- Thoratec PVAD
- Impella CP
- Impella RP
- Other, specify

Question Added: 01 JAN 1993

### 3b.iii

#### VAD Brands

Systemic VAD (for single ventricle patients only)

- Abiomed AB5000
- Abiomed BVS 5000
- Abiomed Impella 2.5
- Abiomed Impella 5.0
- Berlin Heart EXCOR
- Biomedicus
- HeartMate II LVAS
- HeartMate IP
- HeartMate VE
- HeartMate XVE
- HeartWare HVAD
- Impella CP
- Maquet Rotaflow
- Micromed DeBakey VAD - Child
- Novacor PC
- Novacor PCq
- Sorin Revolution
- Tandem Heart
- Thoratec Centrimag (Levitronix)
- Thoratec IVAD

- Thoratec Pedimag
- Thoratec PVAD
- Other, specify

Question Added: 01 JAN 1993

3b.iii

**VAD Brands**

TAH

- AbioCor TAH
- SynCardia CardioWest TAH
- Other, specify

Question Added: 01 JAN 1993

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