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## Form 1: Listing

[Toggle Question Year/Info](#)[Print this Form](#)

Not Started

1

Listing Date

MM/DD/YYYY

Question Added: 01 JAN 1993  
LISTDATE

2

Residence Zip Code at Listing

Missing Reason:

☐ UnknownQuestion Added: 31 AUG 2021  
RES\_ZIP\_LISTING

2a

Long distance patient or remote patient ☐ Yes  
☐ NoLong distanced defined as >30 miles or 50kms from the  
transplant centerQuestion Added: 01 AUG 2022  
LSLDPT

## Height and Weight

3a

Height

☐ Centimeters  
☐ InchesQuestion Added: 01  
JAN 1993

HTLISTU

Missing Reason:

☐ Not Done  
☐ Unknown

HTLIST

**Calculated**BSA: n/a  
BMI: n/a

3b

Weight

☐ Kilograms  
☐ PoundsQuestion Added: 01  
JAN 1993

WTLISTU

Missing Reason:

☐ Not Done  
☐ Unknown

WTLIST

4

Main reason for listing

Select only one primary reason for listing.

- ☐ CHD too high risk for palliative surgical options
- ☐ 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

PRM\_LIST

☐ Other, specify

PRMLSOTH

Question Added: 01 SEPT 2015

4a

**Medically refractory heart failure**

- ☐ Both  
☐ Diastolic Failure  
☐ Systolic Failure  
☐ Unknown

Question Added: 01 SEPT 2015  
PRMMRHF

4b

**Specify malignant Arrhythmia?**

- ☐ Primary tachy-arrhythmias  
☐ Inherited arrhythmias  
☐ Arrhythmogenic cardiomyopathies

PRMSMA

## Surgeries Prior to Listing

5

**Did the patient have any cardiac surgery prior to listing?**

- ☐ Yes  
☐ No  
☐ Unknown

VADs and ECMO should not be reported as a previous cardiac surgery. They should be reported in the status details if applicable (question 6). A Form 15 (MCSD Form) should be entered for each VAD and ECMO event.

Question Added: 01 JAN 1993  
HXSURG

Dataset Name: LISTINGSURGERIES / LS\_SURG

## Surgery Details

5

**If Congenital cardiac surgery, specify surgery:**

- ☐ Ablation (Radio/Cryo)  
☐ AICD Implant  
☐ ALCAPA / ALCAPA Repair  
☐ Ao Root Replacement/Revision  
☐ Aortic Arch Repair / Reconstruction  
☐ Aortic-Apical Conduit  
☐ Aorto-Pulmonary Arterioplasty  
☐ AP Shunt (including BT Shunt, Modified BT Shunt, Waterson Shunt, Pott's Shunt, Central Shunt, and MEE procedure)  
☐ Arterial Switch Operation  
☐ ASD Creation  
☐ ASD Repair  
☐ Atrial Septectomy  
☐ Atrial switch (Senning/Mustard)  
☐ AV Canal Repair  
☐ Blalock-Hanlon Septectomy  
☐ CABG / Coronary artery repair  
☐ Cardiac Tumor Resection  
☐ Coarctation Balloon Arterioplasty  
☐ Coarctation Repair  
☐ Complete AV Septal Defect Repair  
☐ Congenitally Corrected Transposition Repair (classic)

SURGERY

- ☐ Congenitally Corrected Transposition Repair (double switch)
- ☐ Damus Kaye Stansel (DKS)
- ☐ Diaphragm plication
- ☐ Double chamber right ventricle
- ☐ Other, specify

SURG\_OSP

- ☐ Ebstein's Anomaly Repair
- ☐ Endocardial Fibrosis Resection (EFE)
- ☐ Fontan Procedure
- ☐ Glenn Procedure (includes bidirectional Glenn and hemi-Fontan)
- ☐ Glenn Revision
- ☐ Glenn Takedown
- ☐ Hybrid Palliation
- ☐ Interrupted Aortic Arch Repair
- ☐ Kawashima
- ☐ Konno Procedure
- ☐ LV-PA Conduit
- ☐ Maze Procedure
- ☐ Mediastinal Exploration for infection
- ☐ MPA Closure
- ☐ Norwood Stage I: BT Shunt
- ☐ Norwood Stage I: Sano/RV-PA conduit
- ☐ Norwood Stage I: Pulmonary Connection Unknown
- ☐ PA Banding
- ☐ Pacemaker
- ☐ PDA Closure
- ☐ Pericardial Window
- ☐ Pericardiectomy
- ☐ Pulmonary Arterioplasty
- ☐ Rastelli Procedure
- ☐ Repair of Aortopulmonary Window
- ☐ Repair of cor triatriatum
- ☐ Repair of Pulmonary Vein Stenosis
- ☐ Repair of TAPVC
- ☐ Repair PAPVC
- ☐ Ross Procedure
- ☐ RVOT Augmentation
- ☐ RV-PA Conduit
- ☐ Subaortic Resection
- ☐ Subpulmonary Resection
- ☐ Supravalvar AS repair
- ☐ SVC Repair
- ☐ Thoracic Duct Ligation
- ☐ TOF/DORV/RVOTO Repair
- ☐ Truncus Arteriosus Repair
- ☐ Unifocalization
- ☐ Valve Replacement / Repair
- ☐ Vascular Ring Repair
- ☐ Ventricular Resection
- ☐ VSD Enlargement
- ☐ VSD Repair

5

Date of Surgery

Missing Reason:

☐ Unknown

SURGDTE

5

**Congenital cardiac surgery,  
Valve Replacement**

- ☐ Aortic Valve Replacement / Repair  
☐ Mitral Valve Replacement / Repair  
☐ Pulmonary Valve Replacement / Repair  
☐ Tricuspid Valve Replacement / Repair  
☐ Single AV Valve Replacement/Repair  
☐ Other, specify

LSAORTIC  
LSMITRAL  
LSPULMV  
LSTRICV  
LSSNGAVV  
LSVROTH  
LSVROTSP

5

**Homograft Tissue  
in Aortic Valve  
Replacement?**

- ☐ Yes  
☐ No  
☐ Unknown

LSAORHOM

**Status Details at Listing**

6a

**Status at Listing**

- ☐ Brazil  
☐ Canada  
☐ United Kingdom  
☐ United States

Question Added: 01 JAN 2010  
LSCNTRY

6a.i

**Brazil**

- ☐ Non-Priority  
☐ Priority

Question Added: 01 JAN 2010  
LSBRZ\_ST

6a.ii

**Canada**

- ☐ 1  
☐ 2  
☐ 3  
☐ 3.5  
☐ 4  
☐ 4S

Question Added: 01 JAN 2005  
LSCA\_ST

6a.iii

**United Kingdom**

- ☐ Routine  
☐ Urgent

Question Added: 01 JAN 2005  
LSUK\_ST

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  
STATLIST

6b

**Was patient in or out of hospital  
at time of listing?**

- ☐ In hospital  
☐ Out of hospital

Question Added: 01 JAN 1993  
SLHOSP

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

Question Added: 01 JAN 1999  
SLICU

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

Question Added: 01 JAN 1993  
SLVENT

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

Question Added: 01 JAN 1993  
SLVINO

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

Question Added: 01 JAN 2005  
SLINODS

**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  
SLDDPSC

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

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

Question Added: 01 JAN 2010  
LSABOINC

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

SLVAD  
SLECMO  
SLNOMCSD

Question Added: 01 JAN 1993

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

Missing Reason:  
☐ Unknown

Question Added: 01 JAN 1993  
SLVDATE

**6f.ii** Specify initiation date (ECMO)

Missing Reason:  
☐ Unknown

SLECMODT

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  
LSDCD**Infectious Disease Screening**

7a

**HIV Serology**

AIDS testing

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7b

**CMV Serology**

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7c

**CMV PCR**

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 2010

7d

**EBV Serology**

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7e

**EBV PCR**

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 2010

7f

**IFA Toxo**

Toxoplasma testing

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7g

**HBs Ag**

Hepatitis B surface antigen

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7h

**HB core Ab**

Hepatitis B core antibody

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7i

**HBs Ab**

Hepatitis B surface antibody

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7j

**Hep C Ab**

Hepatitis C antibody

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 1993

7k

**RPR/Syphilis**

Syphilis testing

- ☐ Negative ☐ Not Done ☐ Positive ☐ Unknown

Question Added: 01 JAN 2005

## Medical History at time of Listing

8

Medical History ☐ Yes  
☐ No  
☐ Unknown

Question Added: 01 JAN 1993  
HXMED

8a

Type of medical history at Listing

- |  |          |
|--|----------|
| <input type="checkbox"/> Arrythmia                                 | HXARRYTH |
| <input type="checkbox"/> Cardiac Arrest/CPR                        | HXCPR    |
| <input type="checkbox"/> Diabetes                                  | HXDIAB   |
| <input type="checkbox"/> GI/Nutrition                              | HXGI     |
| <input type="checkbox"/> Heterotaxy/Isomerism                      | HXISO    |
| <input type="checkbox"/> Malignancy                                | HXMALIG  |
| <input type="checkbox"/> Metabolic/Disorder                        | HXMET    |
| <input type="checkbox"/> Mitochondrial Disorder                    | HXMIT    |
| <input type="checkbox"/> Neurologic                                | HXNEURO  |
| <input type="checkbox"/> Pacemaker                                 | PACEMAKE |
| <input type="checkbox"/> Peripheral Myopathy/Neuromuscular disease | HXPERMYO |
| <input type="checkbox"/> Prenatal Diagnosis                        | HXPENAT  |
| <input type="checkbox"/> Prior Transfusions                        | HXTRANS  |
| <input type="checkbox"/> Renal Insufficiency                       | HXRENINS |
| <input type="checkbox"/> Respiratory                               | HXRESP   |
| <input type="checkbox"/> Shock                                     | HXSHOCK  |
| <input type="checkbox"/> Syndrome                                  | HXSYN    |
| <input type="checkbox"/> Other, specify                            | HXOTHER  |

SPECOTH

Question Added: 01 JAN 1993

8a.i

Arrhythmia

- |   |          |
|---|----------|
| <input type="checkbox"/> Afib/flutter         | HXAF_FL  |
| <input type="checkbox"/> Complete heart block | HXCHB    |
| <input type="checkbox"/> V Fibrillation       | HXVFIB   |
| <input type="checkbox"/> V Tachycardia        | HXVTACH  |
| <input type="checkbox"/> Unknown              | HXARRUNK |
| <input type="checkbox"/> Other, specify       | HXOTHARR |

SPECARRY

Question Added: 01 JAN 1993

8a.ii

Cardiac arrest/CPR Date

MM/DD/YYYY

Missing Reason:  
☐ Unknown

Question Added: 01 JAN 1996  
CPRDT

8a.iii

Diabetes, Date of last Hgb A1c

MM/DD/YYYY

Missing Reason:  
☐ Unknown

Question Added: 01 SEPT 2015  
HGBDATE

8a.iii

Diabetes, Value of last Hgb A1c

Missing Reason:  
☐ Unknown

Question Added: 01 SEPT 2015

HGBVALUE

8a.iii

Diabetes, Treating with ☐ Yes  
☐ No

HXINSUL

insulin ☐ 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

HXFAIL  
 HXFONLVR  
 HXHEP  
 HXPLE  
 HXGIOT  
 HXGIOTSP

Question Added: 01 SEPT 2015

8a.iv.1

GI/Nutrition,  
Infectious hepatitis type

- ☐ A  
☐ B  
☐ C  
☐ Unknown  
☐ Other, specify

HXHEPTYA  
 HXHEPTYB  
 HXHEPTYC  
 HXHEPTYU  
 HXHEPTYO  
 HXHEPSP

Question Added: 01 SEPT 2015

8a.v

Medical History,  
Heterotaxy/Isomerism

- ☐ Asplenia  
☐ Polysplenia  
☐ Unspecified  
☐ Other, specify

HXASPLEN  
 HXPLYSPL  
 HXISOUSP  
 HXISOTH  
 HXISO\_SP

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

HXLYMLEU  
 HXSPBMT  
 HXSPCRAD  
 HXSOLORG  
 HXMALUNK  
 HXMALOTH  
 SPECMAL

Question Added: 01 JAN 1993

8a.vii

Specify Metabolic  
Disorder

Question Added: 01 SEPT 2015  
 HXMETSP

8a.viii

Medical History,  
Mitochondrial  
Disorder, specify

- ☐ Barth's  
☐ Unspecified  
☐ Other, specify

HXMITSP

Question Added: 01 SEPT 2015  
 HXMITTY

8a.ix

Medical History,  
Neurologic

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

ANXINJ  
 HXCVA  
 NEUROTH  
 NEUROTSP

Question Added: 01 SEPT 2015



8a.ix.1	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown
Neurologic, Anoxic brain injury Last Date		Question Added: 01 SEPT 2015 ANXINJDT
MM/DD/YYYY		
8a.ix.2	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown
Neurologic, Hemorrhagic and/or thromboembolic stroke Date Last		Question Added: 01 SEPT 2015 CVADT
MM/DD/YYYY		
8a.x	Pacemaker <input type="checkbox"/> Defibrillator/AICD <input type="checkbox"/> Pacemaker, CRT/biventricular pacing <input type="checkbox"/> Pacemaker, not CRT and not ICD	HXAICD LSPACEBIV LPACE Question Added: 01 JAN 1993
8a.x.1	Pacemaker, <input type="text"/> Defibrillator/AICD Date Placed	Missing Reason: <input type="radio"/> Unknown
MM/DD/YYYY		Question Added: 01 JAN 1993 to 31 DEC 2004   01 JAN 2010 AICDDT
8a.x.2	Pacemaker, <input type="text"/> CRT/biventricular pacing, Date Placed	Missing Reason: <input type="radio"/> Unknown
MM/DD/YYYY		Question Added: 01 JAN 2010 BIVDTE
8a.x.3	Pacemaker, not CRT and not ICD, Date Placed	Missing Reason: <input type="radio"/> Unknown
MM/DD/YYYY		Question Added: 01 JAN 1993 PACEMDT
8a.xi	Medical History, Peripheral myopathy/neuromuscular disease <input type="checkbox"/> Becker MuscularDystrophy <input type="checkbox"/> Duschenne Muscular Dystrophy <input type="checkbox"/> Freidrich's Ataxia <input type="checkbox"/> Unspecified <input type="checkbox"/> Other, specify <input type="text"/>	HXBECKMD HXDMD HXFREIDR PERMUNK PERMOTHR PERMOSP Question Added: 01 SEPT 2015
8a.xii	History Dialysis <input type="radio"/> Dialysis, acute (within past 30 days) <input type="radio"/> Dialysis, chronic (>1 month duration) <input type="radio"/> Dysfunction, not dialysis	HXDYS DIA

- ☐ Unknown  
☐ Other, specify

HXRENSP

Question Added: 01 JAN 2010

8a.xiii

**Medical History,  
Respiratory**

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

HXPULDIS  
HXPB  
HXTRACH  
HXRESPUN  
HXOTRESP  
HXSPRESP

Question Added: 01 SEPT 2015

8a.xiv

**Shock,  
Date of last  
appropriate  
Shock**

MM/DD/YYYY

Missing Reason:

- ☐ Unknown

Question Added: 01 JAN 1996  
SHOCKDT

8a.xv

**Medical History,  
Syndrome**

- ☐ Cardiofaciocutaneous Syndrome  
☐ Costello Syndrome  
☐ Digeeorge (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

HXCRD  
HXCOSTLO  
HXDIGORG  
HXDOWNS  
HXELRDAN  
HXLLEOPRD  
HXLSDTZ  
HXMARFNS  
HXNOONAN  
HXMRFNLK  
HXTURNER  
HXSUN\_U  
HXWILLIM  
HXOTHRNS  
OTHRNSNP

Question Added: 01 SEPT 2015

**Insurance**

9

**Primary Insurance**

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

P\_SPINS

Question Added: 01 JAN 1996  
P\_INS

- 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. Includes Single Payer Non-US.
- Private – Refers to funds from agencies such as Blue Cross/Blue Shield, etc. This also includes TRICARE.
- 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  
LSPRA**10a.i****T Cell**  
%**Range Information**  
Too Low: < 0  
Normal: Between 0 and 101  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSCPRA

**10a.ii****B Cell**  
%**Range Information**  
Too Low: < 0  
Normal: Between 0 and 101  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSCPRA

**10a.iii****Date (Cytotoxic PRA)**Missing Reason:  
☐ UnknownQuestion Added: 01 JAN 1993  
LSCPRA**10b****Cytotoxic PRA, DTE/DTT** ☐ Done  
☐ Not DonePanel 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  
LSPRA**10b.i****T Cell**  
%**Range Information**  
Too Low: < 0  
Normal: Between 0 and 101  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ Unknown

Question Added: 01 JAN 1993

LSPRA

**10b.ii****B Cell**  
%**Range Information**  
Too Low: < 0  
Normal: Between 0 and 101  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ Unknown

Question Added: 01 JAN 1993

LSPRA

**10b.iii****Date (Cytotoxic PRA,  
DTE/DTT)**Missing Reason:  
☐ UnknownQuestion Added: 01 JAN 1993  
LSPRA**10c****Flow Cytometry or Luminex  
PRA** ☐ Done  
☐ Not DoneQuestion Added: 01 JAN 1996  
LSFPCRA

10c.i

Class I

  
%

## Range Information

Too Low: < 0  
Normal: Between 0 and 101  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ UnknownQuestion Added: 01 JAN  
1996

LSFPRAT

10c.ii

Class II

  
%

## Range Information

Too Low: < 0  
Normal: Between 0 and 101  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ UnknownQuestion Added: 01 JAN  
1996

LSFPRAB

10c.iii

Date

MM/DD/YYYY

Missing Reason:

☐ UnknownQuestion Added: 01 JAN 1996  
LSFPRADT

10d

Listed for prospective  
crossmatch☐ Yes  
☐ No  
☐ UnknownQuestion Added: 01 JAN 2010  
LSPROCMT

10d.i

Prospective Crossmatch  
Results☐ Donor Cells  
☐ Donor Cells and Virtual  
☐ Virtual  
☐ UnknownQuestion Added: 01 JAN 2010  
LSPCMT

10d.i.1

Virtual  
Crossmatch☐ Avoidance of donor antigens to all antibodies  
present  
☐ Avoidance of donor antigens to antibodies above  
pre-specified threshold  
☐ Avoidance of donor antigens to C1q fixing  
antibodies only  
☐ UnknownQuestion Added: 01 SEPT 2015  
LSVCMA

## 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.

11

Were hemodynamics done  
prior to listing?☐ Yes  
☐ No  
☐ UnknownQuestion Added: 01 JAN 1993  
LSHEMO

11a

Date

MM/DD/YYYY

Missing Reason:

☐ Not Done  
☐ UnknownQuestion Added: 01 JAN 1993  
LSHEMDT

11b

Fontan Mean  
Pressure  
mmHg

## Range Information

Too Low: < 0  
Normal: Between 0 and 40  
Question Zone: > 41  
Red Flag Zone: > 41

Missing Reason:

☐ Not Done  
☐ UnknownQuestion Added: 01  
SEPT 2015

LSFPRES

11c

RAm (RAP or CVP)

Right Atrial Mean Pressure

  
mmHg

## Range Information

Too Low: < 0  
Normal: Between 0 and 40  
Question Zone: > 41  
Red Flag Zone: > 41

Missing Reason:

☐ Not DoneQuestion Added: 01 JAN  
1993

LSBRAM

☐ Unknown

11d

**PAm**

Pulmonary Artery Mean

  
mmHg
**Range Information**

Too Low: < 0  
Normal: Between 0 and 50  
Question Zone: > 51  
Red Flag Zone: > 51

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSBPAM

11e

**PCW**

Mean Pulmonary Capillary Wedge Pressure

  
mmHg
**Range Information**

Too Low: < 0  
Normal: Between 0 and 60  
Question Zone: > 61  
Red Flag Zone: > 61

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSBPCW

11f

**SVC Sat**

Oxygen Saturation in the SVC

  
%
**Range Information**

Too Low: < 0  
Normal: Between 0 and 100  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 2010

LSSVCSAT

11g

**AO Sat**

Aortic Saturation

  
%
**Range Information**

Too Low: < 0  
Normal: Between 0 and 100  
Question Zone: > 101  
Red Flag Zone: > 101

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 2005

LSBAOSAT

11h

**Rp, PVRI**Pulmonary resistance indexed to body surface area (BSA)  
Woods Units  $\times$  m<sup>2</sup>
  
wu  $\times$  m<sup>2</sup>
**Range Information**

Too Low: < 0  
Normal: Between 0 and 50  
Question Zone: > 51  
Red Flag Zone: > 51

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSBRP

11i

**Rs, SVRI**Systemic resistance indexed to body surface area (BSA)  
Woods Units  $\times$  m<sup>2</sup>
  
wu  $\times$  m<sup>2</sup>
**Range Information**

Too Low: < 0  
Normal: Between 0 and 40  
Question Zone: > 41  
Red Flag Zone: > 41

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSBRS

11j

**EDP**

End diastolic pressure of systemic ventricle

  
mmHg
**Range Information**

Too Low: < 0  
Normal: Between 0 and 60  
Question Zone: > 61  
Red Flag Zone: > 61

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 2010

LSEDP

11k

**C.O.**

Cardiac Output (i.e. Qs)

  
L/min
**Range Information**

Too Low: < 0  
Normal: Between 0 and 20  
Question Zone: > 21  
Red Flag Zone: > 21

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSBCO

11l

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

Too Low: < 0  
Normal: Between 0 and 15  
Question Zone: > 16  
Red Flag Zone: > 16

Missing Reason:

☐ Not Done  
☐ Unknown

Question Added: 01 JAN 1993

LSBCI

11m

**Was patient on mechanical support at time of Hemodynamics**

☐ Yes  
☐ No  
☐ Unknown

Question Added: 01 SEPT 2015  
LSMSHEMO

11n

**Hemodynamic Agents Used**

☐ Yes  
☐ No  
☐ Unknown

Question Added: 01 JAN 1993  
LSHEMAGT

11n.i

**Indicate agent for best hemodynamics**

☐ 100% O2  
☐ Dobutamine  
☐ Dopamine  
☐ Unknown  
☐ Epinephrine

LSHPO2  
LSDOBUT  
LSDOPA  
LSUNKN  
LSEPI

- |   |          |
|---|----------|
| <input type="checkbox"/> Isoproterenol (Isuprel)      | LSISUPRO |
| <input type="checkbox"/> Milrinone (Primacor)         | LSMILRIN |
| <input type="checkbox"/> Nesiritide                   | LSHNES   |
| <input type="checkbox"/> Nitric Oxide                 | LSNOX    |
| <input type="checkbox"/> Nitroglycerin                | LSNITRO  |
| <input type="checkbox"/> Nitroprusside (Nipride)      | LSNITROP |
| <input type="checkbox"/> Norepinephrine               | LSNOREPI |
| <input type="checkbox"/> PGE (Alprostadiil)           | LSPGE    |
| <input type="checkbox"/> PGI (Flolan)                 | LSPGI    |
| <input type="checkbox"/> Phenylephrine/ Neosynephrine | LSPHEN   |
| <input type="checkbox"/> Sildenafil                   | LSSILD   |
| <input type="checkbox"/> Vasopressin                  | LSVASO   |
| <input type="checkbox"/> Other, specify               | LSOHMD   |
| <input type="text"/>                                  | LSOHMDSP |

Question Added: 01 JAN 1993

## Schooling

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

Question Added: 01 JAN 1996  
LSCHOOL

- 12** Are they at the age appropriate level
- ☐ Yes  
☐ No  
☐ Unknown

AASCHOOL

- 12b** Are they in a special education class
- ☐ Yes  
☐ No  
☐ Unknown

Question Added: 01 JAN 1996  
SPSCHOOL

## Exercise Test

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

Question Added: 01 JAN 2005  
LSTTPERF

- 13a** If exercise test not performed, specify reason
- ☐ Age inappropriate  
☐ Too sick  
☐ Unknown  
☐ Other, specify

TTNDRS

Question Added: 01 JAN 2015  
TTNDR

Question Added: 01 JAN 2015  
PCPAGE

## 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

2005

## 13c

### Max VO<sub>2</sub>

Maximum oxygen consumption ml/kg/min

Missing Reason:

- ☐ Unknown  
☐ Not Done

Question Added: 01 JAN  
1996

TTMAXVO2

## 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

TTRMAX

## 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

Too 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

LSBILI\_T\_U

LSBILI\_T

## 14b

### Direct Bilirubin

- ☐ mg/dL  
☐ umol/L

#### Range Information

Too 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

LSBILI\_D\_U

LSBILI\_D

## 14c

### AST

Aspartate transaminase (also SGOT) U/L

#### Range Information

Too Low: < 0  
Normal: Between 10 and 60  
Question Zone: > 120  
Red Flag Zone: > 1000

Missing Reason:

- ☐ Not Done  
☐ Unknown

Question Added: 01 JAN  
2005

LSAST

## 14d

### ALT

Alanine transaminase (also SGPT) U/L

#### Range Information

Too Low: < 0  
Normal: Between 7 and 45  
Question Zone: > 90  
Red Flag Zone: > 1000

Missing Reason:

- ☐ Not Done  
☐ Unknown

Question Added: 01 JAN  
2005

LSALT

## 14e

### BNP

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

#### Range Information

Too Low: < 0  
Normal: Between 10 and 100  
Question Zone: > 1000  
Red Flag Zone: > 10000

Missing Reason:

- ☐ Not Done  
☐ Unknown

Question Added: 01 JAN  
2010

LBNP

## 14f

### Pro BNP

Pro NT B-type natriuretic peptide

- ☐ pg/mL or ng/L  
☐ pmol/L

#### Range Information

Too Low: < 0  
Normal: Between 10 and 300  
Question Zone: > 3000  
Red Flag Zone: > 30000

Missing Reason:

- ☐ Not Done  
☐ Unknown

Question Added: 01  
SEPT 2015

LSPBNP\_U

LSPBNP

14g	<b>CRP</b> C reactive protein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mg/L	<b>Range Information</b> Too Low: < 0 Normal: Between 0 and 0.5 Question Zone: > 5 Red Flag Zone: > 50	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
			LCRP_U	LCRP	
14h	<b>Creatinine</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	<b>Range Information</b> Too Low: < 0 Normal: Between 0.2 and 1.3 Question Zone: > 2.6 Red Flag Zone: > 10	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 93 to 31 DEC 2004   01 JAN 2010 - CURRENT
			LCREAT_U	LCREAT	
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> Too Low: < 0 Normal: Between 4 and 20 Question Zone: > 40 Red Flag Zone: > 120	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
			LBUN_U	LBUN	
14j	<b>Cystatin C</b>	<input type="text"/> mg/L	<b>Range Information</b> Too Low: < 0 Normal: Between 0.5 and 1.4 Question Zone: > 2.8 Red Flag Zone: > 10	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 SEPT 2015
			LSCSTAT	LSCSTAT	
14k	<b>Total Protein</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Too Low: < 0 Normal: Between 3.6 and 8.1 Question Zone: > 12 Red Flag Zone: > 16	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999
			LSTP_U	LSTP	
14l	<b>Pre Albumin</b>	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> g/L	<b>Range Information</b> Too Low: < 0 Normal: Between 15 and 40 Question Zone: > 60 Red Flag Zone: > 80	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2015
			LSPALB_U	LSPALB	
14m	<b>Serum Albumin</b>	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	<b>Range Information</b> Too Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999
			LSSAB_U	LSSAB	
14n	<b>Cholesterol</b> Total Cholesterol	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Too Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
			LCHOL_U	LCHOL	
14o	<b>TG</b> Triglycerides	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Too Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
			LTG_U	LTG	
14p	<b>LDL</b> Low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Too Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
			LLDL_U	LLDL	
14q	<b>HDL</b> High density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	<b>Range Information</b> Too Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	<b>Missing Reason:</b> <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
			LHDL_U	LHDL	
			<b>Range Information</b>	LVLDL	



14r

VLDL

Very low density lipoprotein

- ☐
- mg/dL
- 
- ☐
- mmol/L

Too Low: < 0  
Normal: Between 2 and 30  
Question Zone: > 60  
Red Flag Zone: > 250

Missing Reason:

- ☐
- Not Done
- 
- ☐
- Unknown

Question Added: 01 JAN  
2010

LVLDL\_U

## NYHA and Ross' Heart Failure

15

NYHA Class

- ☐
- 1
- 
- ☐
- 2
- 
- ☐
- 3
- 
- ☐
- 4
- 
- ☐
- Not Done
- 
- ☐
- Unknown

Question Added: 01 JAN 2005  
LSNYHA

## 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  
LSRHFL

## 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.