Form 1: Listing

Listing Date

Question Added: 01 JAN 1993

Height and Weight

Height

Question Added: 01 JAN 1993

Calculated

BSA: n/a
BMI: n/a

Weight

Question Added: 01 JAN 1993

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
- Other, specify

Question Added: 01 SEPT 2015

Medically refractory heart failure

- Both
- Diastolic Failure
- Systolic Failure
- Unknown

Question Added: 01 SEPT 2015

Surgeries Prior to Listing
## Did the patient have any cardiac surgery prior to listing?

- **Yes**
- **No**
- **Unknown**

**Question Added:** 01 JAN 1993

### Surgery Details

#### 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**

#### Date of Surgery:

- **Missing Reason:**
  - Unknown

#### Congenital cardiac surgery, d- Transposition of the Great Vessels Repair

- Arterial Switch Operation
- Atrial Switch (Senning/Mustard)

#### Congenital cardiac surgery, Valve Replacement

- Aortic Valve Replacement
- Mitral Valve Replacement
- Pulmonary Valve Replacement
- Tricuspid Valve Replacement
- **Other, specify**
### Homograft Tissue in Aortic Valve Replacement?

- Yes
- No
- Unknown

### Status Details at Listing

#### 6a

<table>
<thead>
<tr>
<th>Status at Listing</th>
<th>Options</th>
<th>Question Added: 01 JAN 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brazil</td>
<td>Brazil, Non-Priority, Priority</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>1</td>
<td>Question Added: 01 JAN 2010</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4S</td>
<td></td>
</tr>
</tbody>
</table>

#### 6a.i Brazil

- Non-Priority
- Priority

#### 6a.ii Canada

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

#### 6a.iii United Kingdom

- Routine
- Urgent

#### 6a.iv Status at Listing, US

- 1 (this option is only for listings prior to 1999)
- 1A
- 1B
- 2
- 7

#### 6b Was patient in or out of hospital at time of listing?

- In hospital
- Out of hospital

#### 6b.i Was patient in the ICU at time of listing?

- Yes
- No
- Unknown
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

<table>
<thead>
<tr>
<th>Donor Blood Type</th>
<th>A</th>
<th>B</th>
<th>AB</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>ABO compatible</td>
<td>ABO incompatible</td>
<td>ABO compatible</td>
<td>ABO incompatible</td>
</tr>
<tr>
<td>B</td>
<td>ABO incompatible</td>
<td>ABO compatible</td>
<td>ABO compatible</td>
<td>ABO incompatible</td>
</tr>
<tr>
<td>AB</td>
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<tr>
<td>O</td>
<td>ABO compatible</td>
<td>ABO compatible</td>
<td>ABO compatible</td>
<td>ABO compatible</td>
</tr>
</tbody>
</table>

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)
- Yes
- No
### Infectious Disease Screening

<table>
<thead>
<tr>
<th>Question</th>
<th>Result</th>
<th>Date Added</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>7a</strong> HIV Serology</td>
<td>AIDS testing</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7b</strong> CMV Serology</td>
<td></td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7c</strong> CMV PCR</td>
<td></td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7d</strong> EBV Serology</td>
<td></td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7e</strong> EBV PCR</td>
<td></td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7f</strong> IFA Toxo</td>
<td>Toxoplasma testing</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7g</strong> HBs Ag</td>
<td>Hepatitis B surface antigen</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7h</strong> HB core Ab</td>
<td>Hepatitis B core antibody</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7i</strong> HBs Ab</td>
<td>Hepatitis B surface antibody</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7j</strong> Hep C Ab</td>
<td>Hepatitis C antibody</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
<tr>
<td><strong>7k</strong> RPR/Syphilis</td>
<td>Syphilis testing</td>
<td>Negative, Unknown, Not Done, Positive</td>
</tr>
</tbody>
</table>

### Medical History at time of Listing

<table>
<thead>
<tr>
<th>Question</th>
<th>Result</th>
<th>Date Added</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>8</strong> Medical History</td>
<td></td>
<td>Yes, No, Unknown</td>
</tr>
</tbody>
</table>
### 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

- Date
  
  MM/DD/YYYY

**Missing Reason:** Unknown

**Question Added:** 01 SEPT 2015

### 8a.iii Diabetes, Value of last Hgb A1c

- Value

**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

**Question Added:** 01 JAN 1993
<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>8a.iv.1</td>
<td>GI/Nutrition, Infectious hepatitis type</td>
</tr>
<tr>
<td>A</td>
<td>A</td>
</tr>
<tr>
<td>B</td>
<td>B</td>
</tr>
<tr>
<td>C</td>
<td>C</td>
</tr>
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<td>8a.v</td>
<td>Medical History, Heterotaxy/Isomerism</td>
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<tr>
<td>Asplenia</td>
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<td>Polysplenia</td>
<td>Polysplenia</td>
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<td>Unspecified</td>
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<td>Other, specify</td>
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<td>Question Added: 01 SEPT 2015</td>
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<tbody>
<tr>
<td>8a.vi</td>
<td>Medical History, Malignancy</td>
</tr>
<tr>
<td>Lymphoma, leukemia</td>
<td>Lymphoma, leukemia</td>
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<td>s/p BMT</td>
<td>s/p BMT</td>
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<tr>
<td>s/p Chest Radiation</td>
<td>s/p Chest Radiation</td>
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<td>Solid organ cancer</td>
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<td>Other, specify</td>
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<td>Question Added: 01 JAN 1993</td>
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<tr>
<td>8a.vii</td>
<td>Specify Metabolic Disorder</td>
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<tr>
<td>8a.viii</td>
<td>Medical History, Mitochondrial Disorder, specify</td>
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<td>Barth's</td>
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<td>Question Added: 01 SEPT 2015</td>
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<tr>
<th>Question</th>
<th>Details</th>
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<tbody>
<tr>
<td>8a.ix</td>
<td>Medical History, Neurologic</td>
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<tr>
<td>Anoxic brain injury</td>
<td>Anoxic brain injury</td>
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<tr>
<td>Hemorrhagic and/or thromboembolic stroke</td>
<td>Hemorrhagic and/or thromboembolic stroke</td>
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<tr>
<td>Other, specify</td>
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<th>Details</th>
</tr>
</thead>
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<tr>
<td>8a.ix.1</td>
<td>Neurologic, Anoxic brain injury Last Date</td>
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<td></td>
</tr>
<tr>
<td>Question Added: 01 SEPT 2015</td>
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</table>

| Missing Reason | Unknown |

https://phts.uab.edu/WBDE/Listing/Add/13951?printForm=1
8a.ix.2
Neurologic, Hemorrhagic and/or thromboembolic stroke
Date Last
MM/DD/YYYY

Question Added: 01 SEPT 2015

8a.x
Pacemaker
- Defibrillator/AICD
- Pacemaker, CRT/biventricular pacing
- Pacemaker, not CRT and not ICD

Question Added: 01 JAN 1993

8a.x.1
Pacemaker, Defibrillator/AICD
Date Placed
MM/DD/YYYY

Question Added: 01 JAN 1993 to 31 DEC 2004 | 01 JAN 2010

8a.x.2
Pacemaker, CRT/biventricular pacing, Date Placed
MM/DD/YYYY

Question Added: 01 JAN 2010

8a.x.3
Pacemaker, not CRT and not ICD, Date Placed
MM/DD/YYYY

Question Added: 01 JAN 1993

8a.xi
Medical History, Peripheral myopathy/neuromuscular disease
- Becker Muscular Dystrophy
- Duschenne Muscular Dystrophy
- Freidrich's Ataxia
- Unspecified
- Other, specify

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
Insurance

9 Primary Insurance

- 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)

<table>
<thead>
<tr>
<th>Section</th>
<th>Question</th>
<th>Missing Reason</th>
<th>Date (Cytotoxic PRA)</th>
<th>Cytotoxic PRA, DTE/DTT</th>
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</thead>
<tbody>
<tr>
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<td></td>
<td></td>
<td></td>
<td>Cytotoxic PRA</td>
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<tr>
<td>10a.i</td>
<td></td>
<td></td>
<td></td>
<td>T Cell</td>
</tr>
<tr>
<td>10a.ii</td>
<td></td>
<td></td>
<td></td>
<td>B Cell</td>
</tr>
<tr>
<td>10a.iii</td>
<td></td>
<td></td>
<td></td>
<td>Date (Cytotoxic PRA)</td>
</tr>
<tr>
<td>10b</td>
<td></td>
<td></td>
<td></td>
<td>Cytotoxic PRA, DTE/DTT</td>
</tr>
<tr>
<td>10b.i</td>
<td></td>
<td></td>
<td></td>
<td>T Cell</td>
</tr>
<tr>
<td>10b.ii</td>
<td></td>
<td></td>
<td></td>
<td>B Cell</td>
</tr>
<tr>
<td>10b.iii</td>
<td></td>
<td></td>
<td></td>
<td>Date (Cytotoxic PRA, DTE/DTT)</td>
</tr>
<tr>
<td>10c</td>
<td></td>
<td></td>
<td></td>
<td>Flow Cytometry or Luminex PRA</td>
</tr>
</tbody>
</table>

- **Question Added:** 01 JAN 1993
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.

<table>
<thead>
<tr>
<th>11</th>
<th>Were hemodynamics done prior to listing?</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
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<tbody>
<tr>
<td>11a</td>
<td>Date</td>
<td>MM/DD/YYYY</td>
<td>Missing Reason:</td>
<td>Not Done</td>
</tr>
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<td></td>
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<td></td>
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</tr>
</tbody>
</table>
### Schooling

**12 Is the patient in school?**

- Yes
- No
- Not Applicable, <6 years
- Unknown

**Question Added:** 01 JAN 1996
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$_2$% Predicted for Age
   - Refers to predicted maximum VO$_2$ 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$_2$
   - Maximum oxygen consumption
   - ml/kg/min
   (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.
<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Range Information</th>
<th>Missing Reason</th>
<th>Question Added</th>
</tr>
</thead>
<tbody>
<tr>
<td>14a Total Bilirubin</td>
<td>mg/dL</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 JAN 2005</td>
</tr>
<tr>
<td>14b Direct Bilirubin</td>
<td>mg/dL</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 JAN 2005</td>
</tr>
<tr>
<td>14c AST</td>
<td>U/L</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 JAN 2005</td>
</tr>
<tr>
<td>14d ALT</td>
<td>U/L</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 JAN 2005</td>
</tr>
<tr>
<td>14e BNP</td>
<td>pg/mL or ng/L</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 JAN 2010</td>
</tr>
<tr>
<td>14f Pro BNP</td>
<td>pg/mL or ng/L</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 SEPT 2015</td>
</tr>
<tr>
<td>14g CRP</td>
<td>mg/dL</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>01 JAN 2010</td>
</tr>
<tr>
<td>14h Creatinine</td>
<td>mg/dL</td>
<td>Too Low: &lt; 0</td>
<td>Not Done</td>
<td>93 to 31 DEC 2004</td>
</tr>
<tr>
<td>Test</td>
<td>Unit 1</td>
<td>Unit 2</td>
<td>Range Information</td>
<td>Missing Reason</td>
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<td>--------------</td>
<td>--------</td>
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<td>----------------</td>
</tr>
<tr>
<td>BUN</td>
<td>mg/dL</td>
<td>Urea mmol/L</td>
<td>Too Low: &lt; 0 Normal: Between 4 and 20</td>
<td>Not Done</td>
</tr>
<tr>
<td>Cystatin C</td>
<td>mg/L</td>
<td></td>
<td>Too Low: Between 0.5 and 1.4 Normal: 2.8 Question Zone: &gt; 10</td>
<td>Not Done</td>
</tr>
<tr>
<td>Total Protein</td>
<td>g/dL</td>
<td>g/L</td>
<td>Too Low: &lt; 0 Normal: Between 3.6 and 8.1</td>
<td>Not Done</td>
</tr>
<tr>
<td>Pre Albumin</td>
<td>mg/dL</td>
<td>g/L</td>
<td>Too Low: &lt; 0 Normal: Between 15 and 40 Question Zone: &gt; 60</td>
<td>Not Done</td>
</tr>
<tr>
<td>Serum Albumin</td>
<td>g/dL</td>
<td>g/L</td>
<td>Too Low: &lt; 0 Normal: Between 1.9 and 5.8 Question Zone: &gt; 12</td>
<td>Not Done</td>
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<tr>
<td>Cholesterol</td>
<td>mg/dL</td>
<td>mmol/L</td>
<td>Too Low: &lt; 50 Normal: Between 50 and 199 Question Zone: &gt; 300</td>
<td>Not Done</td>
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<tr>
<td>TG</td>
<td>mg/dL</td>
<td>mmol/L</td>
<td>Too Low: &lt; 40 Normal: Between 40 and 159</td>
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</tr>
</tbody>
</table>

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14p

NYHA and Ross' Heart Failure

15

NYHA Class
1. 1
2. 2
3. 3
4. 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. 1
2. 2
3. 3
4. 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.