### 3 Month / 6 Month Follow-up

**Followup Status**

- **Select one of the following**
  - [ ] Inpatient
  - [ ] Outpatient
  - [ ] Other Facility
  - [ ] Unable to obtain follow-up information

- **Follow-up date**
  - [ ]

- **Facility Type**
  - [ ] Nursing Home/Assisted Care
  - [ ] Hospice
  - [ ] Another hospital
  - [ ] Rehabilitation Facility
  - [ ] Unknown

- **State reason why you are unable to obtain follow-up information:**
  - [ ] Patient didn't come to clinic
  - [ ] Not able to contact patient
  - [ ] Not addressed by site

- **Was patient intubated?**
  - [ ] Yes
  - [ ] No
  - [ ] Unknown

- **Was patient on dialysis?**
  - [ ] Yes
  - [ ] No
  - [ ] Unknown

- **Current Device Strategy**
  - [ ] Bridge to Recovery
  - [ ] Rescue Therapy
  - [ ] Bridge to Transplant (patient currently listed for transplant)
  - [ ] Possible Bridge to Transplant - Likely to be eligible
  - [ ] Possible Bridge to Transplant - Moderate likelihood of becoming eligible
  - [ ] Possible Bridge to Transplant - Unlikely to become eligible
  - [ ] Destination Therapy
  - [ ] CHRONIC Destination Therapy

This should be determined in conjunction with the heart failure cardiologist and surgeon at the time of the implant. This determination will be re-visited and recorded at 3 months, 6 months, and every 6 months thereafter.

- **List Date for Transplant**
  - [ ]
  - [ ]
  - [ ]

- **Pump Change**

  - **Pump Exchange**
    - Was there a pump exchange of a para- or extra-corporeal pump?
      - [ ] Yes
      - [ ] No
      - [ ] Unknown

  - **If yes, please select one of the following:**
    - [ ] Intracorporeal device
    - [ ] Para- or Extra- corporeal device
    - [ ] Upsizing device because of patient growth status
    - [ ] All other reasons would categorize the pump change as a Device Malfunction
    - [ ] Thrombus NOT associated with hemolysis
Information that you provide in this section will be used to assess the existence of hemolysis and its degree.

**Change in hemodynamics**
- Change in hemodynamics
- Clinical status
- Device parameters

**Excursions**
- **Has the patient had any non-medically required excursions off the unit?**
  - Yes
  - No
  - Unknown

  **If yes, where (please select all that apply)**
  - Playroom
  - Cafeteria
  - Walk outside
  - Sitting room
  - General rehab
  - None

**ZONES**

**Hemolysis Zone**
Information that you provide in this section will be used to assess the existence of hemolysis and its degree.

**Please enter the peak Plasma-free hemoglobin (PFH) since the last**
Enter the Maximum and Minimum HCT or HGB since the last Follow-up visit:

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Minimum HCT</th>
<th>Maximum HCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>ST</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Categorization</td>
<td>Not Done</td>
<td>Not Done</td>
</tr>
</tbody>
</table>

What is your hospital’s upper limit of the normal range of peak PFH:

- ST = Unknown
- Categorization = Not Done

Please enter the peak serum lactate dehydrogenase (LDH) since the last follow-up visit:

- ST = Unknown
- Categorization = Not Done

What is your hospital’s upper limit of the normal range of LDH:

- ST = Unknown
- Categorization = Not Done

Enter the Maximum and Minimum HCT or HGB since the last Follow-up visit:

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Minimum HCT</th>
<th>Maximum HCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>ST</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Categorization</td>
<td>Not Done</td>
<td>Not Done</td>
</tr>
</tbody>
</table>

Highest Total Bilirubin since the last Follow-up period:

- ST = Unknown
- Categorization = Not Done

Has the following been present at any time since the last Follow-up period? Physical Findings (select all that apply):

1. **Hemoglobinuria (Tea-Colored Urine)?**
   - Yes
   - No
   - Unknown

2. **Pump malfunction and/or abnormal pump parameters?**
   - Yes
   - No
   - Unknown

Right Heart Failure Zone
Information that you provide in this section will be used to assess the existence of right heart failure and its degree.

**Clinical Findings – Since the last followup.**

1. **CVP or RAP > 16 mmHg?**
   - Yes
   - No
   - Unknown
Dilated Vena Cava with absence of Inspiratory Variation by Echo?
- Yes
- No
- Unknown

Clinical findings of elevated jugular venous distension at least half way up the neck in an upright patient?
- Yes
- No
- Unknown

Peripheral Edema?
- Yes
- No
- Unknown

Ascites?
- Yes
- No
- Unknown

Has the patient been on Inotropes since the last Follow-up or rehospitalization?
- Yes
- No
- Unknown

If yes, select all that apply:
- Dopamine
- Dobutamine
- Milrinone
- Isoproterenol
- Epinephrine
- Norepinephrine
- Levosimendan
- Unknown
- Vasopressin
- Nitroprusside
- Fenoldopam
- Prostacyclin

Nesiritide?
- Yes
- No
- Unknown

Has the patient had a RVAD implant since the last Follow-up or rehospitalization?
- Yes
- No
- Unknown

Has the patient experienced a Neurological Event since time of implant?
- Yes
- No
- Unknown

If yes, provide Modified Rankin Scale:
- 0 – No symptoms at all
- 1 - No Significant disability: despite symptoms: able to carry out all usual duties and activities
- 2 - Slight disability: unable to carry out all previous activities but able to look after own affairs without assistance
- 3 - Moderate disability: requiring some help, but able to walk without assistance.
- 4 - Moderately severe disability: unable to walk without assistance, and unable to attend to own bodily needs without assistance.
- 5 - Severe disability: bedridden, incontinent and requiring constant nursing care and attention.
- 6 - Dead

ST=
- Not Documented
- Not Done
### Hemodynamics

#### General Hemodynamics (during report interval)

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Systolic blood pressure</strong></td>
<td>mmHg</td>
</tr>
<tr>
<td><strong>Diastolic blood pressure</strong></td>
<td>mmHg</td>
</tr>
<tr>
<td><strong>Mean Arterial Blood Pressure (MAP)</strong></td>
<td>mmHg</td>
</tr>
<tr>
<td><strong>ECG rhythm</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Height</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Weight</strong></td>
<td></td>
</tr>
</tbody>
</table>

#### Invasive Hemodynamics (during report interval)

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pulmonary artery systolic pressure</strong></td>
<td>mmHg</td>
</tr>
<tr>
<td><strong>Pulmonary artery diastolic pressure</strong></td>
<td>mmHg</td>
</tr>
<tr>
<td><strong>Mean RA Pressure</strong></td>
<td>mmHg</td>
</tr>
<tr>
<td>Metric</td>
<td>Value</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>PVR</td>
<td></td>
</tr>
<tr>
<td>Mean Pulmonary artery wedge pressure (mmHg)</td>
<td></td>
</tr>
<tr>
<td>Central venous pressure (CVP) (mmHg)</td>
<td></td>
</tr>
<tr>
<td>Cardiac Index (L/min/M² (by Swan))</td>
<td></td>
</tr>
</tbody>
</table>
## Medications

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the patient sent home with an IV?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACE inhibitors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aldosterone antagonist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amiodarone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Angiotensin receptor blocker drug</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antiplatelet therapy drug</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Select drug(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-thrombolitic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beta-blockers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Digoxin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loop diuretics</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Select drug(s):**
  - Aspirin
  - Dextran
  - Dipyridamole
  - Clopidogrel
  - Ticlopidine
  - Unknown
  - Other, specify

- **If yes, enter dosage:**
  - mg/day

- **Type of Loop Diuretic:**
  - Furosemide

**Type of Loop Diuretic:**
- *Furosemide*
<table>
<thead>
<tr>
<th>Drug</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Torsemide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bumetanide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lovenox</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nitric oxide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sildenafil/Bosentan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UFH: Unfractionated Heparin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Warfarin (coumadin)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arixtra (fondaparinux)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did patient receive new IV or oral medication to treat hypertension?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transfusion**

<table>
<thead>
<tr>
<th>Was there a Tranfusion?</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, enter number of PRBC (Total number of cc's received)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ST= Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Laboratory

**Sodium**
- mEq/L
- mmol/L
- ST: Unknown
- Not done

**Potassium**
- mEq/L
- mmol/L
- ST: Unknown
- Not done

**Blood urea nitrogen**
- mg/dL
- mmol/L
- ST: Unknown
- Not done

**Creatinine**
- mg/dL
- umol/L
- ST: Unknown
- Not done

**SGPT/ALT (alanine aminotransferase/ALT)**
- u/L
- ST: Unknown
- Not done

**SGOT/AST (aspartate aminotransferase/AST)**
- u/L
- ST: Unknown
- Not done

**LDH**
- units/L, U/L, ukat/L
- ST: Unknown
- Not done

**Total bilirubin**
- mg/dL
- umol/L
- ST: Unknown
- Not done

**Bilirubin direct**
- mg/dL
- umol/L
- ST: Unknown
- Not done

**Bilirubin indirect**
- mg/dL
- umol/L
- ST: Unknown
- Not done
<table>
<thead>
<tr>
<th>Test</th>
<th>Value</th>
<th>Unit</th>
<th>Status</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albumin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-albumin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Cholesterol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain natriuretic peptide BNP</td>
<td></td>
<td>pg/ml</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NT pro brain natriuretic peptide Pro-BNP</td>
<td></td>
<td>pg/ml</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White blood cell count</td>
<td></td>
<td>x10³/uL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reticulocyte count</td>
<td></td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemoglobin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Platelets</td>
<td></td>
<td>x10³/uL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test</td>
<td>Value</td>
<td>Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-------</td>
<td>-----------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>INR</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plasma-free hemoglobin</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive antiheparin/platelet antibody (HIT)</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If Yes, are they on direct thrombin inhibitors</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If Yes, Enter Drugs:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aspirin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dipyridamole</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plavix</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heparin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coumadin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct thrombin inhibitors (ex: arg, lip, val...)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ThrombElastoGraph Hemostasis System (TEG) profile, MA k</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ThrombElastoGraph Hemostasis System (TEG) profile, R k</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ThrombElastoGraph Hemostasis System (TEG) profile, R h</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensitivity CRP</td>
<td></td>
<td>Unknown Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lupus Anticoagulant</td>
<td></td>
<td>Positive Negative Unknown</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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### Device Flow Chart

#### Device Function

- **Pump Flow**: LPM  
  ST= Unknown

- **Stroke Volume**: ml  
  ST= Unknown

#### Device Parameters

- **Control Mode**:  
  - Fixed
  - Auto
  - External
  - Not Applicable
  
- **Pump Rate**: BPM  
  ST= Unknown

- **Ejection Duration**: ms  
  ST= Unknown

#### Device Inspection

- **Auscultation**:  
  - Abnormal
  - Normal
  - Not Applicable

- **Driveline**:  
  - Abnormal
  - Normal
  - Not Applicable
## Exercise Function

All patients >= 10 years of age at time of implant should attempt to complete these functional capacity measurements especially for those patients classified as Intermacs patient profile level 4-7.

### 6 minute walk

- **ST=**
- Not done
- Not done: too sick
- Not done: other
- Not done: age inappropriate

This requires an inside hall for which distances (in FEET) should be measured, preferably as long as possible to avoid frequent turns. Patients are instructed to walk steadily to cover as much distance as possible during the 6 minutes. They are advised that they may stop if necessary during the 6 minutes. The staff member performing the test should walk behind the patient to avoid undue influence on the pace. The distance covered during the 6 minutes in feet will be recorded here. **NOTE:** You may use the time from the first 15 feet of the 6 minute walk for the Gait speed test listed below (please see instructions for the gait speed test below.)

### Gait Speed (1st 15 foot walk)

- **ST=**
- Not done
- Not done: too sick
- Not done: other
- Not done: age inappropriate

Instructions: Record the time (seconds) required for the patient to walk the first 15 feet of the 6 minute walk. The “starting” line and the 15 foot line should be clearly marked. Record the time to the first footfall at 0 feet and ends with the first footfall at 15 feet in the nearest. 0.1 sec with a stopwatch. **NOTE:** You may use the time from the first 15 feet of the 6 minute walk for the Gait speed test.

### Peak VO2 Max

- **ST=**
- Not done
- Not done: too sick
- Not done: other
- Not done: age inappropriate

Maximum volume of oxygen the body can consume during exercise (mL/kg/min) is the mL/kg/min of oxygen consumed during symptom-limited exercise testing either on a bicycle or treadmill. The values recorded during the bicycle are usually 1-2 mL/min lower than for the treadmill, but it is assumed that most institutions will use only one instrument. If both are available, the bicycle is preferable as the mode easiest to standardize.

### R Value at peak

- **ST=**
- Not done
- Not done: too sick
- Not done: other
- Not done: age inappropriate

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.

## Medical Condition

### NYHA Class

- Class I: No limitation of physical activity; physical activity does not cause fatigue, palpitation or shortness of breath.
- Class II: Slight limitation of physical activity; comfortable at rest, but ordinary physical activity results in fatigue, palpitations or shortness of breath.
- Class III: Marked limitation of physical activity; comfortable at rest, but less than ordinary activity causes fatigue, palpitation or shortness of breath.
- Class IV: Unable to carry on minimal physical activity without discomfort; symptoms may be present at rest.
- Unknown
<table>
<thead>
<tr>
<th>Ross Classification of Congestive Heart Failure (patient &lt; 2 yrs of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ross Class I: No limitations or symptoms.</td>
</tr>
<tr>
<td>• Ross Class II: No growth failure.</td>
</tr>
<tr>
<td>• Ross Class III: Growth failure.</td>
</tr>
<tr>
<td>• Ross Class IV: Symptomatic at rest.</td>
</tr>
<tr>
<td>• Not applicable: &gt;= 2 years of age</td>
</tr>
<tr>
<td>• Unknown</td>
</tr>
</tbody>
</table>

### Choose all indicated symptoms that apply.

- [ ] Mild tachypnea with feeds in infant
- [ ] Mild diaphoresis with feeds in infant
- [ ] Dyspnea on exercise in older children
- [ ] Unknown

### Choose all indicated symptoms that apply.

- [ ] Marked tachypnea with exertion or with feeding
- [ ] Marked diaphoresis with exertion or with feeding
- [ ] Unknown

### Choose all indicated symptoms that apply.

- [ ] Tachypnea
- [ ] Retractions
- [ ] Grunting
- [ ] Diaphoresis
- [ ] Unknown
### Concerns and Contraindications

Checking any of these contraindications/conditions/concerns does not necessarily mean that a condition is a contraindication or concern for the patient. No specific thresholds are provided for these conditions or contraindications. They should represent the results of formal discussion with the medical and surgical transplant team prior to the decision for device implantation. If there are no contraindications or concerns specified then select No.

<table>
<thead>
<tr>
<th>Concerns / Contraindications</th>
<th>Is condition present?</th>
<th>Limitation for transplant listing?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient does not want transplant</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Musculoskeletal limitation to ambulation</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Contraindication to immunosuppression</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Allosensitization</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Fraility</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Chronic Renal Disease</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Cardiothoracic issues</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequent ICD Shocks</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Pulmonary Disease</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Pulmonary Hypertension</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Recent Pulmonary Embolus</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>History Of Atrial Arrhythmia</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Unfavorable Mediastinal Anatomy (includes sternotomies, sternal resection, radiation, flail chest, etc)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Thoracic Aortic Disease</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Tracheostomy</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Plastic Bronchitis</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Nutritional/GI</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large BMI</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Severe Diabetes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Malnutrition Cachexia</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>History Of GI Ulcers</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>History Of Hepatitis</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Liver Dysfunction</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Anasarca</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Protein Losing enteropathy</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Genetic Syndrome</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td><strong>Vascular issues</strong></td>
<td></td>
<td></td>
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<tr>
<td>Heparin Induced Thrombocytopenia</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Chronic Coagulopathy</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Major Stroke</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Other Cerebrovascular Disease</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Peripheral Vascular Disease</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Oncology/infection issues</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>-----------------------------------------------</td>
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<tr>
<td>History Of Solid Organ Cancer</td>
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<tr>
<td>History Of Lymphoma Leukemia</td>
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<tr>
<td>History Of Bone Marrow Transplant BMT</td>
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<tr>
<td>History Of HIV</td>
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<tr>
<td>Chronic Infectious Concern</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychosocial issues (If patient is &lt; 10 years old at the time of implant, based on chart review of the patient, are the conditions present or absent?)</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Cognition/Understanding</td>
<td></td>
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<td>Limited Social Support</td>
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<tr>
<td>Repeated Noncompliance</td>
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<td>History Of Illicit Drug Use</td>
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<td>History Of Alcohol Abuse</td>
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<td>Narcotic Dependence</td>
<td></td>
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<td>History Of Smoking</td>
<td></td>
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<tr>
<td>Currently Smoking</td>
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<tr>
<td>Severe Depression</td>
<td></td>
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<tr>
<td>Other Major Psychiatric Diagnosis</td>
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<tr>
<td>Neurological // developmental abnormalities</td>
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| Other Comorbidity                                                                               |     |    |         |     |    |

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<tr>
<th>HIV History</th>
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<tr>
<td>If history of HIV is present, answer the HIV questions below.</td>
</tr>
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</table>

**HIV Diagnosis Date**

MMDDYYYY

ST= Unknown

ST= Not Done

**Plasma HIV-1 RNA (Viral load) - Closest to implant**

copies/ml

ST= Not Done

**CD4 T-Cell Count - Closest to implant**

cells/mm3

ST= Not Done

**Erythrocyte Sedimentation Rate (ESR)**

mm/hr

ST= Not Done

**C-Reactive Protein (CRP)**

mg/L

ST= Not Done

**Antiretroviral Therapy**

Select all that apply

- Abacavir (ABC) / Ziagen
- Atripla (FTC/EDV/TDF)
- Atazanavir (ATV) / Reyataz
- Combivir (3TC/ZDV)
- Complera (FTC/RPV/TDF)
- Darunavir (DRV) / Prezista
Delavirdine (DLV) / Rescriptor
Didanosine (ddI) / Videx EC
Dolutegravir / Tivicay
Efavirenz (EFV) / Sustiva
Emtricitabine (FTC) / Emtriva
Enfuvirtide (T20) / Fuzeon
Epzicom (3TC/ABC)
Etravirine (ETR) / Intelence
Fosamprenavir (FPV) / Lexiva
Indinavir (IDV) / Crixivan
Kaletra (LPV/r)
Lamivudine (3TC) / Epivir
Maraviroc (MVC) / Selzentry
Nelfinavir (NFV) / Viracept
Nevirapine (NVP) / Viramune / Viramune XR
Raltegravir (RAL) / Isentress
Rilpivirine (RPV) / Edurant
Ritonavir (RTV) / Norvir
Saquinavir (SQV) / Invirase
Stavudine (d4T) / Zerit
Stribild (FTC/EVG/COBI/TDF)
Tenofovir Disoproxil Fumarate (TDF) / Viread
Tipranavir (TPV) / Aptivus
Trizivir (3TC/ZDV/ABC)
Truvada (FTC/TDF)
Zidovudine (ZDV) / Retrovir

Infection Prophylaxis
Select all that apply
- Atovaquone
- Azithromycin
- Dapsone
- Fluconazole
- Pentamidine, aerosolized
- Trimethoprim-sulfamethoxazole (TMP-SMX)

History of Opportunistic Infection
Select all that apply
- Cryptococcosis
- Cytomegalovirus (CMV)
- Epstein Barr virus (EBV)
- Esophageal candidiasis
- Histoplasmosis
- Kaposi’s sarcoma
- Mycobacterium avium complex (MAC), disseminated
- Pneumocystis jiroveci (carinii) pneumonia (PCP)
- Toxoplasmosis
- Tuberculosis

History of Hepatitis B
- Positive
- Negative
ST= Unknown
- Not Done

History of Hepatitis C
- Positive
- Negative
ST= Unknown
- Not Done
### Quality Of Life

**PedsQL**

- **Did the child complete a form?**
  - Yes
  - No
  - Unknown

- **Please select the 'Child' form:**
  - PedsQL Young Child (5-7 yrs)
  - PedsQL Child (8-12 yrs)
  - PedsQL Teen (13-18 yrs)

**ABOUT MY HEALTH AND ACTIVITIES (problems with...)**

- **It is hard for me to walk more than one block:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **It is hard for me to run:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **It is hard for me to do sports activity or exercise:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **It is hard for me to lift something heavy:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **It is hard for me to take a bath or shower by myself:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **It is hard for me to do chores around the house:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented
I hurt or ache:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

Where?

I have low energy:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

I feel afraid or scared:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

I feel sad or blue:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

I feel angry:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

I have trouble sleeping:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

I worry about what will happen to me:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented

HOW I GET ALONG WITH OTHERS (problems with...)

I have trouble getting along with other kids:  
0 - Never  
1 - Almost never  
2 - Sometimes
<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other kids do not want to be my friend:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>Other kids tease me:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>I cannot do things other kids my age can do:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>It is hard to keep up when I play with other kids:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>ABOUT SCHOOL (problems with...)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>Is it hard to pay attention in class:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>I forget things:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>I have trouble keeping up with my schoolwork:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>I miss school because of not feeling well:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I miss school to go to the doctor or hospital:  
- 4 - Almost always  
- Unknown or Not Documented

If No, Please select a reason why the PedsQOL was not completed:  
- Too sick  
- Administrative

If Administrative: Select a specific reason:  
- Urgent implant, no time  
- Coordinator too busy or forgot  
- Unable to contact patient  
- Other reason (specify)

The VAD noise bothers me when I am awake:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never

The VAD noise bothers me when I am trying to sleep:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never

I have pain or discomfort at the driveline or tubing pump exit site:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never

I have difficulty sleeping due to the position of the driveline or tubing pump exit site:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never

I am bothered by how I look with the VAD:  
- Always  
- Very Often  
- Sometimes  
- Rarely
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry about the VAD breaking or malfunctioning:</td>
<td>○ Always&lt;br&gt;○ Very Often&lt;br&gt;○ Sometimes&lt;br&gt;○ Rarely&lt;br&gt;○ Never</td>
</tr>
<tr>
<td>I am bothered that I cannot visit family or friends outside the home or hospital with the VAD:</td>
<td>○ Always&lt;br&gt;○ Very Often&lt;br&gt;○ Sometimes&lt;br&gt;○ Rarely&lt;br&gt;○ Never</td>
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<tr>
<td>I am bothered that I cannot move easily from place to place with the VAD:</td>
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</tr>
<tr>
<td>I cannot participate in usual play activities with the VAD:</td>
<td>○ Always&lt;br&gt;○ Very Often&lt;br&gt;○ Sometimes&lt;br&gt;○ Rarely&lt;br&gt;○ Never</td>
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<tr>
<td>I find it difficult to express feelings and talk to others about the VAD:</td>
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</tr>
<tr>
<td>Overall, I would describe my day-to-day level of worry with the VAD to be:</td>
<td>○ High&lt;br&gt;○ Between High and Medium&lt;br&gt;○ Medium&lt;br&gt;○ Between Low and Medium&lt;br&gt;○ Low</td>
</tr>
<tr>
<td>Overall, I would describe my day-to-day level of happiness with the VAD to be:</td>
<td>○ High&lt;br&gt;○ Between High and Medium&lt;br&gt;○ Medium&lt;br&gt;○ Between Low and Medium&lt;br&gt;○ Low</td>
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<tr>
<td>If No, Please select a reason why the VADQoL form was not completed:</td>
<td>○ Too sick&lt;br&gt;○ Administrative</td>
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If Administrative: Select a specific reason:

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- Unable to contact patient
- Other reason (specify)
### Quality Of Life

**PedsQL**

**Did the child complete a form?**
- Yes
- No
- Unknown

**Please select the 'Child' form:**
- PedsQL Young Child (5-7 yrs)
- PedsQL Child (8-12 yrs)
- PedsQL Teen (13-18 yrs)

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3 - Often  
4 - Almost always  
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Where?  

I have low energy:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented  

ABOUT MY FEELINGS (problems with...)

I feel afraid or scared:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented  

I feel sad or blue:  
0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
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Unknown or Not Documented  

I feel angry:  
0 - Never  
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HOW I GET ALONG WITH OTHERS (problems with...)

I have trouble getting along with other teens:  
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1 - Almost never  
2 - Sometimes  

3 Month / 6 Month Follow-up  
10/26/2014  
25 of 57
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<thead>
<tr>
<th>Question</th>
<th>0 - Never</th>
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<td><strong>Other teens do not want to be my friend:</strong></td>
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<td><strong>It is hard to keep up with peers:</strong></td>
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*3 Month / 6 Month Follow-up*

*10/26/2014*
I miss school to go to the doctor or hospital:  
○ 0 - Never  
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If No, Please select a reason why the PedsQOL was not completed:  
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VADQoL  

Did the child complete a form?  
○ Yes  
○ No  
○ Unknown  

The VAD noise bothers me when I am awake:  
○ Always  
○ Very Often  
○ Sometimes  
○ Rarely  
○ Never  

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<th>Option 4</th>
<th>Option 5</th>
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<td>I worry about the VAD breaking or malfunctioning:</td>
<td>Rarely</td>
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## Quality Of Life

### PedsQL

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<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

| Please select the 'Child' form: | PedsQL Young Child (5-7 yrs) | PedsQL Child (8-12 yrs) | PedsQL Teen (13-18 yrs) |
|---------------------------------|---------------------------------|--------------------------|

### PHYSICAL FUNCTIONING (problems with...)

| It is hard for you to walk: | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|------------------------------|---------------|---------------|-----------|

| It is hard for you to run: | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|------------------------------|---------------|---------------|-----------|

| It is hard for you to play sports or exercise: | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|-----------------------------------------------|---------------|---------------|-----------|

| It is hard for you to pick up big things: | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|-------------------------------------------|---------------|---------------|-----------|

| It is hard for you to take a bath or shower: | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|-----------------------------------------------|---------------|---------------|-----------|

| It is hard for you to do chores (like pick up your toys): | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|----------------------------------------------------------|---------------|---------------|-----------|

| Do you have hurts or aches: | 0 - Not at all | 2 - Sometimes | 4 - A lot | Unknown or Not Documented |
|------------------------------|---------------|---------------|-----------|

**Where?**

<table>
<thead>
<tr>
<th>Do you ever feel too tired to play:</th>
<th>0 - Not at all</th>
<th>2 - Sometimes</th>
<th>4 - A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>Response Options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EMOTIONAL FUNCTIONING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel scared?</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel sad?</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel mad?</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have trouble sleeping?</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you worry about what will</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>happen to you?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SOCIAL FUNCTIONING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it hard for you to get along</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with other kids:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do other kids say they do not</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>want to play with you?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do other kids tease you?</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can other kids do things that</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>you cannot do:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for you to keep up</td>
<td>0 - Not at all, 2 - Sometimes, 4 - A lot, Unknown or Not Documented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>when you play with other kids:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SCHOOL FUNCTIONING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it hard for you to pay</td>
<td>0 - Not at all, 2 - Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>attention in class:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**VADQoL**

<table>
<thead>
<tr>
<th>Question</th>
<th>0 - Not at all</th>
<th>2 - Sometimes</th>
<th>4 - A lot</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you forget things:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it hard to keep up with schoolwork:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you miss school because of not feeling good:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you miss school because you have to go to the doctor’s or hospital:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If No, Please select a reason why the PedsQOL was not completed:</td>
<td>Too sick</td>
<td>Administrative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If Administrative: Select a specific reason:</td>
<td>Urgent implant, no time</td>
<td>Coordinator too busy or forgot</td>
<td>Unable to contact patient</td>
<td>Other reason (specify)</td>
</tr>
<tr>
<td>VADQoL</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did the child complete a form?</td>
<td>Yes</td>
<td>No</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>The VAD noise bothers me when I am awake:</td>
<td>Always</td>
<td>Very Often</td>
<td>Sometimes</td>
<td>Rarely</td>
</tr>
<tr>
<td>The VAD noise bothers me when I am trying to sleep:</td>
<td>Always</td>
<td>Very Often</td>
<td>Sometimes</td>
<td>Rarely</td>
</tr>
<tr>
<td>I have pain or discomfort at the driveline or tubing pump exit site:</td>
<td>Always</td>
<td>Very Often</td>
<td>Sometimes</td>
<td>Rarely</td>
</tr>
</tbody>
</table>
I have difficulty sleeping due to the position of the driveline or tubing pump exit site:

- Always
- Very Often
- Sometimes
- Rarely
- Never

I am bothered by how I look with the VAD:

- Always
- Very Often
- Sometimes
- Rarely
- Never

I worry about the VAD breaking or malfunctioning:

- Always
- Very Often
- Sometimes
- Rarely
- Never

I am bothered that I cannot visit family or friends outside the home or hospital with the VAD:

- Always
- Very Often
- Sometimes
- Rarely
- Never

I am bothered that I cannot move easily from place to place with the VAD:

- Always
- Very Often
- Sometimes
- Rarely
- Never

I cannot participate in usual play activities with the VAD:

- Always
- Very Often
- Sometimes
- Rarely
- Never

I find it difficult to express feelings and talk to others about the VAD:

- Always
- Very Often
- Sometimes
- Rarely
- Never

Overall, I would describe my day-to-day level of worry with the VAD to be:

- High
- Between High and Medium
- Medium
- Between Low and Medium
Overall, I would describe my day-to-day level of happiness with the VAD to be:

- High
- Between High and Medium
- Medium
- Between Low and Medium
- Low

If No, Please select a reason why the VADQoL form was not completed:

- Too sick
- Administrative

If Administrative: Select a specific reason:

- Urgent implant, no time
- Coordinator too busy or forgot
- Unable to contact patient
- Other reason (specify)
### Quality Of Life (Parent)

#### PedsQL

<table>
<thead>
<tr>
<th>Did the parent complete a form?</th>
<th>○ Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○ No</td>
</tr>
<tr>
<td></td>
<td>○ Unknown</td>
</tr>
</tbody>
</table>

| Please select the 'Parent' form: | ○ PedsQL Toddler (2-4 yrs) |
|  | ○ PedsQL Young Child (5-7 yrs) |
|  | ○ PedsQL Child (8-12 yrs) |
|  | ○ PedsQL Teen (13-18 yrs) |

#### PHYSICAL FUNCTIONING (problems with...)

| Walking more than one block: | ○0 - Never |
|  | ○1 - Almost never |
|  | ○2 - Sometimes |
|  | ○3 - Often |
|  | ○4 - Almost always |
|  | ○ Unknown or Not Documented |

| Running: | ○0 - Never |
|  | ○1 - Almost never |
|  | ○2 - Sometimes |
|  | ○3 - Often |
|  | ○4 - Almost always |
|  | ○ Unknown or Not Documented |

| Participating in sports activity or exercise: | ○0 - Never |
|  | ○1 - Almost never |
|  | ○2 - Sometimes |
|  | ○3 - Often |
|  | ○4 - Almost always |
|  | ○ Unknown or Not Documented |

| Lifting something heavy: | ○0 - Never |
|  | ○1 - Almost never |
|  | ○2 - Sometimes |
|  | ○3 - Often |
|  | ○4 - Almost always |
|  | ○ Unknown or Not Documented |

| Taking a bath or shower by him or herself: | ○0 - Never |
|  | ○1 - Almost never |
|  | ○2 - Sometimes |
|  | ○3 - Often |
|  | ○4 - Almost always |
|  | ○ Unknown or Not Documented |

| Doing chores, like picking up his or her toys:: | ○0 - Never |
|  | ○1 - Almost never |
|  | ○2 - Sometimes |
|  | ○3 - Often |
|  | ○4 - Almost always |
EMOTIONAL FUNCTIONING (problems with...)

Having hurts or aches:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

Low energy level:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

EMOTIONAL FUNCTIONING (problems with...)

Feeling afraid or scared:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

Feeling sad or blue:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

Feeling angry:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

Trouble sleeping:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

Worrying about what will happen to him or her:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

SOCIAL FUNCTIONING (problems with...)

Getting along with other children:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
<table>
<thead>
<tr>
<th><strong>SCHOOL FUNCTIONING (problems with...)</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Other kids not wanting to be his or her friend:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
</tr>
<tr>
<td>2 - Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Getting teased by other children:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
</tr>
<tr>
<td>2 - Sometimes</td>
<td></td>
</tr>
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<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Not able to do things that other children his or her age can do:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
</tr>
<tr>
<td>2 - Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Keeping up when playing with other children:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
</tr>
<tr>
<td>2 - Sometimes</td>
<td></td>
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<tr>
<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Paying attention in class:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
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<tr>
<td>2 - Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Forgetting things:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
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<td>2 - Sometimes</td>
<td></td>
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<tr>
<td>3 - Often</td>
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</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Keeping up with school activities:</strong></td>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
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<tr>
<td>2 - Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
<td></td>
</tr>
<tr>
<td><strong>Missing school because of not feeling well:</strong></td>
<td></td>
</tr>
<tr>
<td>0 - Never</td>
<td></td>
</tr>
<tr>
<td>1 - Almost never</td>
<td></td>
</tr>
<tr>
<td>2 - Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 - Often</td>
<td></td>
</tr>
<tr>
<td>4 - Almost always</td>
<td></td>
</tr>
</tbody>
</table>
Missing school to go to the doctor or hospital:  
- 0 - Never  
- 1 - Almost never  
- 2 - Sometimes  
- 3 - Often  
- 4 - Almost always  
○ Unknown or Not Documented  

If No, Please select a reason why the PedsQOL was not completed:  
○ Too sick  
○ Administrative  

If Administrative: Select a specific reason:  
- Urgent implant, no time  
- Coordinator too busy or forgot  
- Unable to contact patient  
- Other reason (specify)  

VADQoL  
Did the parent complete a form?  
- Yes  
- No  
- Unknown  

Please select the ‘Parent’ form:  
○ VADQoL: Parent (child < 2 yrs)  
○ VADQoL: Parent (child >= 2 yrs)  

The VAD noise bothers my child when he or she is awake:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never  

The VAD noise bothers my child when he or she is trying to sleep:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never  

My child has pain or discomfort at the driveline or tubing pump exit site:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never  

My child has difficulty sleeping due to the position of the driveline or tubing pump exit site:  
- Always  
- Very Often  
- Sometimes  
- Rarely  
- Never  

My child is bothered by how he or she looks with the VAD:  
- Always  
- 3 Month / 6 Month Follow-up
she looks with the VAD: 
- Very Often
- Sometimes
- Rarely
- Never

My child worries about the VAD breaking or malfunctioning: 
- Always
- Very Often
- Sometimes
- Rarely
- Never

My child is bothered that he or she cannot visit family or friends outside the home or hospital with the VAD: 
- Always
- Very Often
- Sometimes
- Rarely
- Never

My child is bothered that he or she cannot move easily from place to place with the VAD: 
- Always
- Very Often
- Sometimes
- Rarely
- Never

My child cannot participate in usual play activities with the VAD: 
- Always
- Very Often
- Sometimes
- Rarely
- Never

My child finds it difficult to express feelings and talk to others about the VAD: 
- Always
- Very Often
- Sometimes
- Rarely
- Never

Overall, I would describe my child's day-to-day level of worry with the VAD to be: 
- High
- Between High and Medium
- Medium
- Between Low and Medium
- Low

Overall, I would describe my child's day-to-day level of happiness with the VAD to be: 
- High
- Between High and Medium
- Medium
- Between Low and Medium
- Low
<table>
<thead>
<tr>
<th>If No, Please select a reason why the VADQoL form was not completed:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Too sick</td>
</tr>
<tr>
<td>☐ Administrative</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If Administrative: Select a specific reason:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Urgent implant, no time</td>
</tr>
<tr>
<td>☐ Coordinator too busy or forgot</td>
</tr>
<tr>
<td>☐ Unable to contact patient</td>
</tr>
<tr>
<td>☐ Other reason (specify)</td>
</tr>
</tbody>
</table>

3 Month / 6 Month Follow-up

10/26/2014

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### Quality Of Life (Parent)

#### PedsQL

**Did the parent complete a form?**
- Yes
- No
- Unknown

**Please select the 'Parent' form:**
- PedsQL Toddler (2-4 yrs)
- PedsQL Young Child (5-7 yrs)
- PedsQL Child (8-12 yrs)
- PedsQL Teen (13-18 yrs)

#### PHYSICAL FUNCTIONING (problems with...)

**Walking more than one block:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Running:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Participating in sports activity or exercise:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Lifting something heavy:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Taking a bath or shower by him or herself:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Doing chores around the house:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
### EMOTIONAL FUNCTIONING (problems with...)

- **Having hurts or aches:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **Low energy level:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

### EMOTIONAL FUNCTIONING (problems with...)

- **Feeling afraid or scared:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **Feeling sad or blue:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **Feeling angry:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **Trouble sleeping:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

- **Worrying about what will happen to him or her:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
  - Unknown or Not Documented

### SOCIAL FUNCTIONING (problems with...)

- **Getting along with other teens:**
  - 0 - Never
  - 1 - Almost never
  - 2 - Sometimes
  - 3 - Often
  - 4 - Almost always
<table>
<thead>
<tr>
<th>Problem</th>
<th>Code Options</th>
<th>Notes</th>
</tr>
</thead>
</table>
| Other teens not wanting to be his or her friend | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Getting teased by other teens                | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Not able to do things that other teens his or her age can do | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Keeping up when playing with other teens     | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Paying attention in class                   | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Forgetting things                           | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Keeping up with schoolwork                  | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
| Missing school because of not feeling well   | 0 - Never  
1 - Almost never  
2 - Sometimes  
3 - Often  
4 - Almost always  
Unknown or Not Documented |                                          |
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missing school to go to the doctor or hospital</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Unknown or Not Documented</td>
</tr>
<tr>
<td>If No, Please select a reason why the PedsQOL was not completed</td>
<td>Too sick, Administrative</td>
</tr>
<tr>
<td>If Administrative: Select a specific reason:</td>
<td>Urgent implant, no time, Coordinator too busy or forgot, Unable to contact patient, Other reason (specify)</td>
</tr>
<tr>
<td>The VAD noise bothers my child when he or she is awake</td>
<td>Always, Very Often, Sometimes, Rarely, Never</td>
</tr>
<tr>
<td>The VAD noise bothers my child when he or she is trying to sleep</td>
<td>Always, Very Often, Sometimes, Rarely, Never</td>
</tr>
<tr>
<td>My child has pain or discomfort at the driveline or tubing pump exit site</td>
<td>Always, Very Often, Sometimes, Rarely, Never</td>
</tr>
<tr>
<td>My child has difficulty sleeping due to the position of the driveline or tubing pump exit site</td>
<td>Always, Very Often, Sometimes, Rarely, Never</td>
</tr>
<tr>
<td>My child is bothered by how he or she looks with the VAD</td>
<td>Always</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>She looks with the VAD:</td>
<td>Very Often, Sometimes, Rarely, Never</td>
</tr>
<tr>
<td>My child worries about the VAD breaking or malfunctioning:</td>
<td>Always, Very Often, Sometimes, Rarely, Never</td>
</tr>
<tr>
<td>My child is bothered that he or she cannot visit family or friends outside the home or hospital with the VAD:</td>
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<td>My child finds it difficult to express feelings and talk to others about the VAD:</td>
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</tr>
<tr>
<td>Overall, I would describe my child’s day-to-day level of worry with the VAD to be:</td>
<td>High, Between High and Medium, Medium, Between Low and Medium, Low</td>
</tr>
<tr>
<td>Overall, I would describe my child’s day-to-day level of happiness with the VAD to be:</td>
<td>High, Between High and Medium, Medium, Between Low and Medium, Low</td>
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</tbody>
</table>
| If No, Please select a reason why the VADQoL form was not completed: | ☐ Too sick  
☐ Administrative |
| --- | --- |
| If Administrative: Select a specific reason: | ☐ Urgent implant, no time  
☐ Coordinator too busy or forgot  
☐ Unable to contact patient  
☐ Other reason (specify) |
### Quality Of Life (Parent)

#### PedsQL

<table>
<thead>
<tr>
<th>Did the parent complete a form?</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Please select the 'Parent' form:</th>
<th>PedsQL Toddler (2-4 yrs)</th>
<th>PedsQL Young Child (5-7 yrs)</th>
<th>PedsQL Child (8-12 yrs)</th>
<th>PedsQL Teen (13-18 yrs)</th>
</tr>
</thead>
</table>

#### PHYSICAL FUNCTIONING (problems with...)

<table>
<thead>
<tr>
<th>Walking:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Running:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Participating in active play or exercise:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Lifting something heavy:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Bathing:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Helping to pick up his or her toys:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
</tr>
</thead>
</table>

---

**3 Month / 6 Month Follow-up**

Please answer all questions considering all time since the previous visit and current follow-up date (Data closest to or on visit date preferred.)
<table>
<thead>
<tr>
<th><strong>EMOTIONAL FUNCTIONING (problems with...)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Having hurts or aches:</strong></td>
</tr>
<tr>
<td>0 - Never</td>
</tr>
<tr>
<td>1 - Almost never</td>
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<td>3 - Often</td>
</tr>
<tr>
<td>4 - Almost always</td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td><strong>Low energy level:</strong></td>
</tr>
<tr>
<td>0 - Never</td>
</tr>
<tr>
<td>1 - Almost never</td>
</tr>
<tr>
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<tr>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td><strong>Feeling afraid or scared:</strong></td>
</tr>
<tr>
<td>0 - Never</td>
</tr>
<tr>
<td>1 - Almost never</td>
</tr>
<tr>
<td>2 - Sometimes</td>
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<tr>
<td><strong>Feeling angry:</strong></td>
</tr>
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<tr>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td><strong>Trouble sleeping:</strong></td>
</tr>
<tr>
<td>0 - Never</td>
</tr>
<tr>
<td>1 - Almost never</td>
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<tr>
<td><strong>Worrying:</strong></td>
</tr>
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<tr>
<td><strong>SOCIAL FUNCTIONING (problems with...)</strong></td>
</tr>
<tr>
<td><strong>Playing with other children:</strong></td>
</tr>
<tr>
<td>0 - Never</td>
</tr>
<tr>
<td>1 - Almost never</td>
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<td><strong>SCHOOL FUNCTIONING (problems with...)</strong></td>
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<td><strong>Other kids not wanting to play with him or her:</strong></td>
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<td>☀️ 0 - Never</td>
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<tr>
<td><strong>Getting teased by other children:</strong></td>
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<td><strong>Not able to do things that other children his or her age can do:</strong></td>
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<td>☀️ 4 - Almost always</td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td><strong>Doing the same school activities as peers:</strong></td>
</tr>
<tr>
<td>☀️ 0 - Never</td>
</tr>
<tr>
<td>☀️ 1 - Almost never</td>
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<tr>
<td>☀️ 4 - Almost always</td>
</tr>
<tr>
<td>Unknown or Not Documented</td>
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<tr>
<td><strong>Missing school/daycare because of not feeling well:</strong></td>
</tr>
<tr>
<td>☀️ 0 - Never</td>
</tr>
<tr>
<td>☀️ 1 - Almost never</td>
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<td>☀️ 2 - Sometimes</td>
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<td>☀️ 4 - Almost always</td>
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<tr>
<td>Unknown or Not Documented</td>
</tr>
<tr>
<td><strong>If No, Please select a reason why the PedsQOL was not completed:</strong></td>
</tr>
<tr>
<td>☐ Too sick</td>
</tr>
<tr>
<td>☐ Administrative</td>
</tr>
<tr>
<td><strong>If Administrative: Select a specific reason:</strong></td>
</tr>
<tr>
<td>☐ Urgent implant, no time</td>
</tr>
<tr>
<td>☐ Coordinator too busy or forgot</td>
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</tbody>
</table>
3 Month / 6 Month Follow-up

**VADQoL**

<table>
<thead>
<tr>
<th><strong>Did the parent complete a form?</strong></th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>☐ Unknown</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>Please select the 'Parent' form:</strong></th>
<th>☐ VADQoL: Parent (child &lt; 2 yrs)</th>
<th>☐ VADQoL: Parent (child &gt;= 2 yrs)</th>
</tr>
</thead>
</table>

**The VAD noise bothers my child when he or she is awake:**

<table>
<thead>
<tr>
<th>☐ Always</th>
<th>☐ Very Often</th>
<th>☐ Sometimes</th>
<th>☐ Rarely</th>
<th>☐ Never</th>
</tr>
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</table>

**The VAD noise bothers my child when he or she is trying to sleep:**

<table>
<thead>
<tr>
<th>☐ Always</th>
<th>☐ Very Often</th>
<th>☐ Sometimes</th>
<th>☐ Rarely</th>
<th>☐ Never</th>
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</table>

**My child has pain or discomfort at the driveline or tubing pump exit site:**

<table>
<thead>
<tr>
<th>☐ Always</th>
<th>☐ Very Often</th>
<th>☐ Sometimes</th>
<th>☐ Rarely</th>
<th>☐ Never</th>
</tr>
</thead>
</table>

**My child has difficulty sleeping due to the position of the driveline or tubing pump exit site:**

<table>
<thead>
<tr>
<th>☐ Always</th>
<th>☐ Very Often</th>
<th>☐ Sometimes</th>
<th>☐ Rarely</th>
<th>☐ Never</th>
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</thead>
</table>

**My child is bothered by how he or she looks with the VAD:**

<table>
<thead>
<tr>
<th>☐ Always</th>
<th>☐ Very Often</th>
<th>☐ Sometimes</th>
<th>☐ Rarely</th>
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**My child worries about the VAD breaking or malfunctioning:**

<table>
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<tr>
<th>☐ Always</th>
<th>☐ Very Often</th>
<th>☐ Sometimes</th>
<th>☐ Rarely</th>
<th>☐ Never</th>
</tr>
</thead>
</table>

**My child is bothered that he or she cannot visit family or friends outside:**

| Always | 3 Month / 6 Month Follow-up | 10/26/2014 | 50 of 57 |
cannot visit family or friends outside the home or hospital with the VAD:
○ Very Often
○ Sometimes
○ Rarely
○ Never

My child is bothered that he or she cannot move easily from place to place with the VAD:
○ Always
○ Very Often
○ Sometimes
○ Rarely
○ Never

My child cannot participate in usual play activities with the VAD:
○ Always
○ Very Often
○ Sometimes
○ Rarely
○ Never

My child finds it difficult to express feelings and talk to others about the VAD:
○ Always
○ Very Often
○ Sometimes
○ Rarely
○ Never

Overall, I would describe my child's day-to-day level of worry with the VAD to be:
○ High
○ Between High and Medium
○ Medium
○ Between Low and Medium
○ Low

Overall, I would describe my child's day-to-day level of happiness with the VAD to be:
○ High
○ Between High and Medium
○ Medium
○ Between Low and Medium
○ Low

If No, Please select a reason why the VADQoL form was not completed:
○ Too sick
○ Administrative

If Administrative: Select a specific reason:
○ Urgent implant, no time
○ Coordinator too busy or forgot
○ Unable to contact patient
○ Other reason (specify)
### Quality Of Life (Parent)

**PedsQL**

**Did the parent complete a form?**
- ☐ Yes
- ☐ No
- ☐ Unknown

**Please select the 'Parent' form:**
- ☐ PedsQL Toddler (2-4 yrs)
- ☐ PedsQL Young Child (5-7 yrs)
- ☐ PedsQL Child (8-12 yrs)
- ☐ PedsQL Teen (13-18 yrs)

**PHYSICAL FUNCTIONING (problems with...)**

**Walking more than one block:**
- ☐ 0 - Never
- ☐ 1 - Almost never
- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
- ☐ Unknown or Not Documented

**Running:**
- ☐ 0 - Never
- ☐ 1 - Almost never
- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
- ☐ Unknown or Not Documented

**Participating in sports activity or exercise:**
- ☐ 0 - Never
- ☐ 1 - Almost never
- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
- ☐ Unknown or Not Documented

**Lifting something heavy:**
- ☐ 0 - Never
- ☐ 1 - Almost never
- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
- ☐ Unknown or Not Documented

**Taking a bath or shower by him or herself:**
- ☐ 0 - Never
- ☐ 1 - Almost never
- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
- ☐ Unknown or Not Documented

**Doing chores, like picking up his or her toys:**
- ☐ 0 - Never
- ☐ 1 - Almost never
- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
### EMOTIONAL FUNCTIONING (problems with...)

<table>
<thead>
<tr>
<th>Having hurts or aches:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
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<th>4 - Almost always</th>
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<tbody>
<tr>
<td>Low energy level:</td>
<td>0 - Never</td>
<td>1 - Almost never</td>
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</tbody>
</table>

### FEELING AFRAID OR SCARED:

<table>
<thead>
<tr>
<th>Feeling afraid or scared:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
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</table>

### FEELING SAD OR BLUE:

<table>
<thead>
<tr>
<th>Feeling sad or blue:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
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</tr>
</thead>
</table>

### FEELING ANGRY:

<table>
<thead>
<tr>
<th>Feeling angry:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
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</thead>
</table>

### TROUBLE SLEEPING:

<table>
<thead>
<tr>
<th>Trouble sleeping:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

### WORRYING ABOUT WHAT WILL HAPPEN TO HIM OR HER:

<table>
<thead>
<tr>
<th>Worrying about what will happen to him or her:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
<th>Unknown or Not Documented</th>
</tr>
</thead>
</table>

### SOCIAL FUNCTIONING (problems with...)

<table>
<thead>
<tr>
<th>Getting along with other children:</th>
<th>0 - Never</th>
<th>1 - Almost never</th>
<th>2 - Sometimes</th>
<th>3 - Often</th>
<th>4 - Almost always</th>
</tr>
</thead>
</table>
### SCHOOL FUNCTIONING (problems with...)

**Other kids not wanting to be his or her friend:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Getting teased by other children:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Not able to do things that other children his or her age can do:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Keeping up when playing with other children:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**SCHOOL FUNCTIONING (problems with...)**

**Paying attention in class:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Forgetting things:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Keeping up with school activities:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

**Missing school because of not feeling well:**
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
### VADQoL

#### Missing school to go to the doctor or hospital:
- 0 - Never
- 1 - Almost never
- 2 - Sometimes
- 3 - Often
- 4 - Almost always
- Unknown or Not Documented

#### If No, Please select a reason why the PedsQOL was not completed:
- Too sick
- Administrative

**If Administrative:** Select a specific reason:
- Urgent implant, no time
- Coordinator too busy or forgot
- Unable to contact patient
- Other reason (specify)

#### VADQoL

**Did the parent complete a form?**
- Yes
- No
- Unknown

**Please select the 'Parent' form:**
- VADQoL: Parent (child < 2 yrs)
- VADQoL: Parent (child >= 2 yrs)

**The VAD noise bothers my child when he or she is awake:**
- Always
- Very Often
- Sometimes
- Rarely
- Never

**The VAD noise bothers my child when he or she is trying to sleep:**
- Always
- Very Often
- Sometimes
- Rarely
- Never

**My child has pain or discomfort at the driveline or tubing pump exit site:**
- Always
- Very Often
- Sometimes
- Rarely
- Never

**My child has difficulty sleeping due to the position of the driveline or tubing pump exit site:**
- Always
- Very Often
- Sometimes
- Rarely
- Never

**My child is bothered by how he or she looks with the VAD:**
- Always
<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>she looks with the VAD:</td>
<td></td>
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<tr>
<td>My child worries about the VAD breaking or malfunctioning:</td>
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<tr>
<td>My child is bothered that he or she cannot visit family or friends outside the home or hospital with the VAD:</td>
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<tr>
<td>My child is bothered that he or she cannot move easily from place to place with the VAD:</td>
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<tr>
<td>My child cannot participate in usual play activities with the VAD:</td>
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<td>My child finds it difficult to express feelings and talk to others about the VAD:</td>
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<tr>
<td>Overall, I would describe my child's day-to-day level of worry with the VAD to be:</td>
<td></td>
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<tr>
<td>Overall, I would describe my child's day-to-day level of happiness with the VAD to be:</td>
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<tr>
<td>If No, Please select a reason why the VADQoL form was not completed:</td>
<td></td>
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<tr>
<td>---------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Too sick</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Administrative</td>
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</table>

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<th>If Administrative: Select a specific reason:</th>
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<td>☐ Urgent implant, no time</td>
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<td>☐ Coordinator too busy or forgot</td>
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<tr>
<td>☐ Unable to contact patient</td>
</tr>
<tr>
<td>☐ Other reason (specify)</td>
</tr>
</tbody>
</table>

3 Month / 6 Month Follow-up

10/26/2014

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