

3 Month Followup - Pedimacs 12/02/2022

Blank View

Followup Status (3 Month Followup (+/- 1 month))

- Select one of the following
- ☐ Inpatient

☐ Outpatient

☐ Other Facility

☐ Unable to obtain follow-up information

☐ Telehealth Consultation

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

Patient's Home Street Address

ST= ☐ Unknown

Patient's Home City

ST= ☐ Unknown

- Patient's Home State/Territory/Province
- ☐ Alabama

☐ Alaska

☐ American Samoa

☐ Arizona

☐ Arkansas

☐ California

☐ Colorado

☐ Connecticut

☐ Delaware

☐ District of Columbia

☐ Federated States of Micronesia

☐ Florida

☐ Georgia

☐ Guam

☐ Hawaii

☐ Idaho

☐ Illinois

☐ Indiana

☐ Iowa

☐ Kansas

☐ Kentucky

☐ Louisiana

☐ Maine

☐ Marshall Islands

☐ Maryland

☐ Massachusetts

☐ Michigan

☐ Minnesota

☐ Mississippi

☐ Missouri

☐ Montana

☐ Nebraska

☐ Nevada

☐ New Hampshire

☐ New Jersey

☐ New Mexico

☐ New York

☐ North Carolina

☐ North Dakota

☐ Northern Mariana Islands

☐ Ohio

☐ Oklahoma

☐ Oregon

☐ Palau

☐ Pennsylvania

☐ Puerto Rico

☐ Rhode Island

☐ South Carolina

☐ South Dakota

☐ Tennessee

☐ Texas

☐ Utah

☐ Vermont

☐ Virgin Islands

☐ Virginia

☐ Washington

☐ West Virginia

☐ Wisconsin

☐ Wyoming

☐ Alberta

☐ Ontario

☐ Nova Scotia

☐ British Columbia

☐ Manitoba

☐ Quebec

☐ New Brunswick

☐ Prince Edward Island

☐ Saskatchewan

☐ Newfoundland and Labrador

☐ Unknown

Patient's Home Zip Code

ST= ☐ Unknown

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

List Date for Transplant

ST= ☐ Unknown

Since the last follow-up has the patient tested positive for COVID-19?

- ☐ Yes
- ☐ No
- ☐ Unknown

If yes, select all symptoms that apply:

- ☐ Cough
- ☐ Diarrhea
- ☐ Fever
- ☐ Anosmia (loss of sense of smell)
- ☐ Sore Throat
- ☐ Difficulty Breathing
- ☐ None
- ☐ Other, Specify

If yes, select all interventions that apply:

- ☐ Intubation
- ☐ New Inotropes
- ☐ ECMO
- ☐ Dialysis
- ☐ RVAD
- ☐ None
- ☐ Other, Specify

If yes, select all therapies the patient received (select all that apply):

- ☐ Hydroxychloroquine
- ☐ Azithromycin
- ☐ Immunoglobulin
- ☐ Anti-viral therapy
- ☐ None
- ☐ Other, Specify

Anti-viral therapy, specify:

Console Change

Was there a Console Change?

- ☐ Yes
- ☐ No
- ☐ Unknown

Date of console change

ST= ☐ Unknown

Original Console Name

New Console Name

Functional Capacity

Sedated

- ☐ Yes
- ☐ No
- ☐ Unknown

Paralyzed

- ☐ Yes
- ☐ No
- ☐ Unknown

Intubated

- ☐ Yes
- ☐ No
- ☐ Unknown

Ambulating

- ☐ Yes
- ☐ No
- ☐ Unknown

Primary Nutrition

- ☐ Orally
- ☐ Per feeding tube
- ☐ TPN
- ☐ Not Applicable

Excursions

Has the patient had any non-medically required excursions off the unit?

- ☐ Yes
- ☐ No
- ☐ Unknown
- ☐ Not Applicable

If yes, where (please select all that apply)

- ☐ Playroom
- ☐ Cafeteria
- ☐ Walk outside
- ☐ Sitting room
- ☐ General rehab
- ☐ None

ZONES

Hemolysis Zone

Please enter the peak Plasma-free hemoglobin (PFH) since the last follow-up visit:

ST= ☐ Unknown
☐ Not Done

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

ST= ☐ Unknown
☐ Not Done

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

ST= ☐ Unknown
☐ Not Done

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

ST= ☐ Unknown
☐ Not Done

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

Min. HCT:

ST= ☐ Unknown
☐ Not Done

Max. HCT:

ST= ☐ Unknown
☐ Not Done

Min. HGB:

ST= ☐ Unknown
☐ Not Done

Max. HGB:

ST= ☐ Unknown
☐ Not Done

Highest Total Bilirubin since the last Follow-up period:

ST= ☐ Unknown
☐ Not Done

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

Hemoglobinuria (Tea-Colored Urine)?

- ☐ Yes
☐ No
☐ Unknown

Pump malfunction and/or abnormal pump parameters?

- ☐ Yes
☐ No
☐ Unknown

Right Heart Failure Zone

Clinical Findings – Since the last followup.**CVP or RAP > 16 mmHg?**

- ☐ Yes
☐ No
☐ Unknown
☐ Not Done

Dilated Vena Cava with absence of Inspiratory Variation by Echo?

- ☐ Yes
☐ No
☐ Unknown
☐ Not Done

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?

- ☐ 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, please enter the Modified Rankin Scale.

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

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Hemodynamics

For all sections, data may be entered that was collected/performed from the last time the patient was seen for follow-up to the current visit date.

General Hemodynamics

Systolic blood pressure

mmHg

ST= ☐ Unknown

☐ Not done

Diastolic blood pressure

mmHg

ST= ☐ Unknown

☐ Not done

Mean Arterial Blood Pressure (MAP)

mmHg

ST= ☐ Unknown

☐ Not done

ECG rhythm

☐ Sinus

☐ Atrial fibrillation

☐ Atrial Flutter

☐ Paced: Atrial pacing

☐ Paced: Ventricular pacing

☐ Paced: Atrial and ventricular pacing

☐ Unknown

☐ Not done

☐ Other, specify

Height

in

cm

ST= ☐ Unknown

☐ Not done

Weight

lbs

kg

ST= ☐ Unknown

☐ Not done

Invasive Hemodynamics

Pulmonary artery
systolic pressure

mmHg

ST= ☐ Unknown

☐ Not Done

**Pulmonary artery
diastolic pressure**

mmHg

ST= ☐ Unknown

☐ Not Done

Mean RA Pressure

mmHg

ST= ☐ Unknown

☐ Not Done

PVR

wood units

ST= ☐ Unknown

☐ Not Done

**Mean Pulmonary artery wedge
pressure**

mmHg

ST= ☐ Unknown

☐ Not Done

Central venous pressure (CVP)

mmHg

ST= ☐ Unknown

☐ Not Done

Cardiac Index

L/min/M² (by Swan)

ST= ☐ Unknown

☐ Not Done

**Was Cardiac Index Measured by
Fick or Thermodilution?**

☐ Yes

☐ No

☐ Unknown

Choose Method

☐ Fick

☐ Thermodilution

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Medications

Was the patient sent home with an IV?

☐ Yes

☐ No

☐ Unknown

ACE inhibitors

☐ Yes

☐ No

☐ Unknown

Aldosterone antagonist

☐ Yes

☐ No

☐ Unknown

Amiodarone

☐ Yes

☐ No

☐ Unknown

Angiotensin receptor blocker drug

☐ Yes

☐ No

☐ Unknown

Beta-blockers

☐ Yes

☐ No

☐ Unknown

Digoxin

☐ Yes

☐ No

☐ Unknown

Loop diuretics

☐ Yes

☐ No

☐ Unknown

If yes, enter dosage:

mg/day

ST= ☐ Unknown

Type of Loop Diuretic:

☐ Furosemide

☐ Torsemide

☐ Bumetanide

☐ Other

Nitric oxide

☐ Yes

☐ No

☐ Unknown

Sildenafil/ Bosentan

☐ Yes

☐ No

☐ Unknown

Arixtra (fondaparinux)

- ☐ Yes
- ☐ No
- ☐ Unknown

Did patient receive new IV or oral medication to treat hypertension?

- ☐ Yes
- ☐ No
- ☐ Unknown

Transfusion

Was there a Tranfusion?

- ☐ Yes
- ☐ No
- ☐ Unknown

If yes, enter number of PRBC (Total number of cc's received)

ST= ☐ Unknown

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Antithrombotic

Unfractionated heparin used?

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Lower target**

seconds

ST= ☐ Unknown**Upper target**

seconds

ST= ☐ Unknown**Date goal first achieved**ST= ☐ Unknown**Low molecular weight heparin used? (Lovenox, Fragmin, Innohep)**

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Lower target**

IU/ml

ST= ☐ Unknown**Upper target**

IU/ml

ST= ☐ Unknown**Date goal first achieved**ST= ☐ Unknown**Warfarin used? (coumadin)**

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Lower target**ST= ☐ Unknown**Upper target**ST= ☐ Unknown**Date goal first achieved**ST= ☐ Unknown

Argatroban used?

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Lower target**

seconds

ST= ☐ Unknown**Upper target**

seconds

ST= ☐ Unknown**Date goal first achieved**ST= ☐ Unknown**Bivalirudin used?**

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Lower target**

seconds

ST= ☐ Unknown**Upper target**

seconds

ST= ☐ Unknown**Date goal first achieved**ST= ☐ Unknown**Aspirin used?**

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Dipyridamole used?**

- ☐ Yes
☐ No
☐ Unknown

Date startedST= ☐ Unknown**Clopidogrel used?**

- ☐ Yes
☐ No
☐ Unknown

Date started

ST= ☐ Unknown

Thrombolytic used?

- ☐ Yes
- ☐ No
- ☐ Unknown

Other antithrombotic medication
used?

- ☐ Yes
- ☐ No
- ☐ Unknown

Medication Name

Date started

ST= ☐ Unknown

Lab Test Name

Lower target

ST= ☐ Unknown

Upper target

ST= ☐ Unknown

Date goal first achieved

ST= ☐ Unknown

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

Albumin

g/dL

g/L

ST= ☐ Unknown
☐ Not done

Pre-albumin

mg/dL

mg/L

ST= ☐ Unknown
☐ Not done

Total Cholesterol

mg/dL

mmol/L

ST= ☐ < 50 mg/dL
☐ Unknown
☐ Not done

Brain natriuretic peptide BNP

pg/ml

ng/L

ST= ☐ > 7500 pg/mL
☐ Unknown
☐ Not done

NT pro brain natriuretic peptide Pro-BNP

pg/ml

ng/L

ST= ☐ Unknown
☐ Not done

White blood cell count

x10³/uL

x10⁹/uL

ST= ☐ Unknown
☐ Not done

Reticulocyte count

%

ST= ☐ Unknown
☐ Not Done

Hemoglobin

g/dL

g/L

mmol/L

ST= ☐ Unknown
☐ Not done

Platelets

 x10³/uL x10⁹/uLST= ☐ Unknown☐ Not done

Hemoglobin A1C

 % mmol/mol

Estimated Average Glucose (eAG):

 mg/dL mmol/LST= ☐ Unknown☐ Not Done

INR

 international unitsST= ☐ Unknown☐ Not done

Plasma-free hemoglobin

 mg/dL g/LST= ☐ less than 30mg☐ Unknown☐ Not DonePositive antiheparin/platelet
antibody (HIT)☐ Yes☐ No☐ UnknownIf Yes, are they on direct thrombin
inhibitors☐ Yes☐ No☐ Unknown

If Yes, Enter Drugs:

☐ Aspirin☐ Dipyridamole☐ Plavix☐ Heparin☐ Coumadin☐ Direct thrombin inhibitors (ex: arg, lip, val...)

Was a TEG done?

☐ Yes☐ No☐ UnknownThrombElastoGraph Hemostasis
System (TEG) profile, MA k max amplitude in kaolinST= ☐ Unknown☐ Not DoneThrombElastoGraph Hemostasis
System (TEG) profile, R k reaction time in kaolinST= ☐ Unknown☐ Not Done

ThrombElastoGraph
HemostasisSystem (TEG) profile, R
h

reaction time w/heparinase

ST= ☐ Unknown

☐ Not Done

Sensitivity CRP

mg/L

ST= ☐ Unknown

☐ Not done

Lupus Anticoagulant

☐ Positive

☐ Negative

☐ Unknown

Fibrinogen

mg/dL

g/L

ST= ☐ Unknown

Anti-Factor Xa

units/mL

ST= ☐ Unknown

PTT

seconds

ST= ☐ Unknown

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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

 feet

ST= ☐ Not done

☐ Not done: too sick

☐ Not done: other

☐ Not done: age inappropriate

☐ Not done: patient refused to walk

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 6minute walk for the Gait speed test listed below (please see instructions for the gait speed test below.)**

Gait Speed (1st 15 foot walk)

 seconds

ST= ☐ Not done

☐ Not done: too sick

☐ Not done: other

☐ Not done: age inappropriate

☐ Not done: patient refused to walk

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

 mL/kg/min

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

Ross Classification of Congestive Heart Failure

- ☐ Ross Class I: No limitations or symptoms.
- ☐ Ross Class II: No growth failure.
- ☐ Ross Class III: Growth failure.
- ☐ Ross Class IV: Symptomatic at rest.
- ☐ Not applicable: ≥ 2 years of age
- ☐ Unknown

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

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Concerns and Contraindications

Concerns / Contraindications	Is condition present?		Limitation for transplant listing?	
Overall Status	Yes	No	Yes	No
Patient does not want transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Musculoskeletal limitation to ambulation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contraindication to immunosuppression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Allosensitization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frailty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic Renal Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of dialysis dependent renal failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of neurological brain injury other than CVA	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiothoracic issues	Yes	No	Yes	No
Frequent ICD Shocks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary Hypertension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recent Pulmonary Embolus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History Of Atrial Arrhythmia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unfavorable Mediastinal Anatomy (includes sternotomies, sternal resection, radiation, flail chest, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoracic Aortic Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tracheostomy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Plastic Bronchitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutritional/GI	Yes	No	Yes	No
Large BMI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Severe Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Malnutrition Cachexia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History Of GI Ulcers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History Of Hepatitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Liver Dysfunction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anasarca	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protein Losing enteropathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic Syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vascular issues	Yes	No	Yes	No
Heparin Induced Thrombocytopenia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic Coagulopathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Major Stroke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Cerebrovascular Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peripheral Vascular Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Oncology/infection issues	Yes	No	Unknown	Yes	No
History Of Solid Organ Cancer	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
History Of Lymphoma Leukemia	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
History Of Bone Marrow Transplant BMT	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
History Of HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic Infectious Concerns	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Psychosocial issues (If patient is < 10 years old at the time of implant, based on chart review of the patient, are the conditions present or absent?)

	Yes	No	Unknown	Yes	No
Limited Cognition/Understanding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Limited Social Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Repeated Noncompliance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History Of Illicit Drug Use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History Of Alcohol Abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Narcotic Dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History Of Smoking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Currently Smoking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Severe Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Major Psychiatric Diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurological // developmental abnormalities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Comorbidity	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

HIV History

HIV Diagnosis Date

ST= ☐ Unknown

☐ 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

- ☐ 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
- ☐ Unknown
- ☐ None

Infection Prophylaxis

- ☐ Atovaquone
- ☐ Azithromycin
- ☐ Dapsone
- ☐ Fluconazole
- ☐ Pentamidine, aerosolized
- ☐ Trimethoprim-sulfamethoxazole (TMP-SMX)
- ☐ Unknown
- ☐ None

Has patient had an opportunistic infection since last follow-up?

- ☐ Yes
- ☐ No
- ☐ Unknown

If yes, enter infection date:

- ST= ☐ Unknown
- ☐ Not Done

If yes, enter Type of 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

3 Month Followup - Pedimacs

Device Flow Chart

Device Function

Left Flow LPM
ST= ☐ Unknown

Right Flow LPM
ST= ☐ Unknown
☐ Not Applicable

Left Fill Volume: ml
ST= ☐ Unknown

Right Fill Volume ml
ST= ☐ Unknown
☐ Not Applicable

Device Parameters

Pump Rate BPM
ST= ☐ Unknown

Vacuum Pressure mm Hg
ST= ☐ Unknown
☐ Not Applicable

Left Drive Pressure mm Hg
ST= ☐ Unknown
☐ Not Applicable

Right Drive Pressure mm Hg
ST= ☐ Unknown
☐ Not Applicable

Device Inspection

Auscultation ☐ Abnormal
☐ Normal
☐ Not Applicable

3 Month Followup - Pedimacs

Device Flow Chart

Device Function

Pump Flow

LPM

ST= ☐ Unknown

Pulsality Index

ST= ☐ Unknown

Pump Power

Watts

ST= ☐ Unknown

Device Parameters

Pump Speed

RPM

ST= ☐ Unknown

Low Speed

RPM

ST= ☐ Unknown

Device Inspection

Auscultation

- ☐ Abnormal
☐ Normal
☐ Not Applicable

Driveline

- ☐ Abnormal
☐ Normal
☐ Not Applicable

3 Month Followup - Pedimacs

Device Flow Chart

Device Function

Pump Flow LPM
ST= ☐ Unknown

Pump Power Watts
ST= ☐ Unknown

Device Parameters

Pump Speed RPM
ST= ☐ Unknown

Device Inspection

Auscultation ☐ Abnormal
☐ Normal
☐ Not Applicable

Driveline ☐ Abnormal
☐ Normal
☐ Not Applicable

3 Month Followup - Pedimacs

Device Flow Chart

Device Function

Pump Flow LPM
ST= ☐ Unknown

Device Parameters

Control Mode ☐ Synchronous
☐ Asynchronous
☐ Independent
☐ Not Applicable

Pump Rate BPM
ST= ☐ Unknown

Device Inspection

Depositions ☐ Yes
☐ No
☐ Not Applicable

Depositions Description

Full Ejection ☐ Yes
☐ No
☐ Not Applicable

Systolic Pressure: mm Hg
ST= ☐ Unknown

Diastolic Pressure: mm Hg
ST= ☐ Unknown

Percent Systole: %
ST= ☐ Unknown

Device Function (RVAD)

Pump Flow (RVAD) LPM
ST= ☐ Unknown

Device Parameters (RVAD)

Control Mode (RVAD) Both ☐ Synchronous
☐ Asynchronous
☐ Independent
☐ Not Applicable

Pump Rate (RVAD) BPM
ST= ☐ Unknown

Device Inspection (RVAD)

Depositions (RVAD) ☐ Yes

☐ No

☐ Not Applicable

Depositions Description (RVAD)

Full Ejection (RVAD)

- ☐ Yes
- ☐ No
- ☐ Not Applicable

Systolic Pressure (RVAD):

mm Hg

ST= ☐ Unknown

Diastolic Pressure (RVAD):

mm Hg

ST= ☐ Unknown

Percent Systole (RVAD):

%

ST= ☐ Unknown

3 Month Followup - Pedimacs

Device Flow Chart

Device Function

Pump Flow

LPM

ST= ☐ Unknown

Pump Power

Watts

ST= ☐ Unknown

Device Parameters

Pump Speed

RPM

ST= ☐ Unknown

Device Inspection

Auscultation

- ☐ Abnormal
☐ Normal
☐ Not Applicable

Driveline

- ☐ Abnormal
☐ Normal
☐ Not Applicable

Device Funtion (RVAD)

Pump Flow (RVAD)

LPM

ST= ☐ Unknown

Device Parameters (RVAD)

Pump Speed (RVAD)

RPM

ST= ☐ Unknown

Device Inspection (RVAD)

Depositions

- ☐ AbNormal
☐ Normal
☐ Not Applicable

3 Month Followup - Pedimacs

Quality Of Life

(QOL surveys cannot be administered after the visit date)

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)

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?**Do you ever feel too tired to play:**

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

EMOTIONAL FUNCTIONING (problems with...)**Do you feel scared:**

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

Do you feel sad:

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

Do you feel mad:

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

Do you have trouble sleeping:

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

**Do you worry about what will
happen to you:**

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

SOCIAL FUNCTIONING (problems with...)**Is it hard for you to get along with
other kids:**

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

**Do other kids say they do not want
to play with you:**

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

Do other kids tease you:

- ☐ 0 - Not at all
☐ 2 - Sometimes
☐ 4 - A lot
☐ Unknown or Not Documented

**Can other kids do things that you
cannot do:**

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ Unknown or Not Documented

**It is hard for you to keep up when
you play with other kids:**

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ Unknown or Not Documented

SCHOOL FUNCTIONING (problems with...)

**Is it hard for you to pay attention in
class:**

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ Unknown or Not Documented

Do you forget things:

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ Unknown or Not Documented

**Is it hard to keep up with
schoolwork:**

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ Unknown or Not Documented

**Do you miss school because of not
feeling good:**

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ Unknown or Not Documented

**Do you miss school because you
have to go to the doctor's or
hospital:**

- ☐ 0 - Not at all
- ☐ 2 - Sometimes
- ☐ 4 - A lot
- ☐ 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 child complete a form?

- ☐ Yes
- ☐ No
- ☐ Unknown

**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
- ☐ 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
- ☐ Low

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)

3 Month Followup - Pedimacs

Quality Of Life

(QOL surveys cannot be administered after the visit date)

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 a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard for me to run:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard for me to do sports activity
or exercise:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard for me to lift something
heavy:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard for me to take a bath or
shower by myself:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

**It is hard for me to do chores
around the house:**

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I hurt or ache:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

Where?

I have low energy:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

ABOUT MY FEELINGS (problems with...)

I feel afraid or scared:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I feel sad or blue:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I feel angry:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I have trouble sleeping:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I worry about what will happen to me:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

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

I have trouble getting along with other kids:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

Other kids do not want to be my friend:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

Other kids tease me:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I cannot do things other kids my age can do:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard to keep up when I play with other kids:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

ABOUT SCHOOL (problems with...)

Is it hard to pay attention in class:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I forget things:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I have trouble keeping up with my schoolwork:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I miss school because of not feeling well:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I miss school to go to the doctor or hospital:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ 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 child complete a form?

- ☐ Yes
- ☐ No
- ☐ Unknown

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
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- ☐ Never

I have difficulty sleeping due to the position of the driveline or tubing pump exit site:

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- ☐ Rarely
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- ☐ 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
☐ Low

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day level of happiness with the VAD
to be:**

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☐ Between High and Medium
☐ Medium
☐ Between Low and Medium
☐ Low

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the VADQoL form was not
completed:**

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☐ Administrative

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reason:**

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☐ Other reason (specify)

3 Month Followup - Pedimacs

Quality Of Life

(QOL surveys cannot be administered after the visit date)

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- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard for me to run:

- ☐ 0 - Never a problem
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- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard for me to lift something
heavy:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

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shower by myself:

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- ☐ 4 - Almost always a problem
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- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

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- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
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Where?

I have low energy:

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- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

ABOUT MY FEELINGS (problems with...)

I feel afraid or scared:

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- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I feel sad or blue:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I feel angry:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I have trouble sleeping:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I worry about what will happen to me:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

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

I have trouble getting along with other teens:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

Other teens do not want to be my friend:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

Other teens tease me:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I cannot do things other teens my age can do:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

It is hard to keep up with peers:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

ABOUT SCHOOL (problems with...)

Is it hard to pay attention in class:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I forget things:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I have trouble keeping up with my schoolwork:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I miss school because of not feeling well:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ Unknown or Not Documented

I miss school to go to the doctor or hospital:

- ☐ 0 - Never a problem
- ☐ 1 - Almost never a problem
- ☐ 2 - Sometimes a problem
- ☐ 3 - Often a problem
- ☐ 4 - Almost always a problem
- ☐ 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 child complete a form?

- ☐ Yes
- ☐ No
- ☐ Unknown

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
- ☐ 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
☐ Low

**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)

3 Month Followup - Pedimacs

Quality Of Life (Parent)

(QOL surveys cannot be administered after the visit date)

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: Walking more than one block:

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

Running: Running:

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

Participating in active play or exercise: 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: Lifting something heavy:

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

Bathing: 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

**Helping to pick up his or her toys:
Doing chores around the house:**

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

**Having hurts or aches: Having hurts
or aches:**

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

Low energy level: 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: Feeling
afraid or scared:**

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

**Feeling sad or blue: Feeling sad or
blue:**

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

Feeling angry: Feeling angry:

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

Trouble sleeping: Trouble sleeping:

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

**Worrying: 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...)

Playing with other children: Getting along with other teens:

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

Other kids not wanting to play with him or her: 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 children: 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 children his or her age can do: 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 children: Keeping up when playing with other teens:

- ☐ 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

Doing the same school activities as peers: Keeping up with schoolwork:

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

Missing school/daycare because of not feeling well: Missing school because of not feeling well:

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

Missing school/daycare to go to the doctor or hospital: 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
- ☐ 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

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)

3 Month Followup - Pedimacs

Quality Of Life (Parent)

(QOL surveys cannot be administered after the visit date)

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
- ☐ Unknown or Not Documented

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
- ☐ Unknown or Not Documented

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
- ☐ Unknown or Not Documented

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
- ☐ 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

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)

3 Month Followup - Pedimacs

Quality Of Life (Parent)

(QOL surveys cannot be administered after the visit date)

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
- ☐ Unknown or Not Documented

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
- ☐ Unknown or Not Documented

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
- ☐ Unknown or Not Documented

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
- ☐ 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

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)

3 Month Followup - Pedimacs

Quality Of Life (Parent)

(QOL surveys cannot be administered after the visit date)

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
- ☐ Unknown or Not Documented

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
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**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
- ☐ Unknown or Not Documented

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:

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- ☐ 2 - Sometimes
- ☐ 3 - Often
- ☐ 4 - Almost always
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Not able to do things that other teens his or her age can do:

- ☐ 0 - Never
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- ☐ 2 - Sometimes
- ☐ 3 - Often
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Keeping up when playing with other teens:

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SCHOOL FUNCTIONING (problems with...)**Paying attention in class:**

- ☐ 0 - Never
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- ☐ 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:

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