#### **1 Month Followup - Pedimacs** Followup Status (1 Month Followup (+/- 7 days)) 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 Patient didn't come to clinic obtain follow-up information Not able to contact patient Not addressed by site Was patient intubated? Yes No Unknown Was patient on dialysis? Yes No Unknown **Pump Change Pump Exchange** Yes No Unknown If yes, please select one of the Intracorporeal device following: Para- or Extra- corporeal device Upsizing device because of patient growth status All other reasons would categorize the pump change as a Device Malfunction Please select appropriate reason: Thrombus NOT associated with hemolysis Change in hemodynamics Clinical status Device parameters Was there a Console Change? Yes

- No
- Unknown

Date of console change	
	ST= Olnknown
Original Console Name	
New Console Name	
Medical Condition	
NYHA Class	<ul> <li>Class I: No limitation of physical activity; physical activity does not cause fatigue, palpitation or shortness of breath.</li> <li>Class II: Slight limitation of physical activity; comfortable at rest, but ordinary physical activity results in fatigue, palpitations or shortness of breath.</li> <li>Class III: Marked limitation of physical activity; comfortable at rest, but less than ordinary activity causes fatigue, palpitation or shortness of breath.</li> <li>Class IV: Unable to carry on minimal physical activity without discomfort; symptoms may be present at rest.</li> <li>Unknown</li> </ul>
Ross Classification of Congestive Heart Failure	<ul> <li>Ross Class I: No limitations or symptoms.</li> <li>Ross Class II: No growth failure.</li> <li>Ross Class III: Growth failure.</li> <li>Ross Class IV: Symptomatic at rest.</li> <li>Not applicable: &gt;= 2 years of age</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Mild tachypnea with feeds in infant</li> <li>Mild diaphoresis with feeds in infant</li> <li>Dyspnea on exercise in older children</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Marked tachypnea with exertion or with feeding</li> <li>Marked diaphoresis with exertion or with feeding</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Tachypnea</li> <li>Retractions</li> <li>Grunting</li> <li>Diaphoresis</li> <li>Unknown</li> </ul>
Functional Capacity	
Sedated	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Paralyzed	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Intubated	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>

Ambulating	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Primary Nutrition	<ul> <li>Orally</li> <li>Per feeding tube</li> <li>TPN</li> <li>Not Applicable</li> </ul>
Excursions	
Has the patient had any non- medically required excursions off the unit?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> <li>Not Applicable</li> </ul>
lf yes, where (please select all that apply)	<ul> <li>Playroom</li> <li>Cafeteria</li> <li>Walk outside</li> <li>Sitting room</li> <li>General rehab</li> <li>None</li> </ul>
ZONES	
lemolysis Zone	
Please enter the peak Plasma-free hemoglobin (PFH) since the last 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 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 o	r HGB since the last visit.
Min. HCT:	ST= Unknown Not Done

Max. HCT:	
	ST= OUnknown
	Not Done
	- Not Done
Min. HGB:	
	ST= Ounknown
	Not Done
Max. HGB:	
	ST= Olnknown
	Not Done
Highest Total Bilirubin since the last visit:	
visit.	ST= Olnknown
	Not Done
Has the following been present at any til Physical Findings (select all that apply):	
Physical Findings (select all that apply):	
Hemoglobinuria (Tea-Colored	• Yes
Urine)?	No
	Unknown
Pump malfunction and/or abnormal	• Yes
pump parameters?	<ul> <li>No</li> </ul>
	Unknown
Right Heart Failure Zone	
Right fleart Fahre Zone	
Clinical Findings – Since the last visit.	
CVP or RAP > 16 mmHg?	• Yes
	○ No
	Unknown
	Not Done
Dilated Vena Cava with absence of	• Yes
Inspiratory Variation by Echo?	O No
	Unknown
	Not Done
<b>A</b>	
Clinical findings of elevated jugular	• Yes
venous distension at least half way up the neck in an upright patient?	No
ap the neok in an upright patient?	Unknown
Peripheral Edema?	Yes
	No
	Unknown
Ascites?	• Yes
	No
	Unknown

since the last visit?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, select all that apply:	<ul> <li>Dopamine</li> <li>Dobutamine</li> <li>Milrinone</li> <li>Isoproterenol</li> <li>Epinephrine</li> <li>Norepinephrine</li> <li>Levosimendan</li> <li>Unknown</li> <li>Vasopressin</li> <li>Nitroprusside</li> <li>Fenoldopam</li> <li>Prostacyclin</li> </ul>
Nesiritide?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Has the patient had a RVAD implant since the last visit?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Has the patient experienced a Neurological Event since time of implant?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, please enter the Modified Rankin	Scale.
Modified Rankin Scale	<ul> <li>0 – No symptoms at all</li> <li>1 - No Significant disability: despite symptoms: able to carry out all usual duties and activities</li> <li>2 - Slight disability: unable to carry out all previous activities but able to look after own affairs without assistance</li> <li>3 - Moderate disability: requiring some help, but able to walk without assistance.</li> <li>4 - Moderately severe disability: unable to walk without assistance, and unable to attend to own bodily needs without assistance.</li> <li>5 - Severe disability: bedridden, incontinent and requiring constant nursing care and attention.</li> <li>6 - Dead</li> </ul>
	ST= Not Documented

	1	Month	Followup	- Pedimacs
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modynamics			
eneral Hemodynamics			
Systolic blood pressure		mmHg	
	ST= Ounknown		
	Not done		
Diastolic blood pressure		mmHg	
	ST= Unknown		
	Not done		
Mean Arterial Blood Pressure (MAP)		mmHg	
	ST= Unknown		
	<ul> <li>Not done</li> </ul>		
ECG rhythm	Sinus		
	Atrial fibrillation		
	Atrial Flutter		
	Paced: Atrial pacing     Paced: Vertrieview pacing		
	Paced: Ventricular     Daged: Atrial and w		
	Paced: Atrial and v Unknown		
	Not done		
	Other, specify		
Height		in	
		cm	
	ST= OUnknown		
	Not done		
Weight		lbs	
		kg	
	ST= Unknown		
	Not done		
nvasive Hemodynamics			
Date of Measurement			
	ST= Unknown		
	Not Done		
Pulmonary artery		mmHg	
systolic pressure	ST= Unknown		
	Not Done		

Pulmonary artery diastolic pressure	ST= Unknown Not Done	mmHg
Mean RA Pressure	ST= Unknown Not Done	mmHg
PVR	ST= Unknown Not Done	wood units
Mean Pulmonary artery wedge pressure	ST= Unknown Not Done	mmHg
Central venous pressure (CVP)	ST= Unknown Not Done	mmHg
Cardiac Index	ST= Unknown Not Done	L/min/M <sup>2</sup> (by Swan)
Was Cardiac Index Measured by Fick or Thermodilution?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Choose Method	<ul><li>Fick</li><li>Thermodilution</li></ul>	

### Medications

edications	
Was the patient sent home with an IV?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
ACE inhibitors	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Aldosterone antagonist	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Amiodarone	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Angiotensin receptor blocker drug	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Antiplatelet therapy drug	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Select drug(s)	<ul> <li>Aspirin</li> <li>Dextran</li> <li>Dipyridamole</li> <li>Clopidogrel</li> <li>Ticlopidine</li> <li>Unknown</li> <li>Other, specify</li> </ul>
Thrombolytic	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Beta-blockers	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Calcium channel blockers	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Digoxin	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>

Hydralazine	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Loop diuretics	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
If yes, enter dosage:	ST= OUnknown	mg/day
Type of Loop Diuretic:	<ul><li>Furosemide</li><li>Torsemide</li><li>Bumetanide</li><li>Other</li></ul>	
Low molecular weight heparin (Lovenox, Fragmin, Innohep)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Nitric oxide	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Sildenafil/ Bosentan	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
UFH: Unfractionated Heparin	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Warfarin (coumadin)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Arixtra (fondaparinux)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Did patient receive new IV or oral medication to treat hypertension?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Transfusion		
Was there a Tranfusion?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
If yes, enter number of PRBC (Total number of cc's received)	ST= Ounknown	

oratory		
Sodium		mEq/L
		mmol/L
	ST= OUnknown	
	Not done	
Potassium		mEq/L
		mmol/L
	ST= OUnknown	
	Not done	
Blood urea nitrogen		mg/dL
		mmol/L
	ST= OUnknown	
	Not done	
Creatinine		mg/dL
		umol/L
	ST= OUnknown	unove
	<ul> <li>Not done</li> </ul>	
SGPT/ALT (alanine		u/L
aminotransferase/ALT)	ST= Unknown	
	Not done	
SGOT/AST (aspartate		u/L
aminotransferase/AST)	ST= OUnknown	
	Not done	
LDH		units/L, U/L, ukat/L
	ST= Unknown	
	Not done	
Total bilirubin		mg/dL
		umol/L
	ST= Olnknown	
	<ul> <li>Not done</li> </ul>	
Bilirubin direct		mg/dL
		umol/L
	ST= Unknown Not Done	

Bilirubin indirect		mg/dL	
		umol/L	
	ST= OUnknown		
	Not Done		
Albumin		g/dL	
		g/L	
	ST= Unknown		
	Not done		
Pre-albumin		mg/dL	
		mg/L	
	ST= Olnknown		
	Not done		
Total Cholesterol		mg/dL	
		mmol/L	
	ST=		
	Unknown		
	Not done		
Brain natriuretic peptide BNP		pg/ml	
		ng/L	
	ST= 0 > 7500 pg/mL		
	Unknown     Not done		
	Not done		
NT pro brain natriuretic peptide Pro- BNP		pg/ml	
DAP		ng/L	
	ST= Unknown		
	Not done		
White blood cell count		x10 <sup>3</sup> /uL	
		x10 <sup>9</sup> /uL	
	ST= Unknown		
	Not done		
Reticulocyte count		%	
	ST= Unknown		
	Not Done		
Hemoglobin		g/dL	
		g/L	
		mmol/L	
	ST= Unknown		
	Not done		

Hemoglobin A1C		%
		mmol/mol
Estimated Average Glucose (eAG):		
		mg/dL
		] mmol/L
	ST= Unknown Not Done	
Platelets		x10 <sup>3</sup> /uL
		x10 <sup>9</sup> /uL
	ST= Unknown	
	Not done	
INR		international units
	ST= Unknown	
	Not done	
Disama free homoglabin		
Plasma-free hemoglobin		] mg/dL
	ST= Ounknown	_g/L
	Not Done	
Positive antiheparin/platelet antibody (HIT)	• Yes	
antibody (mm)	<ul><li>No</li><li>Unknown</li></ul>	
If Yes, are they on direct thrombin	• Yes	
inhibitors	<ul><li>No</li></ul>	
	Unknown	
If Yes, Enter Drugs:	Aspirin	
	<ul><li>Dipyridamole</li><li>Plavix</li></ul>	
	Heparin	
	<ul> <li>Coumadin</li> <li>Direct thrombin inhibitors</li> </ul>	s (ex: arg, lip, val)
Was a TEG done?	• Yes	
	<ul><li>No</li><li>Unknown</li></ul>	
		2
ThrombElastoGraph Hemostasis System (TEG) profile, MA k		max amplitude in kaolin
	ST= Unknown Not Done	
ThromhElastaGraph Homostopic		л
ThrombElastoGraph Hemostasis System (TEG) profile, R k	ST= OUnknown	reaction time in kaolin
	Not Done	

ThrombElastoGraph HemostasisSystem (TEG) profile, R h	ST= Unknown Not Done	reaction time w/heparinase
CRP or hs-CRP	ST= Unknown Not done	mg/dL
Lupus Anticoagulant	<ul><li>Positive</li><li>Negative</li><li>Unknown</li></ul>	

# 1 Week Followup - Pedimacs

Inpatient
Outpatient
Other Facility
<ul> <li>Unable to obtain follow-up information</li> </ul>
Nursing Home/Assisted Care
Hospice
Another hospital
Rehabilitation Facility
Unknown
Patient didn't come to clinic
Not able to contact patient
Not addressed by site
<ul> <li>Yes</li> <li>No</li> </ul>
Yes
O No
Unknown
○ Yes
No
Unknown
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
Change in hemodynamics
Clinical status
Device parameters
• Yes
<ul><li>Yes</li><li>No</li></ul>

Date of console change	
	ST= Ouknown
Original Console Name	
New Console Name	
Medical Condition	
NYHA Class	<ul> <li>Class I: No limitation of physical activity; physical activity does not cause fatigue, palpitation or shortness of breath.</li> <li>Class II: Slight limitation of physical activity; comfortable at rest, but ordinary physical activity results in fatigue, palpitations or shortness of breath.</li> <li>Class III: Marked limitation of physical activity; comfortable at rest, but less than ordinary activity causes fatigue, palpitation or shortness of breath.</li> <li>Class IV: Unable to carry on minimal physical activity without discomfort; symptoms may be present at rest.</li> </ul>
Ross Classification of Congestive Heart Failure	<ul> <li>Ross Class I: No limitations or symptoms.</li> <li>Ross Class II: No growth failure.</li> <li>Ross Class III: Growth failure.</li> <li>Ross Class IV: Symptomatic at rest.</li> <li>Not applicable: &gt;= 2 years of age</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Mild tachypnea with feeds in infant</li> <li>Mild diaphoresis with feeds in infant</li> <li>Dyspnea on exercise in older children</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Marked tachypnea with exertion or with feeding</li> <li>Marked diaphoresis with exertion or with feeding</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Tachypnea</li> <li>Retractions</li> <li>Grunting</li> <li>Diaphoresis</li> <li>Unknown</li> </ul>
Functional Capacity	
Sedated	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Paralyzed	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Intubated	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>

Ambulating	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Primary Nutrition	<ul> <li>Orally</li> <li>Per feeding tube</li> <li>TPN</li> <li>Not Applicable</li> </ul>
Excursions	
Has the patient had any non- medically required excursions off the unit?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> <li>Not Applicable</li> </ul>
If yes, where (please select all that apply)	<ul> <li>Playroom</li> <li>Cafeteria</li> <li>Walk outside</li> <li>Sitting room</li> <li>General rehab</li> <li>None</li> </ul>
ZONES	
lemolysis Zone	
Please enter the peak Plasma-free hemoglobin (PFH) since Post-Op Day 4:	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 Post- Op Day 4:	ST= Ounknown 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 o	or HGB since the Post-Op Day 4.
Min. HCT:	ST= Unknown
	Not Done

Max. HCT:	
	ST= OUnknown
	Not Done
	- Not Done
Min. HGB:	
	ST= OUnknown
	Not Done
	- Not Done
May UCD.	
Max. HGB:	
	ST= Unknown
	Not Done
Highest Total Bilirubin since Post-	
Op Day 4:	ST= OUnknown
	Not Done
Has the following been present at any ti	
Physical Findings (select all that apply):	
Hemoglobinuria (Tea-Colored	• Yes
Urine)?	<ul> <li>No</li> </ul>
	Unknown
Pump malfunction and/or abnormal	No.
pump parameters?	• Yes
pump parameters:	○ No
	Unknown
Right Heart Failure Zone	
Right Heart Fandre Zone	
Clinical Findings – Since the last visit.	
π	
CVP or RAP > 16 mmHg?	Ves
	No
	Unknown
	Not Done
Dilated Vena Cava with absence of	• Yes
Inspiratory Variation by Echo?	No
	Unknown
	Not Done
Clinical findings of elevated jugular	Ves
venous distension at least half way	No
up the neck in an upright patient?	Unknown
Peripheral Edema?	• Yes
-	No
	Unknown
Ascites?	No.
ASCILES ?	<ul> <li>Yes</li> <li>No</li> </ul>
	Unknown

Has the patient been on Inotropes	○ Yes
since the last visit?	No
	Unknown
	- CIRIOWI
If yes, select all that apply:	Dopamine
	Dobutamine
	Milrinone
	Isoproterenol
	Epinephrine
	Norepinephrine
	Levosimendan
	Unknown
	Vasopressin
	Nitroprusside
	Fenoldopam
	Prostacyclin
Nesiritide?	• Yes
	<ul> <li>No</li> </ul>
	Unknown
Has the patient had a RVAD implant	○ Yes
since the last visit?	No
	Unknown
Hee the notiont experienced e	
Has the patient experienced a Neurological Event since time of	Ves
implant?	<ul> <li>No</li> <li>Unknown</li> </ul>
If yes, please enter the Modified Rankir	
Modified Rankin Scale	<ul> <li>0 – No symptoms at all</li> </ul>
	<ul> <li>1 - No Significant disability: despite symptoms: able to carry out all usus</li> </ul>
	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 sum had it was a low it has a state of the second sec
	unable to attend to own bodily needs without assistance.
	5 - Severe disability: bedridden, incontinent and requiring constant nursing care and attention.
	<ul> <li>6 - Dead</li> </ul>
	ST= ONot Documented
	Not Done

1	Week	<b>Followup</b>	-	<b>Pedimacs</b>
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eneral Hemodynamics		
Systolic blood pressure		mmHg
	ST= Unknown	
	Not done	
Diastolic blood pressure		mmHg
	ST= Unknown	
	Not done	
lean Arterial Blood Pressure (MAP)		mmHg
	ST= Ounknown	
	<ul> <li>Not done</li> </ul>	
ECG rhythm	Sinus	
	Atrial fibrillation	
	Atrial Flutter	
	Paced: Atrial pacing	
	Paced: Ventricular p	
	Paced: Atrial and ve	entricular pacing
	<ul> <li>Unknown</li> <li>Not done</li> </ul>	
	Other, specify	
Height		in
-		
	ST= Unknown	cm
	<ul> <li>Not done</li> </ul>	
Weight		lbs
		kg
	ST= Unknown	
	Not done	
vasive Hemodynamics		
Date of Measurement		
	ST= Unknown	
	Not Done	
Pulmonary artery		mmHg
Pulmonary artery systolic pressure	ST= OUnknown	mmHg

Pulmonary artery diastolic pressure	ST= Unknown Not Done	mmHg
Mean RA Pressure	ST= Unknown Not Done	mmHg
PVR	ST= Unknown Not Done	wood units
Mean Pulmonary artery wedge pressure	ST= Unknown Not Done	mmHg
Central venous pressure (CVP)	ST= Unknown Not Done	mmHg
Cardiac Index	ST= Unknown Not Done	L/min/M <sup>2</sup> (by Swan)
Was Cardiac Index Measured by Fick or Thermodilution?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Choose Method	<ul><li>Fick</li><li>Thermodilution</li></ul>	

## 1 Week Followup - Pedimacs

### Medications

Was the patient sent home with an	○ Yes
IV?	No
	Unknown
ACE inhibitors	○ ¥
ACE INITIDITORS	
	○ No
	Unknown
Aldosterone antagonist	○ Yes
-	O No
	Unknown
Amiodarone	○ Yes
	No
	Unknown
Angiotensin receptor blocker drug	○ Yes
	<ul> <li>No</li> </ul>
	Unknown
Antiplatelet therapy drug	○ Yes
	No
	Unknown
Select drug(s)	Aspirin
	Dextran
	Dipyridamole
	Ticlopidine
	Unknown
	Other, specify
Thrombolytic	○ Yes
· · · · · · · · · · · · · · · · · · ·	<ul> <li>No</li> </ul>
	Unknown
Beta-blockers	○ Yes
	No
	Unknown
Calcium channel blockers	O Yes
	<ul> <li>No</li> </ul>
Digoxin	○ Yes
	No
	Unknown

Hydralazine	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Loop diuretics	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Low molecular weight heparin (Lovenox, Fragmin, Innohep)	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Nitric oxide	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Sildenafil/ Bosentan	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
UFH: Unfractionated Heparin	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Warfarin (coumadin)	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Arixtra (fondaparinux)	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Did patient receive new IV or oral medication to treat hypertension?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Transfusion	
Was there a Tranfusion?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, enter number of PRBC (Total number of cc's received)	ST= Unknown

# 1 Week Followup - Pedimacs

atory		
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		u/L
aminotransferase/ALT)	ST= Unknown	
	Not done	
SGOT/AST (aspartate		u/L
aminotransferase/AST)	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	

Bilirubin indirect		mg/dL
		umol/L
	ST= Ounknown	
	Not Done	
Albumin		g/dL
	ST= Ounknown	g/L
	Not done	
Pre-albumin		mg/dL
		mg/L
	ST= Unknown	
	Not done	
Total Cholesterol		mg/dL
		mmol/L
	ST=	
	Unknown	
	Not done	
Brain natriuretic peptide BNP		pg/ml
		ng/L
	ST=	
	Unknown	
	Not done	
NT pro brain natriuretic peptide Pro-		pg/ml
BNP		ng/L
	ST= Unknown	
	Not done	
White blood cell count		x10 <sup>3</sup> /uL
		x10 <sup>9</sup> /uL
	ST= Ounknown	
	Not done	
Reticulocyte count		%
	ST= Unknown	
	Not Done	
Hemoglobin		g/dL
Hemoglobin		
Hemoglobin		g/L
Hemoglobin	ST= Unknown	

Hemoglobin A1C		%
		mmol/mol
Estimated Average Glucose (eAG):		
		mg/dL
		mmol/L
	ST= Unknown Not Done	
Platelets		x10 <sup>3</sup> /uL
		x10 <sup>9</sup> /uL
	ST= OUnknown	
	Not done	
INR		international units
	ST= Unknown	
	Not done	
Plasma-free hemoglobin		mg/dL
		g/L
	ST= Unknown	5
	Not Done	
Positive antiheparin/platelet antibody (HIT)	• Yes	
	<ul><li>No</li><li>Unknown</li></ul>	
If Yes, are they on direct thrombin	Yes	
inhibitors	No	
	Unknown	
If Yes, Enter Drugs:	Aspirin	
	<ul><li>Dipyridamole</li><li>Plavix</li></ul>	
	Heparin	
	<ul> <li>Coumadin</li> <li>Direct thrombin inhibitor</li> </ul>	rs (ex: ara lin val )
		S (ex. alg, ii), val)
Was a TEG done?		
Was a TEG dolle:	<ul><li>Yes</li><li>No</li></ul>	
	Unknown	
ThrombElastoGraph Hemostasis		max amplitude in kaolin
System (TEG) profile, MA k	ST= Unknown	
	Not Done	
ThrombElastoGraph Hemostasis		reaction time in kaolin
System (TEG) profile, R k	ST= Unknown	
	Not Done	

ThrombElastoGraph HemostasisSystem (TEG) profile, R h	ST= Unknown Not Done	reaction time w/heparinase
CRP or hs-CRP	ST= Unknown Not done	mg/dL
Lupus Anticoagulant	<ul><li>Positive</li><li>Negative</li><li>Unknown</li></ul>	

Х

	J
Date of Event	
eath	
Is the patient deceased ?	• Yes
	No
Death Date	
Primary cause of death	Despiratory: Vanaus Thromboombaliam Evant
Finnary cause of death	<ul> <li>Respiratory: Venous Thromboembolism Event</li> <li>Respiratory: Respiratory Failure</li> </ul>
	<ul> <li>Respiratory: Pulmonary: Other, specify</li> </ul>
	<ul> <li>Circulatory: Arterial Non-CNS Thromboembolism</li> </ul>
	<ul> <li>Circulatory: Myocardial Infarction</li> </ul>
	<ul> <li>Circulatory: Myocardial Rupture</li> </ul>
	<ul> <li>Circulatory: Ruptured Aortic aneurysm</li> </ul>
	<ul> <li>Circulatory: Right Heart Failure</li> </ul>
	<ul> <li>Circulatory: Major Bleeding</li> </ul>
	<ul> <li>Circulatory: Cardiac Arrhythmia</li> </ul>
	Circulatory: Hemolysis
	Circulatory: Hypertension
	Circulatory: Other, Specify
	Circulatory: Sudden unexplained death
	Circulatory: CHF
	Circulatory: Heart Disease
	Circulatory: End Stage Cardiomyopathy
	Circulatory: End Stage Ischemic Cardiomyopathy
	Circulatory: Pericardial Fluid Collection (effusion)
	Digestive (Intestinal or GI/GU): Hepatic Dysfunction
	Digestive (Intestinal or GI/GU): Renal Dysfunction
	Digestive (Intestinal or GI/GU): GI Disorder
	Digestive (Intestinal or GI/GU): Fluid/Electrolyte Disorder
	Digestive (Intestinal or GI/GU): Pancreatitis
	Nervous System: Neurological Dysfunction
	Psychiatric Episode/Suicide
	Major Infection
	Device Malfunction
	Multiple System Organ Failure (MSOF)
	Withdrawal of Support, specify
	Wound Dehiscence
	Trauma/accident, specify
	Hematological
	Other, specify

1 Year Post Recovery	1	Year	Post	Recovery	
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Cancer	CNS
	GI
	O Lymph
	O ENT
	Pulmonary
	Renal
	⊖ Breast
	<ul> <li>Reproductive</li> </ul>
	Skin
	Other
	Olnknown
Specify support withdrawn	
Specify	
Transplant	
Was the patient transplanted ?	○ Yes
	No
Transplant date	
- -	

Select one of the following	
	Other Facility
	Unable to obtain follow-up information
Follow-up date	
Facility Type	Nursing Home/Assisted Care
	Another hospital
	Rehabilitation Facility
	Unknown
State reason why you are unable to	Patient didn't come to clinic
obtain follow-up information:	Not able to contact patient
	Not addressed by site
Was patient intubated?	O 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= OUnknown
Pump Change	
	Vaa
Pump Exchange	<ul> <li>Yes</li> <li>No</li> </ul>

If yes, please select one of the following:	<ul> <li>Intracorporeal device</li> <li>Para- or Extra- corporeal device</li> <li>Upsizing device because of patient growth status</li> <li>All other reasons would categorize the pump change as a Device Malfunction</li> </ul>
Please select appropriate reason:	<ul> <li>Thrombus NOT associated with hemolysis</li> <li>Change in hemodynamics</li> <li>Clinical status</li> <li>Device parameters</li> </ul>
Was there a Console Change?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Date of console change	ST= Unknown
Original Console Name	
New Console Name	
Functional Capacity	
Sedated	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Paralyzed	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Intubated	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Ambulating	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Primary Nutrition	<ul> <li>Orally</li> <li>Per feeding tube</li> <li>TPN</li> <li>Not Applicable</li> </ul>
Excursions	
Has the patient had any non- medically required excursions off the unit?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> <li>Not Applicable</li> </ul>

If yes, where (please select all that apply)	<ul> <li>Playroom</li> <li>Cafeteria</li> <li>Walk outside</li> <li>Sitting room</li> <li>General rehab</li> <li>None</li> </ul>
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 o	r 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 Yes Urine)? No Unknown Pump malfunction and/or abnormal Yes pump parameters? 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** Yes **Inspiratory Variation by Echo?** No Unknown Not Done Clinical findings of elevated jugular Yes venous distension at least half way No up the neck in an upright patient? Unknown **Peripheral Edema?** Yes No Unknown Ascites? Yes No Unknown Has the patient been on Inotropes Yes since the last Follow-up? 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?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Has the patient experienced a Neurological Event since time of implant?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, please enter the Modified Rankin S Modified Rankin Scale	
Moumeu Kankin Scale	<ul> <li>0 – No symptoms at all</li> <li>1 - No Significant disability: despite symptoms: able to carry out all usual duties and activities</li> <li>2 - Slight disability: unable to carry out all previous activities but able to look after own affairs without assistance</li> <li>3 - Moderate disability: requiring some help, but able to walk without assistance.</li> <li>4 - Moderately severe disability: unable to walk without assistance, and unable to attend to own bodily needs without assistance.</li> <li>5 - Severe disability: bedridden, incontinent and requiring constant nursing care and attention.</li> <li>6 - Dead</li> </ul>
	ST= ONt Documented
	Not Done

General Hemodynamics			
Systolic blood pressure		mmHg	
,	ST= Unknown		
	<ul> <li>Not done</li> </ul>		
Diastolic blood pressure		mmHg	
	ST= Unknown		
	Not done		
Mean Arterial Blood Pressure (MAP)		mmHg	
	ST= Unknown		
	<ul> <li>Not done</li> </ul>		
ECG rhythm	Sinus		
	Atrial fibrillation		
	Atrial Flutter		
	Paced: Atrial pacing     Daged: Mantriaular		
	<ul> <li>Paced: Ventricular</li> <li>Paced: Atrial and v</li> </ul>		
	Not done		
	Other, specify		
Height		in	
		cm	
	ST= 🔍 Unknown		
	Not done		
Weight		lbs	
		kg	
	ST= Unknown		
	Not done		
Invasive Hemodynamics			
Pulmonary artery		mmHg	
systolic pressure	ST= Unknown		
	Not Done		
Pulmonary artery		mmHg	
diastolic pressure	ST= Olnknown		

Mean RA Pressure		mmHg
	ST= Unknown	
	Not Done	
PVR		wood units
	ST= Olnknown	
	Not Done	
Mean Pulmonary artery wedge		mmHg
pressure	ST= Olnknown	
	Not Done	
0 (0)/D)		
Central venous pressure (CVP)		mmHg
	ST= Ounknown	
	Not Done	
Cardiac Index		L/min/M <sup>2</sup> (by Swan)
		L/min/m <sup>2</sup> (by Swan)
	ST= Unknown Not Done	
Was Cardiac Index Measured by	• Yes	
Fick or Thermodilution?	No	
	Unknown	
Choose Method	Fick	
	Thermodilution	

ledications		
Was the patient sent home with an IV?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
ACE inhibitors	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Aldosterone antagonist	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Amiodarone	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Angiotensin receptor blocker drug	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Antiplatelet therapy drug	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Select drug(s)	<ul> <li>Aspirin</li> <li>Dextran</li> <li>Dipyridamole</li> <li>Clopidogrel</li> <li>Ticlopidine</li> <li>Unknown</li> <li>Other, specify</li> </ul>	
Thrombolytic	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Beta-blockers	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Digoxin	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Loop diuretics If yes, enter dosage:	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> <li>ST= Unknown</li> </ul>	mg/day
----------------------------------------------------------------------	---------------------------------------------------------------------------------	--------
Type of Loop Diuretic:	<ul><li>Furosemide</li><li>Torsemide</li><li>Bumetanide</li><li>Other</li></ul>	
Low molecular weight heparin (Lovenox, Fragmin, Innohep)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Nitric oxide	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Sildenafil/ Bosentan	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
UFH: Unfractionated Heparin	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Warfarin (coumadin)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Arixtra (fondaparinux)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Did patient receive new IV or oral medication to treat hypertension?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Transfusion		
Was there a Tranfusion?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
If yes, enter number of PRBC (Total number of cc's received)	ST= OUnknown	

# 3 Month Followup - Pedimacs

atory		
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		u/L
aminotransferase/ALT)	ST= Unknown	
	Not done	
SGOT/AST (aspartate		u/L
aminotransferase/AST)	ST= Unknown	
	Not done	
LDH		units/L, U/L, ukat/L
	ST= Unknown	
	Not done	
Total bilirubin		mg/dL
		umol/L
	ST= Ounknown	
	Not done	
Bilirubin direct		mg/dL
		umol/L
	ST= Ounknown	
	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= 0 < 50 mg/dL	
	Unknown	
	Not done	
Brain natriuretic peptide BNP		pg/ml
		ng/L
	ST= 0 > 7500 pg/mL	
	Unknown	
	O Not done	
NT pro brain natriuretic peptide Pro- BNP		pg/ml
BRI		ng/L
	ST= 🔍 Unknown	
	Not done	
White blood cell count		x10 <sup>3</sup> /uL
		x10 <sup>9</sup> /uL
	ST= Unknown	
	Not done	
Reticulocyte count		%
	ST= Unknown	
	Not Done	
Hemoglobin		g/dL
		g/L
		mmol/L
	ST= OUnknown	
	Not done	

Hemoglobin A1C		%
		mmol/mol
Estimated Average Glucose (eAG):		
<b>č</b> ( <i>, ,</i>		mg/dL
		mmol/L
	ST= Unknown	
	Not Done	
Platelets		x10 <sup>3</sup> /uL
		x10 <sup>9</sup> /uL
	ST= Unknown	
	Not done	
INR		international units
	ST= Unknown	
	Not done	
Plasma-free hemoglobin		mg/dL
		g/L
	ST= 🔍 Unknown	
	Not Done	
Positive antiheparin/platelet	• Yes	
antibody (HIT)	No	
	Unknown	
If Yes, are they on direct thrombin	Ves	
inhibitors	No	
	Unknown	
If Yes, Enter Drugs:	<ul><li>Aspirin</li><li>Dipyridamole</li></ul>	
	<ul> <li>Dipyridamole</li> <li>Plavix</li> </ul>	
	Heparin	
	<ul> <li>Coumadin</li> <li>Direct thrombin inhibito</li> </ul>	ors (ex: arg, lip, val)
		· · · · ·
Was a TEG done?	• Yes	
	No	
	Unknown	
ThrombElastoGraph Hemostasis System (TEG) profile, MA k		max amplitude in kaolin
	ST= Unknown	
	Not Done	
ThrombElastoGraph Hemostasis		reaction time in kaolin
System (TEG) profile, R k	ST= Unknown	
	Not Done	

ThrombElastoGra HemostasisSystem (TEG) profile	aph e, R h	ST= Unknown Not Done	reaction time w/heparinase
Sensitivity C	RP	ST= Unknown Not done	mg/L
Lupus Anticoagul	lant	<ul><li>Positive</li><li>Negative</li><li>Unknown</li></ul>	

### 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

vice Flow Chart		
Device Function		
Pump Flow		LPM
	ST= Unknown	
Pulsality Index		
	ST= Unknown	
Pump Power		Watts
	ST= Olnknown	
Device Parameters		
Pump Speed		RPM
	ST= Ounknown	
Lew Greed		
Low Speed	ST= Ounknown	RPM
Device Inspection		
Auscultation	<ul> <li>Abnormal</li> <li>Normal</li> </ul>	
	<ul> <li>Not Applicable</li> </ul>	
Driveline	Abnormal	
	Normal	
	Not Applicable	

evice Flow Chart		
Device Function		
Pump Flow		LPM
	ST= OUnknown	
Pump Power		Watts
	ST= Unknown	
Device Parameters		
Pump Speed		RPM
	ST= Ounknown	
Device Inspection		
Auscultation	Abnormal	
	<ul> <li>Normal</li> <li>Not Applicable</li> </ul>	
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 Funtion (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

	<ul><li>No</li><li>Not Applicable</li></ul>	
Depositions Description (RVAD)		
Full Ejection (RVAD)	<ul><li>Yes</li><li>No</li><li>Not Applicable</li></ul>	
Systolic Pressure (RVAD):	ST= OUnknown	mm Hg
Diastolic Pressure (RVAD):	ST= OUnknown	mm Hg
Percent Systole (RVAD):	ST= OUnknown	%

vice Flow Chart		
Device Function		
Pump Flow		LPM
	ST= OUnknown	
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= OUnknown	
Device Inspection (RVAD)		
Depositions	AbNormal	
	<ul> <li>Normal</li> <li>Not Applicable</li> </ul>	

### **3 Month Followup - Pedimacs**

#### **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

		feet
	ST= Not done	
	Not done: too sick	
	Not done: other	
	Not done: age inapprop	riate
instructed to walk steadily to cover as much distan 6 minutes. The staff member performing the test sl	ce as possible during the 6 minutes. hould walk behind the patient to avoid You may use the time from the first	oly as long as possible to avoid frequent turns. Patients are They are advised that they may stop if necessary during the d undue influence on the pace. The distance covered during at 15 feet of the 6minute walk for the Gait speed test
Gait Speed (1st 15 foot walk)		seconds
	ST= ONot done	
	Not done: too sick	
	Not done: other	
	Not done: age inapprop	riate
Peak VO2 Max		mL/kg/min
Peak VO2 Max		ml /ka/min
		IIIE/Kg/IIIII
	ST= Not done	
	Not done: too sick	
	<ul><li>Not done: too sick</li><li>Not done: other</li></ul>	
exercise testing either on a bicycle or treadmill. Th	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e during exercise (mL/kg/min) is the revalues recorded during the bicycle</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is
exercise testing either on a bicycle or treadmill. Th	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e during exercise (mL/kg/min) is the revalues recorded during the bicycle</li> </ul>	riate nl/kg/min of oxygen consumed during symptom-limited
exercise testing either on a bicycle or treadmill. Th	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e during exercise (mL/kg/min) is the revalues recorded during the bicycle</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is
exercise testing either on a bicycle or treadmill. Th assumed that most institutions will use only one ins	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e during exercise (mL/kg/min) is the revalues recorded during the bicycle</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is cycle is preferable as the mode easiest to standardize.
exercise testing either on a bicycle or treadmill. Th assumed that most institutions will use only one ins	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e during exercise (mL/kg/min) is the revalues recorded during the bicycle strument. If both are available, the bic</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is cycle is preferable as the mode easiest to standardize.
exercise testing either on a bicycle or treadmill. Th assumed that most institutions will use only one ins	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e values recorded during the bicycle strument. If both are available, the bic</li> <li>ST= Not done</li> <li>Not done: too sick</li> <li>Not done: other</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is cycle is preferable as the mode easiest to standardize.
exercise testing either on a bicycle or treadmill. Th assumed that most institutions will use only one ins	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e during exercise (mL/kg/min) is the revalues recorded during the bicycle strument. If both are available, the bic</li> <li>ST= Not done</li> <li>Not done: too sick</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is cycle is preferable as the mode easiest to standardize.
exercise testing either on a bicycle or treadmill. Th assumed that most institutions will use only one in <b>R Value at peak</b> R Value at peak is the respiratory quotient of carbo	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e values recorded during the bicycle strument. If both are available, the bid</li> <li>ST= Not done</li> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is cycle is preferable as the mode easiest to standardize. % riate en consumption, and is used as an index of how vigorously
exercise testing either on a bicycle or treadmill. Th assumed that most institutions will use only one ins <b>R Value at peak</b>	<ul> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> <li>e values recorded during the bicycle strument. If both are available, the bid</li> <li>ST= Not done</li> <li>Not done: too sick</li> <li>Not done: other</li> <li>Not done: age inapprop</li> </ul>	riate ml/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it is cycle is preferable as the mode easiest to standardize. % riate en consumption, and is used as an index of how vigorously

	<ul> <li>breath.</li> <li>Class III: Marked limitation of physical activity; comfortable at rest, but less than ordinary activity causes fatigue, palpitation or shortness of breath.</li> <li>Class IV: Unable to carry on minimal physical activity without discomfort; symptoms may be present at rest.</li> <li>Unknown</li> </ul>
Ross Classification of Congestive Heart Failure	<ul> <li>Ross Class I: No limitations or symptoms.</li> <li>Ross Class II: No growth failure.</li> <li>Ross Class III: Growth failure.</li> <li>Ross Class IV: Symptomatic at rest.</li> <li>Not applicable: &gt;= 2 years of age</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Mild tachypnea with feeds in infant</li> <li>Mild diaphoresis with feeds in infant</li> <li>Dyspnea on exercise in older children</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Marked tachypnea with exertion or with feeding</li> <li>Marked diaphoresis with exertion or with feeding</li> <li>Unknown</li> </ul>
Choose all indicated symptoms that apply.	<ul> <li>Tachypnea</li> <li>Retractions</li> <li>Grunting</li> <li>Diaphoresis</li> <li>Unknown</li> </ul>

## 3 Month Followup - Pedimacs

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 Child (8-12 yrs)         PedsQL FUNCTIONING (problems with)       PedsQL Teen (13-18 yrs)         PHYSICAL FUNCTIONING (problems with)       0 - Not at all         It is hard for you to walk:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       Unknown or Not Documented         It is hard for you to run:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       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       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       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       2 - Sometimes         4 - A lot       Unknown or Not Docume	
No         Please select the 'Child' form:         PedsQL Young Child (5-7 yrs)         PedsQL Child (8-12 yrs)         PedsQL 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 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	
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 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 pick up big things:       0 - Not at all 2 - Sometimes 4 - A lot         Unknown or Not Documented       Unknown or Not Documented         It is hard for you to take a bath or shower:       0 - Not at all 2 - Sometimes 4 - A lot	
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 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	
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<ul> <li>PedsQL Child (8-12 yrs)</li> <li>PedsQL Teen (13-18 yrs)</li> </ul> PHYSICAL FUNCTIONING (problems with) It is hard for you to walk: <ul> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul> It is hard for you to run: <ul> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul> It is hard for you to run: <ul> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul> It is hard for you to play sports or exercise: <ul> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul> It is hard for you to pick up big things: <ul> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul> It is hard for you to take a bath or shower: <ul> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul>	
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It is hard for you to walk:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         It is hard for you to run:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         2 - Sometimes       4 - A lot	
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It is hard for you to run:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       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       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         A lot       A lot	
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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 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 play sports or exercise:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         It is hard for you to pick up big things:       0 - Not at all         2 - Sometimes       4 - A lot         Unknown or Not Documented       0 - Not at all         2 - Sometimes       4 - A lot         0 - Not at all       2 - Sometimes         4 - A lot       0 - Not at all         2 - Sometimes       4 - A lot         2 - Sometimes       4 - A lot	
exercise:       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         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       0 - Not at all         4 - A lot       Unknown or Not Documented	
exercise:       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         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       0 - Not at all         4 - A lot       Unknown or Not Documented	
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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 0 - Not at all 2 - Sometimes 4 - A lot	
things:       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	
things:       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	
<ul> <li>4 - A lot</li> <li>Unknown or Not Documented</li> <li>It is hard for you to take a bath or shower:</li> <li>0 - Not at all</li> <li>2 - Sometimes</li> <li>4 - A lot</li> </ul>	
Unknown or Not Documented It is hard for you to take a bath or shower: 0 - Not at all 2 - Sometimes 4 - A lot	
shower: 2 - Sometimes 4 - A lot	
shower: 2 - Sometimes 4 - A lot	
<ul> <li>4 - A lot</li> </ul>	
Unknown or Not Documented	
It is hard for you to do chores (like 0 - Not at all pick up your toys):	
• 4 - A lot	
Unknown or Not Documented	
Do you have hurts or aches: 0 - Not at all	
2 - Sometimes	
4 - A lot	

Where?	
Do you ever feel too tired to play:	O - Not at all
	2 - Sometimes
	4 - A lot
	Unknown or Not Documented
EMOTIONAL FUNCTIONING (problems w	/ith)
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	○ 0 - Not at all
happen to you:	2 - Sometimes
	4 - A lot
	Unknown or Not Documented
SOCIAL FUNCTIONING (problems with	)
Is it hard for you to get along with	○ 0 - Not at all
other kids:	2 - Sometimes
	4 - A lot
	Unknown or Not Documented
Do other kids say they do not want	◯ 0 - Not at all
to play with you:	○ 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

	◯ 0 - Not at all	
	© 2 - Sometimes	
	4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
It is hard for you to keep up when	◯ 0 - Not at all	
you play with other kids:	2 - Sometimes	
	$\sim$ 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
SCHOOL FUNCTIONING (problems with	)	
Is it hard for you to pay attention in	◯ 0 - Not at all	
class:	2 - Sometimes	
	4 - A lot	
	Unknown or Not Documented	
Do you forget things:	○ 0 - Not at all	
	© 2 - Sometimes	
	• 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Is it hard to keep up with	◯ 0 - Not at all	
schoolwork:	© 2 - Sometimes	
	4 - A lot	
	Unknown or Not Documented	
Do you miss school because of not	◯ 0 - Not at all	
feeling good:	2 - Sometimes	
	4 - A lot	
	Our Unknown or Not Documented	
Do you miss school because you	© 0 - Not at all	
have to go to the doctor's or	© 2 - Sometimes	
hospital:	• 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
If No, Please select a reason why	Too sick	
the PedsQOL was not completed:	<ul> <li>Administrative</li> </ul>	
If Administrative: Select a specific	O Urgent implant, no time	
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>	
	<ul> <li>Unable to contact patient</li> </ul>	
	Other reason (specify)	
/ADQoL		
Did the child complete a form?	○ Yes	
v v v v v v v v v v v v v v v v v	<ul> <li>No</li> </ul>	
	Unknown	
The VAD noise bothers me when I		

The VAD noise bothers me when I am awake:

	Always
	Very Often
	Sometimes
	Rarely
	Never
The VAD noise bothers me when I	Always
am trying to sleep:	Very Often
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never
	L
I have pain or discomfort at the	
I have pain or discomfort at the driveline or tubing pump exit site:	Always
arreance of tubing pump exit site.	<ul> <li>Very Often</li> </ul>
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never
I have difficulty sleeping due to the	
position of the driveline or tubing	
pump exit site:	Very Often
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never
I am bothered by how I look with the	Always
VAD:	Very Often
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never
I worry about the VAD breaking or	Always
malfunctioning:	Very Often
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never
I am bothered that I cannot visit	<ul> <li>Always</li> </ul>
family or friends outside the home or hospital with the VAD:	Very Often
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never

3	Month	Followur	o - Quality	of Life	Child	(5-7 v	vrs`	)
~	101011011	1 01101101	, acaunty		Orma i		<b>,</b>	,

onth Followup - Quality of Life Child (5-7 y	rs)	version date: 9/27/2017
I am bothered that I cannot move easily from place to place with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
l cannot participate in usual play activities with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I find it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
Overall, I would describe my day-to- day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>	
Overall, I would describe my day-to- day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>	
If No, Please select a reason why the VADQoL form was not completed:	<ul><li>Too sick</li><li>Administrative</li></ul>	
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>	

### 3 Month Followup

Quality Of Life	
(QOL surveys cannot be administered after the	e 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 ACTIVITES (pro	
It is hard for me to walk more than	
one block:	0 - Never a problem
	<ul> <li>1 - Almost never a problem</li> <li>2 - Comparing a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> <li>2 - Often a number</li> </ul>
	<ul> <li>3 - Often a problem</li> <li>4 - Almost shugue a problem</li> </ul>
	<ul> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
It is hard for me to run:	0 - Never a problem
	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	○ 4 - Almost always a problem
	Unknown or Not Documented
It is hard for me to do sports activity	0 - Never a problem
or exercise:	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	0 Nover e problem
heavy:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	<ul> <li>4 - Almost always a problem</li> </ul>
	<ul> <li>Unknown or Not Documented</li> </ul>
It is hard for me to take a bath or	0 - Never a problem
shower by myself:	<ul> <li>1 - Almost never a problem</li> </ul>
	2 - Sometimes a problem
	○ 3 - Often a problem
	4 - Almost always a problem
	Unknown or Not Documented

#### 3 Month Followup - Quality of Life Child (8-12 yrs)

It is hard for me to do chores around the house:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I hurt or ache:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
Where?		
I have low energy:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
ABOUT MY FEELINGS (problems with)		
I feel afraid or scared:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
l feel sad or blue:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel angry:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I have trouble sleeping:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	

I worry about what will happen to me: HOW I GET ALONG WITH OTHERS (prob I have trouble getting along with other kids:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
Other kids do not want to be my friend:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
Other kids tease me:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
l cannot do things other kids my age can do:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
It is hard to keep up when I play with other kids:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
ABOUT SCHOOL (problems with) Is it hard to pay attention in class:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>

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	○ 0 - Never a problem
schoolwork:	<ul> <li>1 - Almost never a problem</li> </ul>
	2 - Sometimes a problem
	3 - Often a problem
	○ 4 - Almost always a problem
	Our Unknown or Not Documented
I miss school because of not feeling	○ 0 - Never a problem
well:	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	○ 0 - Never a problem
hospital:	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:	<ul> <li>Too sick</li> <li>Administrative</li> </ul>
•	Administrative
If Administrative: Select a specific	Ourgent implant, no time
reason:	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	○ Always
am awake:	Very Often
	<ul> <li>Sometimes</li> </ul>
	Rarely
	Never
The VAD noise bothers me when I am trying to sleep:	<ul> <li>Always</li> <li>Very Often</li> </ul>

	Sometimes	
	Rarely	
	Never	
I have pain or discomfort at the		
driveline or tubing pump exit site:	Always	
	Very Often	
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	۲.
I have difficulty sleeping due to the	Always	
position of the driveline or tubing pump exit site:	Very Often	
pump exit site.	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	
		-
I am bothered by how I look with the	<ul> <li>Always</li> </ul>	
VAD:	Very Often	
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
I worry about the VAD breaking or	Always	
malfunctioning:	Very Often	
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	
I am bothered that I cannot visit	Always	
family or friends outside the home	Very Often	
or hospital with the VAD:	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	r
I am bothered that I cannot move	Al	
easily from place to place with the		
easily from place to place with the VAD:	Very Often	
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	~
I cannot participate in usual play activities with the VAD:	Always	
	Very Often	
	<ul> <li>Sometimes</li> </ul>	

	<ul> <li>Rarely</li> <li>Never</li> </ul>
I find it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>
Overall, I would describe my day-to- day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
Overall, I would describe my day-to- day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
If No, Please select a reason why the VADQoL form was not completed:	<ul> <li>Too sick</li> <li>Administrative</li> </ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

### 3 Month Followup

Quality Of Life (OOL surveys cannot be administered after the	visit date)
PedsQL	
Did the child complete a form?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Please select the 'Child' form:	<ul> <li>PedsQL Young Child (5-7 yrs)</li> <li>PedsQL Child (8-12 yrs)</li> <li>PedsQL Teen (13-18 yrs)</li> </ul>
ABOUT MY HEALTH AND ACTIVITES (pro	blems with)
It is hard for me to walk more than one block:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
It is hard for me to run:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
It is hard for me to do sports activity or exercise:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
It is hard for me to lift something heavy:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
It is hard for me to take a bath or shower by myself:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>

#### 3 Month Followup - Quality of Life Child (13-18 yrs)

It is hard for me to do chores	0 - Never a problem	
around the house:	-	
	<ul> <li>1 - Almost never a problem</li> </ul>	
	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	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Association and a problem</li> </ul>	
	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	
	<ul> <li>3 - Often a problem</li> </ul>	
	<ul> <li>4 - Almost always a problem</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
	Onknown of 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	
	Ounknown or Not Documented	
I feel sad or blue:	◯ 0 - Never a problem	
	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> </ul>	
	<ul> <li>2 - Sometimes a problem</li> <li>2 - Often a problem</li> </ul>	
	3 - Often a problem	
	○ 4 - Almost always a problem	
	<ul> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel angry:	Unknown or Not Documented	
l feel angry:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> </ul>	
l feel angry:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> </ul>	
l feel angry:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> </ul>	
l feel angry:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> </ul>	
I feel angry:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> </ul>	
l feel angry:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> </ul>	
I feel angry: I have trouble sleeping:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> </ul>	

#### 3 Month Followup - Quality of Life Child (13-18 yrs)

I worry about what will happen to	○ 0 - Never a problem
me:	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 (prob	plems with)
I have trouble getting along with other teens:	○ 0 - Never a problem
other teens.	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	○ 0 - Never a problem
friend:	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
	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	3 - Often a problem
	4 - Almost always a problem
	Unknown or Not Documented
I cannot do things other teens my	O - Never a problem
age can do:	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	4 - Almost always a problem
	Ounknown or Not Documented
It is hard to keep up with peers:	○ 0 - Never a problem
	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	<ul> <li>4 - Almost always a problem</li> </ul>
	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	
	<ul> <li>1 - Almost never a problem</li> </ul>	
	2 - Sometimes a problem	
	3 - Often a problem	
	4 - Almost always a problem	
	Unknown or Not Documented	
I have trouble keeping up with my	0 - Never a problem	
schoolwork:	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	○ 0 - Never a problem	
well:	1 - Almost never a problem	
	2 - Sometimes a problem	
	○ 3 - Often a problem	
	4 - Almost always a problem	
	Ounknown or Not Documented	
I miss school to go to the doctor or	○ 0 - Never a problem	
hospital:	<ul> <li>1 - Almost never a problem</li> </ul>	
	<ul> <li>2 - Sometimes a problem</li> </ul>	
	<ul> <li>3 - Often a problem</li> </ul>	
	4 - Almost always a problem	
	Unknown or Not Documented	
If No, Please select a reason why	Too sick	
the PedsQOL was not completed:	<ul> <li>Administrative</li> </ul>	
If Administrative: Select a specific	<ul> <li>Urgent implant, no time</li> </ul>	
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>	
	Unable to contact patient	
	Other reason (specify)	
/ADQoL		
Did the child complete a form?	• Yes	
	No	
	Unknown	
The VAD noise bothers me when I	Always	
am awake:	Very Often	
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	○ Never	
The VAD noise bothers me when I	Always	
am trying to sleep:	Very Often	
	-	

	<ul> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I have pain or discomfort at the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I have difficulty sleeping due to the position of the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I am bothered by how I look with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
l worry about the VAD breaking or malfunctioning:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I am bothered that I cannot visit family or friends outside the home or hospital with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I am bothered that I cannot move easily from place to place with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
I cannot participate in usual play activities with the VAD:	<ul><li>Always</li><li>Very Often</li><li>Sometimes</li></ul>	

	<ul> <li>Rarely</li> <li>Never</li> </ul>
I find it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>
Overall, I would describe my day-to- day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
Overall, I would describe my day-to- day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
If No, Please select a reason why the VADQoL form was not completed:	<ul><li>Too sick</li><li>Administrative</li></ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

## 3 Month Followup

Quality Of Life (Parent)	
(QOL surveys cannot be administered after th	e visit date)
PedsQL	
Did the parent complete a form?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Please select the 'Parent' form:	<ul> <li>PedsQL Toddler (2-4 yrs)</li> <li>PedsQL Young Child (5-7 yrs)</li> <li>PedsQL Child (8-12 yrs)</li> <li>PedsQL Teen (13-18 yrs)</li> </ul>
PHYSICAL FUNCTIONING (problems with	h)
Walking: Walking more than one block:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Running: Running:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Participating in active play or exercise: Participating in sports activity or exercise:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Lifting something heavy: Lifting something heavy:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Bathing: Taking a bath or shower by him or herself:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>

Helping to pick up his or her toys: Doing chores around the house:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Having hurts or aches: Having hurts or aches:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Low energy level: Low energy level:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
EMOTIONAL FUNCTIONING (problems w	/ith)
Feeling afraid or scared: Feeling afraid or scared:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling sad or blue: Feeling sad or blue:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling angry: Feeling angry:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Trouble sleeping: Trouble sleeping:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Worrying: Worrying about what will happen to him or her:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>

in Followup - Quality of Life Farent (2-4	yis)	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
	<ul> <li>Onknown of Not Documented</li> </ul>	
SOCIAL FUNCTIONING (problems with	)	
Playing with other children: Getting	0 - Never	
along with other teens:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Other kids not wanting to play with him or her: Other teens not wanting	0 - Never	
to be his or her friend:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Ounknown 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	© 0 - Never	
children his or her age can do: Not	1 - Almost never	
able to do things that other teens his or her age can do:	<ul> <li>2 - Sometimes</li> </ul>	
his or her age can do.	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Keeping up when playing with other children: Keeping up when playing	◯ 0 - Never	
with other teens:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
SCHOOL FUNCTIONING (problems with.	.)	
Paying attention in class:	© 0 - Never	
-	<ul> <li>1 - Almost never</li> </ul>	
	<ul> <li>2 - Sometimes</li> </ul>	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Forgetting things:	0 - Never	
Forgetting things:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>	

This is the second of the second of the second seco	version date	0. 0/21/20
	© 3 - Often	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Daing the same asked setivities as		
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	○ 0 - Never	
not feeling well: Missing school	1 - Almost never	
because of not feeling well:	2 - Sometimes	
	© 3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Missing school/daycare to go to the	◯ 0 - Never	
doctor or hospital: Missing school to go to the doctor or hospital:	1 - Almost never	
to go to the doctor of hospital.	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	<ul> <li>Unknown or Not Documented</li> </ul>	
If No, Please select a reason why	Too sick	
the PedsQOL was not completed:	Administrative	
If Administrative: Select a specific	<ul> <li>Urgent implant, no time</li> </ul>	
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>	
	<ul> <li>Unable to contact patient</li> </ul>	
	·	
	Other reason (specify)	
/ADQoL		
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	○ Always	
when he or she is awake:	-	
	Very Often	
	© Sometimes	
	Rarely	
	Never	
The VAD noise bothers my child	○ Always	
when he or she is trying to sleep:	<ul> <li>Very Often</li> </ul>	

	<ul> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child has pain or discomfort at the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child has difficulty sleeping due to the position of the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered by how he or she looks with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child worries about the VAD breaking or malfunctioning:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered that he or she cannot visit family or friends outside the home or hospital with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered that he or she cannot move easily from place to place with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	]
My child cannot participate in usual play activities with the VAD:	<ul><li>Always</li><li>Very Often</li><li>Sometimes</li></ul>	

	<ul> <li>Rarely</li> <li>Never</li> </ul>	
My child finds it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> </ul>	
	<ul> <li>Rarely</li> <li>Never</li> </ul>	
Overall, I would describe my child's day-to-day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>	
Overall, I would describe my child's day-to-day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>	
If No, Please select a reason why the VADQoL form was not completed:	<ul><li>Too sick</li><li>Administrative</li></ul>	
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>	
# 3 Month Followup

Quality Of Life (Parent)		
(QOL surveys cannot be administered after th	e visit date)	
PedsQL		
Did the parent complete a form?	<ul><li>Yes</li><li>No</li></ul>	
	Unknown	
Please select the 'Parent' form:	PedsQL Toddler (2-4 yrs)	
	PedsQL Young Child (5-7 yrs)	
	<ul> <li>PedsQL Child (8-12 yrs)</li> <li>PedsQL Teen (13-18 yrs)</li> </ul>	
PHYSICAL FUNCTIONING (problems with		
Walking more than one block:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	O 3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Running:	0 - Never	
	1 - Almost never	
	© 2 - Sometimes	
	Often	
	4 - Almost always	
	Unknown or Not Documented	
Participating in sports activity or	0 - Never	
exercise:	1 - Almost never	
	2 - Sometimes	
	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	0 - Never	
herself:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	○ 4 - Almost always	
	Unknown or Not Documented	

Doing chores, like picking up his or her toys:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Having hurts or aches:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Low energy level:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
EMOTIONAL FUNCTIONING (problems w	vith)
Feeling afraid or scared:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling sad or blue:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling angry:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Trouble sleeping:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Worrying about what will happen to him or her:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>

2 - Sometimes         3 - Othen         3 - Almost always         Unknown of Not Documented         SOCIAL FUNCTIONING (problems with)         Getting along with other children:         1 - Almost newer         2 - Sometimes         3 - Othen         4 - Almost always         - Other kids not wanting to be his or her friend:         0 - Never         1 - Almost never         2 - Sometimes         3 - Othen         4 - Almost always         - Unknown of Not Documented         Other kids not wanting to be his or her friend:         0 - Never         1 - Almost never         2 - Sometimes         - Sometimes         - Soften         - Almost always         - Unknown of Not Documented         Mot able to do things that other         - Never         children his or her age can do:         - O - Never         children his or her age can do:         - O - Never         children his or her age can do:         - Internet never         - Sometimes         - Othen         - Almost always         - Unknown of Not Documented         Keeping up whe	Month Followup - Quality of Life Parent (5-7	yrs)	version date: 9/27/2017
<ul> <li>3 - Often         <ul> <li>4 - Almost always             <ul></ul></li></ul></li></ul>		2 - Sometimes	
4 - Almost always         SOCIAL FUNCTIONING (problems with)         Getting along with other children:         0 - Never         1 - Almost always         Winknown or Net Documented         Other kids not wanting to be his or         0 - Never         1 - Almost always         Unknown or Net Documented         Other kids not wanting to be his or         0 - Never         1 - Almost always         Unknown or Net Documented         Other kids not wanting to be his or         0 - Never         1 - Almost always         Unknown or Net Documented         Other kids not wanting to be his or         0 - Never         1 - Almost always         Unknown or Net Documented         Outhorw or Net Documented         Not able to do things that other         children his or her age can do:         2 - Sometimes         3 - Othen         4 - Almost always         Unknown or Net Documented         Keeping up when playing with other         children:         2 - Sometimes         3 - Othen         4 - Almost always         Unknown or Net Documented         SCHOOL FUNCTIONING (problems with)			
SOCIAL FUNCTIONING (problems with)         Getting along with other children:       0 - Never         1 - Annost never         2 - Sometimes         3 - Often         4 - Atmost always         Unknown or Not Documented         Other kids not wanting to be his or her friend:         0 - Never         1 - Annost never         2 - Sometimes         3 - Often         4 - Atmost always         Unknown or Not Documented         Getting teased by other children:         0 - Never         1 - Atmost never         2 - Sometimes         3 - Often         4 - Atmost always         Unknown or Not Documented         Not able to do things that other         children his or her age can do:         0 - Never         1 - Atmost never         2 - Sometimes         3 - Often         4 - Atmost always         Unknown or Not Documented         Keeping up when playing with other children his or her age can do:         0 - Never         1 - Atmost never         2 - Sometimes         3 - Often         4 - Atmost always         Unknown or Not Documented         SCHOOL FUNCTIO			
SOCIAL FUNCTIONING (problems with)         Getting along with other children:       0 - Never         1 - Almost never       2 - Sometimes         2 - Sometimes       3 - Oten         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 - Otten       3 - Otten         4 - Almost never       2 - Sometimes         3 - Otten       4 - Almost never         2 - Sometimes       3 - Otten         4 - Almost never       2 - Sometimes         3 - Otten       - Almost never         2 - Sometimes       3 - Otten         4 - Almost never       2 - Sometimes         3 - Otten       - Almost never         2 - Sometimes       3 - Otten         4 - Almost never       2 - Sometimes         3 - Otten       - Almost never         2 - Sometimes       3 - Otten         4 - Almost never       - Sometimes         3 - Otten       - Almost never         2 - Sometimes       - Othen         4 - Almost never       - Sometimes         3 - Otten       - Almost never         2 - Sometimes       - Othen			
Getting along with other children:       0 - Never         1 - Almost never       2 - Sometimes         2 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         4 - Almost always       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       2 - Sometimes         3 - Otten       4 - Almost always         Unknown or Not Documented       3 - Otten         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       2 - Sometimes         3 - Ofte			
<ul> <li>I - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>Other kids not wanting to be his or her friend:</li> <li>O - Never</li> <li>1 - Almost always</li> <li>Unknown or Not Documented</li> <li>Getting teased by other children:</li> <li>0 - Never</li> <li>1 - Almost always</li> <li>Unknown or Not Documented</li> <li>Getting teased by other children:</li> <li>0 - Never</li> <li>1 - Almost always</li> <li>Unknown or Not Documented</li> <li>Getting teased by other children:</li> <li>0 - Never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>Most always</li> <li>Unknown or Not Documented</li> <li>Keeping up when playing with other children his or her age can do:</li> <li>0 - Never</li> <li>1 - Almost always</li> <li>Unknown or Not Documented</li> <li>School FUNCTIONING (problems with)</li> <li>Paying attention in class:</li> <li>3 - Often</li> <li>4 - Minost always</li> <li>Unknown or Not Documented</li> <li>School FUNCTIONING (problems with)</li> <li>Paying attention in class:</li> <li>3 - Often</li> <li>4 - Minost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>3 - Often</li> <li>4 - Minost always</li> <li>Unknown or Not Documented</li> <li>School FUNCTIONING (problems with)</li> <li>Paying attention in class:</li> <li>0 - Never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Minost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Minost never</li> <li>2 - Sometimes</li></ul>	SOCIAL FUNCTIONING (problems with	)	
<ul> <li>2 - Sometimes         <ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> </li> <li>Other kids not wanting to be his or her friend:         <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> </li> <li>Getting teased by other children:         <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Minost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> </li> <li>SCHOOL FUNCTIONING (problems with)</li> <li>Paying attention in class:             <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li></ul></li></ul>	Getting along with other children:	○ 0 - Never	
- 3 - Often         - A Amost always         - Unknown or Not Documented         Other kids not wanting to be his or her friend:       0 - Never         1 - Amost never         2 - Sometimes         3 - Otten         4 - Amost 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         Mot 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         Mot able to do things that other children his or her age can do:         0 - Never         1 - Almost always         Unknown or Not Documented         Keeping up when playing with other         0 - Never         1 - Minost never         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)         Paying attention in class:		1 - Almost never	
• 4 - Almost always         • Unknown or Not Documented         Other kids not wanting to be his or her friend:       • • Never         • 1 - Almost never       • 2 - Sometimes         • 3 - Otlen       • - Almost always         • Unknown or Not Documented       • • Never         Getting teased by other children:       • • Never         • 1 - Almost never       • 2 - Sometimes         • 3 - Otlen       • - Almost always         • Unknown or Not Documented       • • Never         • Almost always       • Unknown or Not Documented         Not able to do things that other children his or her age can do:       • • • Never         • 1 - Almost always       • Unknown or Not Documented         Most able to do things that other children his or her age can do:       • • • Never         • 2 - Sometimes       • • • • • • • • • • • • • • • • • • •		2 - Sometimes	
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her friend:       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       - Almost always         Or Never       - Almost always         - Unknown or Not Documented       - O - Never         - Almost always       - Unknown or Not Documented         Not able to do things that other       - O - Never         - Almost always       - Unknown or Not Documented         Weeping up when playing with other       - O - Never         - Almost always       - Unknown or Not Documented         Keeping up when playing with other       - O - Never         - Almost always       - Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       - O - Never         Paying attention in class:       - O - Never         - Almost always       - Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       - O - Never         - Almost always       - Unknown or Not Documented         - Almost always       - Unknown or Not Documented         - Almost always       - Unknown or			
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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:         3 - Often         4 - Almost always         Unknown or Not Documented         Not able to do things that other:         children his or her age can do:         3 - Often         4 - Almost always         Unknown or Not Documented         Keeping up when playing with other         children:         children	ner friend:	1 - Almost never	
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         0 - Never         1 - Almost always         Unknown or Not Documented         Not able to do things that other         0 - Never         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         Keeping up when playing with other         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         SCHOOL FUNCTIONING (problems with)         Paying attention in class:         0 - Never         1 - Almost always <tr< th=""><td></td><td>2 - Sometimes</td><td></td></tr<>		2 - Sometimes	
Getting teased by other children:       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         children his or her age can do:       0 - Never         2 - Sometimes       3 - Often         3 - Often       1 - Almost never         2 - Sometimes       3 - Often         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         Keeping up when playing with other       0 - Never         1 - Almost never       2 - Sometimes         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         Paying attention in class:       0 - Never         3 - Often       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         9 - Often       4 - Almost always         0 - Unknown or Not Documented       3 - Often         4 - Almost		3 - Often	
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Getting teased by other children:       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         children his or her age can do:       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         Children his or her age can do:       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         Keeping up when playing with other       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         Paying attention in class:       0 - Never         2 - Sometimes       3 - Often         3 - Often       4 - Almost always         Unknown or Not Documented       3 - Often         3 - Often       4 - Almost always         Unknown or Not Documented       3 - Often         4 - Almost always       Unknown or Not Documented         Forgett		-	
<ul> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Not able to do things that other children his or her age can do: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Keeping up when playing with other children: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>		Onknown of Not Documented	
<ul> <li>2 - Sometimes</li> <li>3 - Orten</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>Not able to do things that other children his or her age can do:</li> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Orten</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Keeping up when playing with other children: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> ScHOOL FUNCTIONING (problems with)           Paying attention in class:         0 - Never           1 - Almost never         2 - Sometimes           3 - Often         4 - Almost always           Unknown or Not Documented         Unknown or Not Documented	Getting teased by other children:	◯ 0 - Never	
3 - Often         4 - Almost always         Unknown or Not Documented         Not able to do things that other         children his or her age can do:         1 - Almost never         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         Keeping up when playing with other         children:         1 - Almost never         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         Keeping up when playing with other         children:         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         Ever         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         Ever         2 - Sometimes         3 - Often		1 - Almost never	
3 - Often         4 - Almost always         Unknown or Not Documented         Not able to do things that other         children his or her age can do:         1 - Almost never         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         Keeping up when playing with other         children:         1 - Almost always         Unknown or Not Documented         Keeping up when playing with other         children:         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 never         2 - Sometimes         3 - Often         4 - Almost never         2 - Sometimes         3 - Often         4 - Almost never         2 - Sometimes         3 - Often         4 - Almost never         2 - Sometimes         3 - Often         4 - Almost always		2 - Sometimes	
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 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 never         2 - Sometimes         3 - Often         4 - Almost never         2 - Sometimes         3 - Often         4 - Almost never         2 - Sometimes         3 - Often         4 - Almost always         Unknown or Not Documented         Forgetting things:         0 - Never         1 - Almost never			
• Unknown or Not Documented         • Not able to do things that other children his or her age can do:         • 0 - Never children his or her age can do:         • 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)       0 - Never 1 - Almost never 2 - Sometimes 3 - Often 4 - Almost never			
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       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost never       2 - Sometimes         3 - Often       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         Paying attention in class:       0 - Never         3 - Often       4 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         1 - Almost			
children his or her age can do:       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       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       4 - Almost never         9 - Never       1 - Almost never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       5CHOOL FUNCTIONING (problems with)         Paying attention in class:       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       4 - Almost always         Unknown or Not Documented       9 - Never         4 - Almost always       Unknown or Not Documented         Forgetting things:       0 - Never         1 - Almost never       1 - Almost never		Onknown of Not Documented	
Image: Sometimes		0 - Never	
<ul> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Keeping up when playing with other children: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost always</li> <li>Unknown or Not Documented</li> </ul>	children his or her age can do:	1 - Almost never	
<ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>Keeping up when playing with other children:</li> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>SCHOOL FUNCTIONING (problems with)</li> <li>Paying attention in class:</li> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost never</li> <li>1 - Almost never</li> </ul>			
<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>Keeping up when playing with other children:</li> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>			
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       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       0 - Never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         Forgetting things:       0 - Never         1 - Almost never       1 - Almost never			
Keeping up when playing with other       0 - Never         children:       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         9 - Never       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       0 - Never         6 - Almost never       2 - Sometimes         3 - Often       4 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         Forgetting things:       0 - Never         1 - Almost always       Unknown or Not Documented			
children:       1 - Almost never         2 - Sometimes       3 - Often         4 - Almost always       Unknown or Not Documented         SCHOOL FUNCTIONING (problems with)       0 - Never         1 - Almost never       2 - Sometimes         3 - Often       4 - Almost never         2 - Sometimes       3 - Often         4 - Almost never       2 - Sometimes         3 - Often       4 - Almost always         Unknown or Not Documented       Unknown or Not Documented		Unknown or Not Documented	
<ul> <li>I - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with)           Paying attention in class:         0 - Never           1 - Almost never         2 - Sometimes           3 - Often         4 - Almost never           2 - Sometimes         3 - Often           4 - Almost never         2 - Sometimes           3 - Often         4 - Almost never           2 - Sometimes         3 - Often           4 - Almost always         Unknown or Not Documented           Forgetting things:         0 - Never           1 - Almost never         1 - Almost never		◯ 0 - Never	
<ul> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>	children:	1 - Almost never	
<ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with) Paying attention in class: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>			
<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> SCHOOL FUNCTIONING (problems with)           Paying attention in class:         0 - Never           1 - Almost never         2 - Sometimes           3 - Often         4 - Almost always           Unknown or Not Documented         0 - Never           Forgetting things:         0 - Never           1 - Almost never         0 - Never           3 - Often         1 - Almost always           Unknown or Not Documented         0 - Never           1 - Almost never         1 - Almost never			
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  1 - Almost never  1 - Almost never			
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         1 - Almost never			
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			
<ul> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>		)	
<ul> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>	Paying attention in class:		
<ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul> Forgetting things: <ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>			
<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>Forgetting things:</li> <li>0 - Never</li> <li>1 - Almost never</li> </ul>			
<ul> <li>Unknown or Not Documented</li> <li>Forgetting things:</li> <li>0 - Never</li> <li>1 - Almost never</li> </ul>		3 - Often	
Forgetting things:       0 - Never         1 - Almost never		4 - Almost always	
1 - Almost never		Unknown or Not Documented	
1 - Almost never	Exporting things		
	Forgetting trings:		
2 - Sometimes			
		2 - Sometimes	

null i ollowup - Quality of Life i alent (5-7		
	© 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	○ 0 - Never	
feeling well:	1 - Almost never	
	© 2 - Sometimes	
	© 3 - Often	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
	Onknown of Not Documented	
Missing school to go to the doctor	◯ 0 - Never	
or hospital:	1 - Almost never	
	O 2 - Sometimes	
	3 - Often	
	○ 4 - Almost always	
	<ul> <li>Unknown or Not Documented</li> </ul>	
If No, Please select a reason why		
the PedsQOL was not completed:	Too sick	
	Administrative	
If Administrative: Select a specific	<ul> <li>Urgent implant, no time</li> </ul>	
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>	
	Unable to contact patient	
	Other reason (specify)	
VADQoL		
Did the parent complete a form?	<ul><li>Yes</li><li>No</li></ul>	
Please select the 'Parent' form:	○ VADQoL: Parent (child < 2 yrs)	
	○ VADQoL: Parent (child >= 2 yrs)	
The VAD noise bothers my child	Always	
when he or she is awake:	Very Often	
	Sometimes	
	<ul> <li>Rarely</li> </ul>	
	<ul> <li>Rareny</li> <li>Never</li> </ul>	
The VAD noise bothers my child when he or she is trying to sleep:	Always	
anon no or one is trying to sicep.	Very Often	

	<ul> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child has pain or discomfort at the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child has difficulty sleeping due to the position of the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered by how he or she looks with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child worries about the VAD breaking or malfunctioning:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered that he or she cannot visit family or friends outside the home or hospital with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered that he or she cannot move easily from place to place with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child cannot participate in usual play activities with the VAD:	<ul><li>Always</li><li>Very Often</li><li>Sometimes</li></ul>	

	<ul> <li>Rarely</li> <li>Never</li> </ul>	
My child finds it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
Overall, I would describe my child's day-to-day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>	
Overall, I would describe my child's day-to-day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>	
If No, Please select a reason why the VADQoL form was not completed:	<ul><li>Too sick</li><li>Administrative</li></ul>	
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>	

# 3 Month Followup

Quality Of Life (Parent)	
(QOL surveys cannot be administered after th	e visit date)
PedsQL	
Did the parent complete a form?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Please select the 'Parent' form:	<ul> <li>PedsQL Toddler (2-4 yrs)</li> <li>PedsQL Young Child (5-7 yrs)</li> <li>PedsQL Child (8-12 yrs)</li> <li>PedsQL Teen (13-18 yrs)</li> </ul>
PHYSICAL FUNCTIONING (problems with	n)
Walking more than one block:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Running:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Participating in sports activity or exercise:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Lifting something heavy:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Taking a bath or shower by him or herself:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>

Doing chores, like picking up his or her toys::	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Having hurts or aches:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Low energy level:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
EMOTIONAL FUNCTIONING (problems w	vith)
Feeling afraid or scared:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling sad or blue:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling angry:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Trouble sleeping:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Worrying about what will happen to him or her:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>

itt i ollowup - Quality of Life i alerit (0-1	z yis)	
	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	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Other kids not wanting to be his or	◯ 0 - Never	
her friend:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Getting teased by other children:	◯ 0 - Never	
	1 - Almost never	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Not able to do things that other	◯ 0 - Never	
children his or her age can do:	1 - Almost never	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Keeping up when playing with other	○ 0 - Never	
children:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	○ 4 - Almost always	
	Unknown or Not Documented	
SCHOOL FUNCTIONING (problems with		
Paying attention in class:	© 0 - Never	
	<ul> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Forgetting things:	0 - Never	
Forgetting things:	0 - Never	
Forgetting things:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> </ul>	

	3 - Often
	4 - Almost always
	<ul> <li>Unknown or Not Documented</li> </ul>
Keeping up with school activities:	© 0 - Never
5 F 5 F 5 F 5 F 5 F 5 F 5 F 5 F 5 F 5 F	0 1 - Almost never
	2 - Sometimes
	© 3 - Often
	<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Missing school because of not feeling well:	◯ 0 - Never
leening wen.	1 - Almost never
	2 - Sometimes
	O 3 - Often
	○ 4 - Almost always
	<ul> <li>Unknown or Not Documented</li> </ul>
Missing school to go to the doctor	© 0 - Never
or hospital:	0 1 - Almost never
	2 - Sometimes
	<ul> <li>3 - Often</li> <li>4 - Alward alward</li> </ul>
	○ 4 - Almost always
	<ul> <li>Unknown or Not Documented</li> </ul>
If No, Please select a reason why	Too sick
the PedsQOL was not completed:	<ul> <li>Administrative</li> </ul>
If Administrative: Select a specific	<ul> <li>Urgent implant, no time</li> </ul>
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>
	Output Unable to contact patient Output Out
	Other reason (specify)
/ADQoL	
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	Alwaya
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
when he of she is trying to sleep:	Very Often

	Sometimes	
	Rarely	
	Never	
		J
My child has pain or discomfort at	<ul> <li>Always</li> </ul>	
the driveline or tubing pump exit site:	Very Often	
Site.	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	
My child has difficulty sleeping due to the position of the driveline or	Always	
tubing pump exit site:	Very Often	
	Sometimes	
	Rarely	
	Never	
		,
My child is bothered by how he or	<ul> <li>Always</li> </ul>	
she looks with the VAD:	Very Often	
	Sometimes	
	Rarely	
	Never	
My child worries about the VAD	Alwaya	
breaking or malfunctioning:	Always	
Stearing of mananettering.	Very Often	
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	
My child is bothered that he or she	<ul> <li>Always</li> </ul>	
cannot visit family or friends	Very Often	
outside the home or hospital with the VAD:	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	
		)
My child is bothered that he or she	Always	
cannot move easily from place to	Very Often	
place with the VAD:		
	<ul> <li>Sometimes</li> </ul>	
	Rarely	
	Never	
My child cannot participate in usual play activities with the VAD:	Always	
play activities with the VAD.	Very Often	
	<ul> <li>Sometimes</li> </ul>	

	<ul> <li>Rarely</li> <li>Never</li> </ul>
My child finds it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>
Overall, I would describe my child's day-to-day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
Overall, I would describe my child's day-to-day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
If No, Please select a reason why the VADQoL form was not completed:	<ul><li>Too sick</li><li>Administrative</li></ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

# 3 Month Followup

Quality Of Life (Parent)		
(QOL surveys cannot be administered after th	e 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	ı)	
Walking more than one block:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
<b>_</b> .		
Running:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Participating in sports activity or	0 - Never	
exercise:	0 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	0 - Never	
herself:	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 burts or achos:	
Having hurts or aches:	0 - Never
	<ul> <li>1 - Almost never</li> <li>2 - Competinger</li> </ul>
	<ul> <li>2 - Sometimes</li> <li>3 - Often</li> </ul>
	4 - Almost always
	Unknown or Not Documented
Low energy level:	○ 0 - Never
	1 - Almost never
	O 2 - Sometimes
	○ 3 - Often
	4 - Almost always
	Unknown or Not Documented
EMOTIONAL FUNCTIONING (problems w	
Feeling afraid or scared:	
reening analu or scaled.	0 - Never
	<ul> <li>1 - Almost never</li> <li>2 - Demotives</li> </ul>
	2 - Sometimes
	<ul> <li>3 - Often</li> </ul>
	4 - Almost always
	Unknown or Not Documented
Feeling sad or blue:	○ 0 - Never
	1 - Almost never
	2 - Sometimes
	3 - Often
	4 - Almost always
	<ul> <li>Unknown or Not Documented</li> </ul>
Feeling angry:	0 - Never
	<ul> <li>1 - Almost never</li> </ul>
	2 - Sometimes
	<ul> <li>3 - Often</li> </ul>
	• 4 - Almost always
	<ul> <li>Unknown or Not Documented</li> </ul>
	Onknown of Not Documented
Trouble sleeping:	◯ 0 - Never
	1 - Almost never
	2 - Sometimes
	3 - Often
	Unknown or Not Documented
Worrying about what will happen to	0 - Never
him or her:	
-	1 - Almost never

ith Followup - Quality of Life Parent (13-	ið yrs)	version date: 9/27/20
	2 - Sometimes	
	○ 2 • 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	0 - Never	
her friend:	1 - Almost never	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	○ 4 - Almost always	
	Unknown or Not Documented	
Getting teased by other teens:	0 - Never	
	<ul> <li>1 - Almost never</li> </ul>	
	<ul> <li>2 - Sometimes</li> </ul>	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Not able to do things that other	0 - Never	
teens his or her age can do:	1 - Almost never	
	<ul> <li>2 - Sometimes</li> </ul>	
	<ul> <li>3 - Often</li> </ul>	
	4 - Almost always	
	Unknown or Not Documented	
Keeping up when playing with other	0 - Never	
teens:	1 - Almost never	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	4 - Almost always	
	Unknown or Not Documented	
CHOOL FUNCTIONING (problems with	)	
Paying attention in class:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	• 4 - Almost always	
	<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>	
Forgetting things:	<ul> <li>Unknown or Not Documented</li> <li>0 - Never</li> </ul>	
Forgetting things:	Unknown or Not Documented	

Often
• 4 - Almost always
Unknown or Not Documented
0 - Never
<ul> <li>1 - Almost never</li> </ul>
2 - Sometimes
3 - Often
○ 4 - Almost always
Unknown or Not Documented
0 - Never
<ul> <li>1 - Almost never</li> </ul>
2 - Sometimes
3 - Often
O 4 - Almost always
Unknown or Not Documented
0 - Never
1 - Almost never
2 - Sometimes
3 - Often
4 - Almost always
Unknown or Not Documented
Too sick
Administrative
<ul> <li>Urgent implant, no time</li> </ul>
Coordinator too busy or forgot
Unable to contact patient
Other reason (specify)
• Yes
No
Unknown
○ VADQoL: Parent (child < 2 yrs)
VADQoL: Parent (child >= 2 yrs)
Very Often
Sometimes
Rarely
○ Never
○ Always
Very Often

	<ul> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child has pain or discomfort at the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child has difficulty sleeping due to the position of the driveline or tubing pump exit site:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered by how he or she looks with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child worries about the VAD breaking or malfunctioning:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered that he or she cannot visit family or friends outside the home or hospital with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child is bothered that he or she cannot move easily from place to place with the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>	
My child cannot participate in usual play activities with the VAD:	<ul><li>Always</li><li>Very Often</li><li>Sometimes</li></ul>	

3 Month	Followup	Quality		Daront /	12 10	(rc)
3 WORLD	Followup	- Quality	y or Life	r aleni (	13-10	y15)

	<ul> <li>Rarely</li> <li>Never</li> </ul>
My child finds it difficult to express feelings and talk to others about the VAD:	<ul> <li>Always</li> <li>Very Often</li> <li>Sometimes</li> <li>Rarely</li> <li>Never</li> </ul>
Overall, I would describe my child's day-to-day level of worry with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
Overall, I would describe my child's day-to-day level of happiness with the VAD to be:	<ul> <li>High</li> <li>Between High and Medium</li> <li>Medium</li> <li>Between Low and Medium</li> <li>Low</li> </ul>
If No, Please select a reason why the VADQoL form was not completed:	<ul> <li>Too sick</li> <li>Administrative</li> </ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

Please enter the date of the event yo are reportin	ju g:		
Please enter a label describing th ever	is .t:		

Was there an occurrence of rehospitalization?	<ul><li>Yes</li><li>No</li></ul>
Data of admination	
Date of admission	ST= OUnknown
Discharge Date	
	ST= Ounknown
Primary reason for rehospitalization	Anticoagulation adjustment
	Arterial Non-CNS Thrombo-embolism
	Cardiac Arrhythmia
	Catastrophe (i.e. weather)
	O Device Malfunction
	Diagnostic Procedure
	◯ Explant
	Fever without known cause
	Fluid Overload
	Gastroenteritis
	GI Disorder
	Hematological
	Hematoma
	Hemolysis
	Hepatic Dysfunction
	Hypertension
	Limb vascular complication
	<ul> <li>Major Bleeding</li> </ul>
	Major Infection
	Metabolic/Electrolyte Disturbance
	Myocardial Infarction
	Neurological Dysfunction
	Other, specify
	Pericardial Fluid Collection
	Planned medical management
	Planned Procedure
	O Pneumonia
	O Psychiatric Episode
	Pulmonary Embolism/Hemorrhage
	Pulmonary, Other
	Renal Dysfunction
	Respiratory Failure
	Right Heart Failure
	Social Issues / Disposition (Foster Care / Eviction)
	<ul> <li>Syncope without known cause</li> </ul>
	Transplant

	Unknown
	Venous Thromboembolic Event
	Wound Complication
	Wound Dehiscence
Rehospitalization intervention	None
	<ul> <li>Transplantation</li> <li>Surgical Procedure</li> <li>Heart Cath</li> <li>Invasive Cardiac Procedures (Other than Heart Cath)</li> <li>Unknown</li> <li>Other</li> </ul>
Type of surgical procedure	<ul> <li>Device related operation</li> <li>Other Cardiac Surgical Procedure</li> <li>Non Cardiac Surgical Procedure</li> <li>Other procedure</li> <li>Unknown</li> </ul>
Type of other cardiac procedure	<ul> <li>Reoperation for Bleeding within 48 hours of implant</li> <li>Reoperation for Bleeding and/or tamponade &gt; 48 hours</li> <li>Surgical Drainage of pericardial effusion</li> <li>Aortic Valve Surgery - Repair (no valve closure)</li> <li>Aortic Valve Surgery - Repair with valve closure</li> <li>Aortic Valve Surgery - Replacement - Biological</li> <li>Aortic Valve Surgery - Replacement - Mechanical</li> <li>Mitral Valve Surgery - Replacement - Biological</li> <li>Mitral Valve Surgery - Replacement - Biological</li> <li>Mitral Valve Surgery - Replacement - Biological</li> <li>Mitral Valve Surgery - Replacement - DeVega</li> <li>Tricuspid Valve Surgery - Repair - Other</li> <li>Tricuspid Valve Surgery - Replacement - Biological</li> <li>Tricuspid Valve Surgery - Replacement - Biological</li> <li>Tricuspid Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Replacement - Biological</li> <li>Other, specify</li> <li>Unknown</li> </ul>
Type of procedure (non cardiac surgical procedure)	
Other procedure	<ul> <li>Intubation and Vent support</li> <li>Dialysis</li> <li>Bronchoscopy</li> <li>Other, specify</li> </ul>
Type of Invasive Cardiac Procedure (Other than Heart Cath)	
Enter PA systolic pressure	mmHg
	ST= Ounknown Not Done

Enter PA diastolic pressure		mmHg		
	ST= Unknown			
	Not Done			
Enter DOW process				
Enter PCW pressure		mmHg		
	ST= Unknown			
	Not Done			
Enter Cardiac output		L/min		
	ST= OUnknown			
	Not Done			
Clinical Observations				
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			
Did patient receive new IV or oral	Yes			
medications to treat hypertension?	No			
	Unknown			
Has the patient experienced a	Yes			
Neurological Event since time of implant?	No			
	Unknown			
If yes, please enter the Modified Rankin	Scale.			
Modified Rankin Scale	0 – No symptoms at			
	duties and activities	sability: despite symptoms: able to carry out all usual		
	<ul> <li>2 - Slight disability: unable to carry out all previous activities but able to</li> </ul>			
	look after own affairs without assistance			
		ty: requiring some help, but able to walk without		
	assistance.	re disability: unable to walk without assistance, and		
		bodily needs without assistance.		
		bedridden, incontinent and requiring constant		
	nursing care and attention	on.		
	6 - Dead			
	ST= ONot Documented	d		
	Not Done	<u> </u>		

ection	
Was there a major infection?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Date of onset	ST= OUnknown
Did this infection contribute to death?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Location of patient	<ul> <li>In hospital</li> <li>Out of hospital</li> <li>Unknown</li> </ul>
Location of infection	<ul> <li>Pump / related - Drive Line</li> <li>Pump / related - Exit Cannula</li> <li>Pump / related - Pump Pocket</li> <li>Pump / related - Pump Interior</li> <li>Positive Blood cultures</li> <li>Line Sepsis</li> <li>Pulmonary</li> <li>Urinary Tract</li> <li>Mediastinum</li> <li>Peripheral Wound</li> <li>GI</li> <li>Unknown</li> <li>Other, specify</li> </ul>
Type of infection	<ul> <li>Bacterial</li> <li>Fungal</li> <li>Viral</li> <li>Protozoan</li> <li>Unknown</li> </ul>
Intervention	<ul> <li>Drug therapy only: Oral</li> <li>Drug therapy only: IV</li> <li>Surgical and drug therapy</li> <li>Surgical therapy only</li> <li>Unknown</li> </ul>
Is this a Device Related Event?	<ul><li>Yes</li><li>No</li></ul>

Was there a Major Bleeding Event?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Date of bleeding episode onset	ST= OUnknown
Location of patient	<ul> <li>In hospital</li> <li>Out of hospital</li> <li>Unknown</li> </ul>
Did the major bleeding episode result in one or more of the following	<ul> <li>Episode resulted in Death</li> <li>Episode resulted in re-intervention</li> <li>Episode resulted in hospitalization</li> <li>Episode resulted in transfusion</li> </ul>
Total units PRBC's (Enter total number of cc's received for this bleeding episode)	ST= OUnknown
Date of first transfusion for this episode	ST= OUnknown
Source/cause/location of bleeding	<ul> <li>Mediastinal: chest wall</li> <li>Mediastinal: outflow-aorta anastomosis</li> <li>Mediastinal: outflow conduit</li> <li>Mediastinal: inflow conduit</li> <li>Mediastinal: aortic-venous cannulation site</li> <li>Mediastinal: coagulopathy with no surgical site</li> <li>Mediastinal: other surgical site</li> <li>Pump pocket</li> <li>Pleural space</li> <li>Intra-abdominal</li> <li>Retroperitoneal</li> <li>Pulmonary</li> <li>Device anastamosis</li> <li>Urinary tract</li> <li>GI: Upper gastrointestinal (colon, rectum, and anus)</li> <li>GI: unknown, but guaiac positive stools</li> <li>Other, specify</li> </ul>
Heparin levels	ST= Unknown Not Done

INR		
	ST= Ounknown	
	Not Done	
Anticoagulant therapy at time of	Warfarin	
event	Heparin	
	Aspirin	
	Dipyridamole	
	Clopidogrel (plavix)	
	Argatroban	
	Bivalirudin	
	Fondaparinux	
	Dextran	
	<ul><li>Ticlopidine</li><li>Hirudin</li></ul>	
	Ximelagatran	
	<ul> <li>None</li> </ul>	
	Other, specify	
Is this a Device Related Event?	Yes	
	No	

Was there a neurological dysfunction?	
aysiulction?	
	Unknown
Date of onset	
	ST= Unknown
Location of patient	In hospital
	Out of hospital
	OUnknown
leurological dysfunction categories	□ TIA
•	O CVA
	○ Seizure
	<ul> <li>Encephalopathy</li> </ul>
	Infarction Seen by Imaging, without Clinical Findings of TIA/Stroke
	Extra-axial Bleeding Seen by imaging study
	Confusion
	None
Type of CVA	Ischemic / Embolism
	Hemorrhagic
	Other
Stroke severity	Left sided weakness
	Right sided weakness
	Left sided paralysis
	Right sided paralysis
	Speech deficit
	Altered mental status
	Coma
	Other, specify
Is this a Device Related Event?	• Yes
	No
Seizure Type	Generalized
	○ Focal
Encephalopathy type	<ul> <li>Metabolic</li> </ul>
	Anoxic
	Other
Did this Neurological Dysfunction	○ Yes
Adverse Event contribute to the	○ No

Location of CNS event	Right hemisphere: frontal	
	Right hemisphere: temporal	
	Right hemisphere: occipital	
	Right hemisphere: parietal	
	<ul> <li>Right hemisphere: unspecified</li> </ul>	
	<ul> <li>Left hemisphere: frontal</li> </ul>	
	Left hemisphere: temporal	
	Left hemisphere: occipital	
	Left hemisphere: parietal	
	Left hemisphere: unspecified	
	Bilateral: frontal	
	Bilateral: temporal	
	Bilateral: occipital	
	Bilateral: parietal	
	Occipital	
	Brain stem	
	Cerebellar	
	Thalamic	
	Subdural	
	Spinal cord	
	Unknown	
	Other, specify	
Method of diagnosis of CNS event	○ CT	
	O MRI	
	<ul> <li>Angiogram</li> </ul>	
	• EEG	
	Ultrasound	
	Unknown	
	Other, specify	
Anticoagulant therapy at time of	Warfarin	
event	Heparin	
	Lovenox	
	Aspirin	
	Dipyridamole	
	<ul><li>Dipyridamole</li><li>Clopidogrel (plavix)</li></ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> <li>None</li> </ul>	
	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> <li>None</li> </ul>	
Hypertension	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> <li>None</li> <li>Other, specify</li> </ul>	
Hypertension	<ul> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> <li>None</li> <li>Other, specify</li> </ul>	

Has the patient experienced a Neurological Event since time of implant?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, please enter the Modified Rankin	Scale.
Modified Rankin Scale	<ul> <li>0 - No symptoms at all</li> <li>1 - No Significant disability</li> <li>2 - Slight disability</li> <li>3 - Moderate disability</li> <li>4 - Moderately severe disability</li> <li>5 - Severe disability</li> <li>6 - Dead</li> </ul> ST= Not Documented <ul> <li>Not Done</li> </ul>

Was there a device malfunction / failure and / or a pump thrombus?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Date of onset	
Device Type	
Location of patient	<ul> <li>In hospital</li> <li>Out of hospital</li> <li>Unknown</li> </ul>
Description of Malfunction	
ombus Event	
Did the patient experience a thrombus event (suspected or confirmed)?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Was the suspected or confirmed thrombus associated with one or more of the following signs or symptoms?	<ul> <li>Hemolysis</li> <li>Heart Failure</li> <li>Abnormal Pump Parameters</li> <li>Stroke</li> <li>TIA</li> <li>Arterial Non-CNS Thromboembolism</li> <li>None</li> <li>Other, Specify</li> </ul>
id the patient have one or more of the following?	<ul> <li>Treatment with intravenous anticoagulation (e.g. heparin)</li> <li>Intravenous thrombolytic (e.g. TPA)</li> <li>Intravenous antiplatelet therapy (e.g. eptifibatide)</li> <li>Other, Specify</li> </ul>
Was the thrombus event confirmed?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Please select method of confirmation:	<ul> <li>Imaging Study</li> <li>Visual Inspection</li> <li>Manufacturer's Report</li> </ul>

Was there a device Malfunction?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>	
Please select all of the component	ts that apply	
Pump	<ul><li>Yes</li><li>No</li></ul>	
Pump Component(s)	<ul> <li>Pump Body (including bearings and rotor)</li> <li>Driveline</li> <li>Inflow Cannula</li> <li>Outflow Graft (including bend relief)</li> </ul>	
Controller	<ul><li>Yes</li><li>No</li></ul>	
Controller	<ul> <li>Primary System Failure (running in backup mode)</li> <li>Complete System Failure (primary and backup failure)</li> <li>Power Cable (attached to controller)</li> <li>Power Connectors (attached to controller)</li> <li>Other, Specify</li> </ul>	
Peripherals	<ul><li>Yes</li><li>No</li></ul>	
Peripheral Component(s)	<ul> <li>External Battery</li> <li>Cell Battery (in controller)</li> <li>Power Module</li> <li>Patient Cable</li> <li>System Monitor / Display</li> <li>Battery Charger</li> <li>Battery Clip</li> </ul>	
Pump (RVAD)	<ul><li>Yes</li><li>No</li></ul>	
Pump Component(s) (RVAD)	<ul> <li>Pump Body (including bearings and rotor)</li> <li>Driveline</li> <li>Inflow Cannula</li> <li>Outflow Graft (including bend relief)</li> </ul>	
Controller (RVAD)	<ul><li>Yes</li><li>No</li></ul>	
Controller Component(s) (RVAD)	<ul> <li>Primary System Failure (running in backup mode)</li> <li>Complete System Failure (primary and backup failure)</li> <li>Power Cable (attached to controller)</li> <li>Power Connectors (attached to controller)</li> <li>Other, Specify</li> </ul>	
Peripherals (RVAD)	<ul><li>Yes</li><li>No</li></ul>	
Peripheral Component(s) (RVAD)	<ul> <li>External Battery</li> <li>Cell Battery (in controller)</li> <li>Power Module</li> </ul>	

	<ul> <li>Patient Cable</li> <li>System Monitor / Display</li> <li>Battery Charger</li> <li>Battery Clip</li> </ul>
Outcomes of Device Adverse Even	t
Patient Outcome	<ul> <li>Death</li> <li>Serious Injury</li> <li>Urgent Transplantation</li> <li>Explant Without Replacement</li> <li>Exchange</li> <li>Breach of Integrity of Drive Line that Required Repair</li> <li>Other Surgical Procedure</li> <li>None of the Above</li> </ul>
Causative or contributing factors to the Device Malfunction	<ul> <li>Patient Accident</li> <li>Patient Non-Compliance</li> <li>Sub Therapeutic Anticoagulation</li> <li>Prothrombotic States</li> <li>End of Component Expected Life</li> <li>Technical and/or Procedural Issues (e.g. cannula or graft malposition or kinking)</li> <li>No Cause Identified</li> </ul>

Were there any additional adverse events?	<ul><li>Yes</li><li>No</li></ul>
Cardiac Arrhythmia	• Yes
	<ul><li>No</li><li>Unknown</li></ul>
Event Date	
	ST= Ounknown
Type of cardiac arrhythmia	<ul> <li>Sustained ventricular arrhythmia requiring defibrillation or cardioversic</li> <li>Sustained supraventricular arrhythmia requiring drug treatment or cardioversion</li> </ul>
	Unknown
Pericardial Effusion	• Yes
	<ul><li>No</li><li>Unknown</li></ul>
Event Date	
	ST= Ounknown
Signs of tamponade	<ul><li>Yes</li><li>No</li></ul>
	Unknown
Method of drainage	OP Cath
	Unknown
Hepatic Dysfunction	O Yes
	<ul><li>No</li><li>Unknown</li></ul>
Total bilirubin measurement	mg/dL
	ST= Ounknown
SGOT / AST measurement	Not Done
ocor / Aor measurement	U/L ST= ○ Unknown
	Not Done
SGPT / ALT measurement	u/L
	ST= Ouknown Not Done
Event Date	

Myocardial Infarction Event Date	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> <li>ST= Unknown</li> </ul>	
Psychiatric Episode Event Date	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> <li>ST= Unknown</li> </ul>	
Renal Dysfunction	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Event Date	ST= OUnknown	
Dialysis duration		days
	ST= Unknown Not Done Ongoing	
Peak creatinine measurement	ST= Unknown Not Done	mg/dL
Respiratory Failure	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Event Date	ST= Unknown Ongoing	
Intubation duration	ST= Unknown Ongoing	days
Was a tracheotomy performed?	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
Arterial Non-CNS Thromboembolism	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	

Date	
	ST= Unknown
Location	Pulmonary
	Renal
	Limb
	Other
Confirmation source	Standard clinical and laboratory t
	Operative findings
	<ul> <li>Autopsy finding</li> </ul>
	Other
	Unknown
Anticoagulant therapy at time of	Warfarin
event	Heparin
	Lovenox
	Aspirin
	Dipyridamole
	<ul><li>Clopidogrel (plavix)</li><li>Argatroban</li></ul>
	Bivalirudin
	Fondaparinux
	Dextran
	Ticlopidine
	Hirudin
	<ul><li>Ximelagatran</li><li>None</li></ul>
	<ul> <li>Other, specify</li> </ul>
Venous Thromboembolism Event	Deep Vein thrombosis
	Pulmonary Embolus
	<ul> <li>Other, specify</li> <li>Unknown</li> </ul>
	<ul> <li>Onknown</li> <li>None</li> </ul>
Enter deep vein thrombosis date	
	ST= Unknown
Enter pulmonary embolus date	
	ST= Unknown
Enter other date	
	ST= Unknown

Anticoagulant therapy at time of event	<ul> <li>Warfarin</li> <li>Heparin</li> <li>Lovenox</li> <li>Aspirin</li> <li>Dipyridamole</li> <li>Clopidogrel (plavix)</li> <li>Argatroban</li> <li>Bivalirudin</li> <li>Fondaparinux</li> <li>Dextran</li> <li>Ticlopidine</li> <li>Hirudin</li> <li>Lepirudin</li> <li>Ximelagatran</li> <li>None</li> <li>Other, specify</li> </ul>
Wound Dehiscence	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Date	ST= OUnknown
Enter location:	<ul> <li>Sternum</li> <li>Driveline Sites</li> <li>Site of thoracotomy</li> <li>Other, specify</li> </ul>
Other Events	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Description	
Event Date	ST= OUnknown

Was Device Explanted for any	Yes
reason (includes exchanges or "turned	No
(includes exchanges of turned off")?	
Explant date	
	ST= OUnknown
Device explanted	LVAD
Explant reason	Explant - Death
	Explant - Transplanted
	Explant - Exchange
	Explant - No new device
	Turned off (decommissioned)
Explant reasons (check all that apply)	Device Malfunction: Elective (Please fill out Device
	Malfunction/Thrombus form) Device Malfunction: Emergent (Please fill out Device)
	Malfunction/Thrombus form)
	Device Thrombosis: Elective (Please fill out Device
	Malfunction/Thrombus form)
	Device Thrombosis: Emergent (Please fill out Device Malfunction/Thrombus form)
	Infection: Elective (Please fill out Infection form)
	Infection: Emergent (Please fill out Infection form)
	Other
Exchanged Device FDA IDE Trial	• Yes
	No
	Unknown
Name of FDA IDE Trial	
Explant reasons (check all that	Recovery
apply)	<ul> <li>Withdrawal of Support</li> </ul>
	Device Malfunction: Elective (Please fill out Device
	Malfunction/Thrombus form)
	Device Malfunction: Emergent (Please fill out Device Malfunction/Thrombus form)
	<ul> <li>Device Thrombosis: Elective (Please fill out Device Malfunction/Thrombus form)</li> </ul>
	Device Thrombosis: Emergent (Please fill out Device
	Malfunction/Thrombus form)
	<ul> <li>Infection: Elective (Please fill out Infection form)</li> <li>Infection: Emergent (Please fill out Infection form)</li> </ul>
Reasons (check all that apply)	<ul> <li>Recovery</li> <li>Withdrawal of Support</li> <li>Device Malfunction: Elective (Please fill out Device Malfunction/Thrombus form)</li> <li>Device Malfunction: Emergent (Please fill out Device Malfunction/Thrombus form)</li> <li>Device Thrombosis: Elective (Please fill out Device Malfunction/Thrombus form)</li> <li>Device Thrombosis: Emergent (Please fill out Device Malfunction/Thrombus form)</li> <li>Device Thrombosis: Emergent (Please fill out Device Malfunction/Thrombus form)</li> <li>Infection: Elective (Please fill out Infection form)</li> <li>Infection: Emergent (Please fill out Infection form)</li> <li>Other</li> </ul>
--------------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------
Evidence of Pump Thrombosis?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Evidence of Pump Thrombosis?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Transplant date	ST= Ounknown
Waitlist ID	

### Adverse Event - Pedimacs

Death	
Did the patient	die? Yes No
Death	date ST= Ounknown
Was device functioning normal	ly? Yes No Unknown
Associated Opera	ation Yes No Unknown
Post mortem device expla	ant? Yes No Unknown
Did the device go to manufactu	o the Yes urer? No Unknown
Location of d	<ul> <li>In hospital</li> <li>Long term care facility</li> <li>Home/Residence</li> <li>Out of hospital, Other</li> <li>Unknown</li> </ul>

#### Primary cause of death

- Respiratory: Respiratory Failure
- Respiratory: Pulmonary: Other, specify
- Circulatory: Arterial Non-CNS Thromboembolism

Respiratory: Venous Thromboembolism Event

- Circulatory: Myocardial Infarction
- Circulatory: Myocardial Rupture
- Circulatory: Ruptured Aortic aneurysm
- Circulatory: Right Heart Failure
- Circulatory: Major Bleeding
- Circulatory: Cardiac Arrhythmia
- Circulatory: Hemolysis
- Circulatory: Hypertension
- Circulatory: Other, Specify
- Circulatory: Sudden unexplained death
- Circulatory: CHF
- Circulatory: Heart Disease
- Circulatory: End Stage Cardiomyopathy
- Circulatory: End Stage Ischemic Cardiomyopathy
- Circulatory: Pericardial Fluid Collection (effusion)
- Digestive (Intestinal or GI/GU): Hepatic Dysfunction
- Digestive (Intestinal or GI/GU): Renal Dysfunction
- Digestive (Intestinal or GI/GU): GI Disorder
- Digestive (Intestinal or GI/GU): Fluid/Electrolyte Disorder
- Digestive (Intestinal or GI/GU): Pancreatitis
- Nervous System: Neurological Dysfunction
- Psychiatric Episode/Suicide
- Major Infection
- Device Malfunction
- Multiple System Organ Failure (MSOF)
- Withdrawal of Support, specify
- Cancer
- Wound Dehiscence
- Trauma/accident, specify
- Endocrine
- Hematological
- Other, specify

Select type of cancer

- CNS
- GI
- Lymph
- ENT
- Pulmonary
- Renal
- Breast
- Reproductive
- Skin
- Other

Unknown

Specify support withdrawn

Specify

22 of 22

<b>Demographics - Pedimacs</b>
--------------------------------

First Name	
Middle Name	
Last Name	
Medical record number	
SSN (last 5 digits)	ST= Not Assigned Undisclosed
Date of Birth	
Gender	<ul> <li>Male</li> <li>Female</li> <li>Unknown</li> </ul>
Ethnicity: Hispanic or Latino	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Race	<ul> <li>American Indian or Alaska Native</li> <li>Asian</li> <li>African-American or Black</li> <li>Hawaiian or other Pacific Islander</li> <li>White</li> <li>Unknown / Undisclosed</li> <li>Other / none of the above</li> </ul>
Is patient involved in a VAD related study?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
What is the name of the study?	
Is this an industry sponsored post approval study?	Yes No Unknown

Implant date	
Payor	<ul> <li>Government Health Insurance</li> <li>Commercial Health Insurance</li> <li>Health Maintenance Organization</li> <li>Non-U.S. Insurance</li> <li>None / Self</li> <li>Unknown</li> </ul>
Government:	<ul> <li>Medicare</li> <li>Medicaid</li> <li>State-Specific Plan</li> <li>Correctional Facility</li> </ul>
Health Insurance Claim Number (HIC):	ST= Unknown
	<ul> <li>Medicare Fee For Service</li> <li>Military Health Care</li> <li>Indian Health Service</li> <li>Not Applicable</li> <li>Other, specify</li> </ul>
National Provider Identifier (NPI) I	nformation
Operator First Name	ST= OUnknown
Operator Middle Name	ST= Unknown
Operator Last Name	ST= OUnknown
Operator NPI	ST= OUnknown
Additional indication for VAD	<ul> <li>Failure to wean from CPB</li> <li>Post Cardiac Surgery</li> <li>None</li> <li>Failure to wean from ECMO</li> </ul>
Device type	<ul> <li>LVAD</li> <li>RVAD</li> <li>BIVAD</li> <li>TAH</li> </ul>

Device brand	Berlin Heart EXCOR (paracorporeal)
	HeartWare HVAD
	HeartMate II LVAS
	HeartMate III
	HeartMate IP
	HeartMate VE
	HeartMate XVE
	Micromed DeBakey VAD - Child
	Novacor PC
	Novacor PCq
	Thoratec IVAD
	Thoratec PVAD
	Abiomed AB5000
	Abiomed BVS 5000
	Thoratec Centrimag (Levitronix)
	Thoratec Pedimag
	TandemHeart
	Biomedicus
	Maquet Rotaflow
	Sorin Revolution
	Abiomed Impella 2.5
	Abiomed Impella 5.0
	Abiomed Impella CP
	Abiomed Impella RP
	Other, Specify
Specify brand:	
Surgical Approach	Sternotomy
0 3	<ul> <li>Thoracotomy</li> </ul>
	Subcostal
	Other, specify
LVAD: Serial Number	
	ST= OUnknown
LVAD: cannulae location-inflow	LA appendage
	LA interatrial groove
	○ LV apex
	LV diaphragmatic surface
	Unknown
	Other, specify
LVAD: cannulae size-inflow	
	ST= 🔍 Unknown

LVAD: cannulae location-outflow	<ul> <li>Ascending aorta</li> <li>Descending thoracic aorta</li> <li>Abdominal aorta</li> <li>Unknown</li> <li>Subclavian</li> <li>Other, Specify</li> </ul>
LVAD: cannulae size-outflow	ST= Ounknown
LVAD: pump size	<ul> <li>10 cc</li> <li>15 cc</li> <li>25 cc</li> </ul>
	<ul> <li>30 cc</li> <li>50 cc</li> <li>60 cc</li> <li>80 cc</li> <li>N/A</li> </ul>
Device brand (RVAD)	
Specify brand (RVAD):	
RVAD: Serial Number	ST= Unknown
RVAD: cannulae location-inflow	<ul> <li>RA</li> <li>RV</li> <li>Unknown</li> </ul>
RVAD: cannulae size-inflow	ST= OUnknown
RVAD: cannulae location-outflow	<ul> <li>MPA (main pulmonary artery)</li> <li>LPA (left pulmonary artery)</li> <li>Conduit</li> <li>Other, Specify</li> </ul>
RVAD: cannulae size-outflow	ST= Unknown
RVAD: pump size	<ul> <li>10 cc</li> <li>15 cc</li> <li>25 cc</li> <li>30 cc</li> <li>50 cc</li> <li>60 cc</li> </ul>

Implant

version	date.	9/27/2017
1013	uale.	3/2//2017

	<ul> <li>─ 80 cc</li> <li>─ N/A</li> </ul>
TAH: Serial Number	ST= OUnknown
Associated findings	<ul> <li>PFO / ASD</li> <li>Aortic Insufficiency</li> <li>Tricuspid Insufficiency</li> <li>Mechanical Valve</li> <li>None</li> </ul>
Aortic Insufficiency	<ul> <li>Mild</li> <li>Moderate</li> <li>Severe</li> </ul>
Tricuspid Insufficiency	<ul> <li>Mild</li> <li>Moderate</li> <li>Severe</li> </ul>
Mechanical Valve	<ul> <li>Mitral Valve</li> <li>Aortic Valve</li> <li>Tricuspid Valve</li> </ul>
Concomitant surgery	<ul> <li>None</li> <li>ASD closure</li> <li>PFO closure</li> <li>PFO closure</li> <li>RVAD Implant</li> <li>RVAD Explant</li> <li>ECMO Decannulation</li> <li>CABG</li> <li>VSD closure</li> <li>IABP Removal</li> <li>Congenital cardiac surgery, other</li> <li>Aortic Valve Surgery - Repair (no valve closure)</li> <li>Aortic Valve Surgery - Repair with valve closure</li> <li>Aortic Valve Surgery - Replacement - Biological</li> <li>Aortic Valve Surgery - Replacement - Biological</li> <li>Aortic Valve Surgery - Replacement - Mechanical</li> <li>Mitral Valve Surgery - Replacement - Biological</li> <li>Mitral Valve Surgery - Replacement - Mechanical</li> <li>Tricuspid Valve Surgery - Replacement - DeVega</li> <li>Tricuspid Valve Surgery - Replar - Dther</li> <li>Tricuspid Valve Surgery - Replacement - Biological</li> <li>Tricuspid Valve Surgery - Replar - Ring</li> <li>Tricuspid Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Repair</li> <li>Pulmonary Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Repair</li> <li>Pulmonary Valve Surgery - Replacement - Mechanical</li> <li>Pulmonary Valve Surgery - Replacement - Mechanical</li> <li>Pulmonary Valve Surgery - Replacement - Mechanical</li> <li>Pulmonary Valve Surgery - Replacement - Biological</li> <li>Pulmonary Valve Surgery - Replacement - Mechanical</li> </ul>
Was the patient put on Cardio Bypass Pump? CPB Time	<ul> <li>Yes</li> <li>No</li> <li>minutes</li> </ul>
	ST= Ounknown

Implant

Was cross clamp used? Enter duration of the cross clamp time in minutes	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul> ST= Unknown <ul> <li>Not Done</li> </ul>	
Was circulatory arrest required? If yes:	<ul><li>Yes</li><li>No</li><li>ST= ○ Unknown</li></ul>	minutes
Surgery Time	ST= OUnknown	minutes

# Implant Discharge - Pedimacs

During the implant hospitalization was the patient?	<ul> <li>Discharged alive with a device in place</li> <li>Died during the implant hospitalization</li> <li>Transplanted during the implant hospitalization</li> <li>Explanted due to recovery during the implant hospitalization</li> </ul>	
Patient discharged to	<ul> <li>Home - residential setting</li> <li>Nursing Home / Assisted Care</li> <li>Hospice</li> <li>Another hospital</li> <li>Rehabilitation Facility</li> <li>Unknown</li> </ul>	
Implant Discharge	ST= OUnknown	
Acute care (ICU / CCU) duration of post-implant stay	ST= ◯ Unknown	
Intermediate / step-down care - duration of post-implant stay	ST= ◯ Unknown	
Date of approximate discontinuation of inotropes	<ul> <li>&lt; 1 week</li> <li>1-2 weeks</li> <li>2-4 weeks</li> <li>&gt; 4 weeks</li> <li>Ongoing</li> <li>Unknown</li> <li>Not applicable</li> </ul>	
Date of extubation	<ul> <li>&lt; 1 week</li> <li>1-2 weeks</li> <li>2-4 weeks</li> <li>&gt; 4 weeks</li> <li>Ongoing</li> <li>Unknown</li> </ul>	
Intervention since implant	<ul> <li>Transplant</li> <li>Invasive Cardiac Procedures (Other than Heart Cath)</li> <li>Unknown</li> <li>None</li> <li>Surgical Procedures:</li> <li>Device Related Operation</li> <li>Surgical Procedure - Non Cardiac Surgical Procedure</li> <li>Surgical Procedure - Other Procedure</li> <li>Surgical Procedure - Unknown</li> <li>Cardiac Surgical Procedures:</li> <li>Reoperation for Bleeding within 48 hours of implant</li> <li>Reoperation for Bleeding and/or tamponade &gt; 48 hours</li> <li>Surgical Drainage of pericardial effusion</li> </ul>	

- Aortic Valve Surgery Repair (no valve closure)
- Aortic Valve Surgery Repair with valve closure
- Aortic Valve Surgery Replacement Biological
- Aortic Valve Surgery Replacement Mechanical
- Mitral Valve Surgery Repair
- Mitral Valve Surgery Replacement Biological
- Mitral Valve Surgery Replacement Mechanical
- Tricuspid Valve Surgery Repair DeVega
- Tricuspid Valve Surgery Repair Ring
- Tricuspid Valve Surgery Repair Other
- Tricuspid Valve Surgery Replacement Biological
- Tricuspid Valve Surgery Replacement Mechanical
- Pulmonary Valve Surgery Repair
- Pulmonary Valve Surgery Replacement Biological
- Pulmonary Valve Surgery Replacement Mechanical
- Other Cardiac Surgical Procedure
- Cardiac Surgical Procedure Unknown

#### **Other Procedures:**

- Reintubation due to Respiratory Failure
- Dialysis
- Bronchoscopy
- Other, specify

#### **Functional Capacity**

Sedated	• Yes
	<ul> <li>No</li> </ul>
	<ul> <li>Unknown</li> </ul>
Paralyzed	• Yes
	O No
	Unknown
Intubated	○ Yes
	No
	<ul> <li>Unknown</li> </ul>
Ambulating	• Yes
	No
	Unknown
Primary Nutrition	Orally
	Per feeding tube
	TPN
	Not Applicable
	• Not Applicable
Excursions	
Has the nationt had any non medically	Vac
Has the patient had any non-medically required excursions off the unit?	<ul> <li>Yes</li> <li>No</li> </ul>
	Unknown
	Not Applicable

If yes, where (please select all that apply)	<ul> <li>Playroom</li> <li>Cafeteria</li> <li>Walk outside</li> <li>Sitting room</li> <li>General rehab</li> <li>None</li> </ul>
Pump Change	
Was there a pump exchange of a para- or extra- corporeal pump?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, please select one of the following:	<ul> <li>Intracorporeal device</li> <li>Para- or Extra- corporeal device</li> <li>Upsizing device because of patient growth status</li> <li>All other reasons would categorize the pump change as a Device Malfunction</li> </ul>
Please select appropriate reason:	<ul> <li>Thrombus NOT associated with hemolysis</li> <li>Change in hemodynamics</li> <li>Clinical status</li> <li>Device parameters</li> </ul>
Was there a Console Change?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Date of console change	ST= Ounknown
Original Console Name	
New Console Name	
Transfusion	
Was there a Tranfusion?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If yes, enter number of PRBC (Total number of cc's received)	ST= OUnknown

PreImplant Status			
Demographics			
Height	in		
	cm		
	ST= Unknown		
	Not Done		
Weight	lbs		
	kg		
	ST= Unknown		
	Not Done		
Plaad Tyma			
Blood Type	0 0		
	● A ● B		
	AB		
	Unknown		
Medical Support Status			
Current Device Strategy at time of implant	<ul> <li>Bridge to Recovery</li> <li>Rescue Therapy</li> <li>Bridge to Transplant (patient currently listed for transplant)</li> <li>Possible Bridge to Transplant - Likely to be eligible</li> <li>Possible Bridge to Transplant - Moderate likelihood of becoming eligible</li> <li>Possible Bridge to Transplant - Unlikely to become eligible</li> <li>Destination Therapy</li> </ul>		
List Date for Transplant			
	ST= OUnknown		
Current ICD device in place?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>		
Patient treated for heart failure prior	Vac		
to admission?	<ul> <li>Yes</li> <li>No</li> </ul>		
	Unknown		
Number of cardiac hospitalizations	○ 0-1		
in the last 12 months	2-3		
	4 or more		
	Unknown		

#### Cardiac diagnosis / Primary

Cancer

Congenital Heart Disease: Biventricular: CAVC/VSD/ASD

Congenital Heart Disease: Biventricular: Congenitally Corrected Transposition (I-TGA) (CC-TGA)

Congenital Heart Disease: Biventricular: Ebstein's Anomaly

Congenital Heart Disease: Biventricular: Kawasaki Disease

Congenital Heart Disease: Biventricular: Left Heart Valve/Structural

#### Hypoplasia

Congenital Heart Disease: Biventricular: TOF/TOF Variant

 Congenital Heart Disease: Biventricular: Transposition of the Great Arteries (d-TGA)

Congenital Heart Disease: Biventricular: Truncus Arteriosus

Congenital Heart Disease: Single Ventricle: Heterotaxy / Complex CAVC

Congenital Heart Disease: Single Ventricle: Hypoplastic Left Heart

Congenital Heart Disease: Single Ventricle: Other

Congenital Heart Disease: Single Ventricle: Pulmonary Artesia with IVS

 Congenital Heart Disease: Single Ventricle: Pulmonary Artesia with IVS (RVDC)

Congenital Heart Disease: Single Ventricle: Unspecified

Coronary Artery Disease

Dilated Myopathy: Adriamycin

Dilated Myopathy: Alcoholic

Dilated Myopathy: Familial

Dilated Myopathy: Idiopathic

Dilated Myopathy: Ischemic

Dilated Myopathy: Myocarditis

Dilated Myopathy: Other, Specify

Dilated Myopathy: Post Partum

Dilated Myopathy: Viral

Dilated Myopathy: LV non-compaction

Dilated Myopathy: Unspecified

Hypertrophic Cardiomyopathy

Post Transplant / Graft Dysfunction

Restrictive Myopathy: Amyloidosis

Restrictive Myopathy: Endocardial Fibrosis

Restrictive Myopathy: Idiopathic

Restrictive Myopathy: Other, specify

Restrictive Myopathy: Sarciodosis

Restrictive Myopathy: Sec to Radiation/Chemotherapy

Restrictive Myopathy: Unspecified

Valvular Heart Disease

- Unknown
- None

Dilated Myopathy: Other, Specify:

Restrictive Myopathy: Other, Specify:

Congenital Heart Disease: Single Ventricle: Other, Specify:


#### Cardiac diagnosis / Secondary

Cancer

Congenital Heart Disease: Biventricular: CAVC/VSD/ASD

Congenital Heart Disease: Biventricular: Congenitally Corrected Transposition (I-TGA) (CC-TGA)

- Congenital Heart Disease: Biventricular: Ebstein's Anomaly
- Congenital Heart Disease: Biventricular: Kawasaki Disease

Congenital Heart Disease: Biventricular: Left Heart Valve/Structural Hypoplasia

Congenital Heart Disease: Biventricular: TOF/TOF Variant

Congenital Heart Disease: Biventricular: Transposition of the Great Arteries (d-TGA)

- Congenital Heart Disease: Biventricular: Truncus Arteriosus
- Congenital Heart Disease: Single Ventricle: Heterotaxy / Complex CAVC
- Congenital Heart Disease: Single Ventricle: Hypoplastic Left Heart
- Congenital Heart Disease: Single Ventricle: Other
- Congenital Heart Disease: Single Ventricle: Pulmonary Artesia with IVS
- Congenital Heart Disease: Single Ventricle: Pulmonary Artesia with IVS (RVDC)
- Congenital Heart Disease: Single Ventricle: Unspecified
- Coronary Artery Disease
- Dilated Myopathy: Adriamycin
- Dilated Myopathy: Alcoholic
- Dilated Myopathy: Familial
- Dilated Myopathy: Idiopathic
- Dilated Myopathy: Ischemic
- Dilated Myopathy: Myocarditis
- Dilated Myopathy: Other, Specify
- Dilated Myopathy: Post Partum
- Dilated Myopathy: Viral
- Dilated Myopathy: LV non-compaction
- Dilated Myopathy: Unspecified
- Hypertrophic Cardiomyopathy
- Post Transplant / Graft Dysfunction
- Restrictive Myopathy: Amyloidosis
- Restrictive Myopathy: Endocardial Fibrosis
- Restrictive Myopathy: Idiopathic
- Restrictive Myopathy: Other, specify
- Restrictive Myopathy: Sarciodosis
- Restrictive Myopathy: Sec to Radiation/Chemotherapy
- Restrictive Myopathy: Unspecified
- Valvular Heart Disease
- Unknown
- None

Dilated Myopathy: Other, Specify:

Restrictive Myopathy: Other, Specify:

Congenital Heart Disease: Single Ventricle: Other, Specify:

**Previous cardiac operation** 

- None
- CABG
- Aneuryomectomy (DOR)
- Aortic Valve replacement / repair
- Mitral valve replacement / repair
- Triscuspid replacement /repair
- Congenital cardiac surgery
- LVAD
- RVAD

	<ul> <li>TAH</li> <li>Previous heart transplant</li> <li>Previous ECMO</li> <li>Other, specify (INCLUDE ONLY OPERATIONS ACTUALLY PERFORMED ON HEART OR GREAT VESSELS)</li> </ul>
Congenital cardiac surgery, Check all that apply	<ul> <li>Congenitally Corrected Transposition Repair (double switch)</li> <li>Congenitally Corrected Transposition Repair (classic)</li> <li>PA Banding</li> <li>TOV/DORV/RVOTO/Repair</li> <li>Ebstein's Anomaly Repair</li> <li>VSD Repair</li> <li>Norwood Stage I</li> <li>Glenn Procedure</li> <li>d- Transposition of the Great Vessels Repair – arterial switch operation</li> <li>d- Transposition of the Great Vessels Repair – atrial switch operation</li> <li>d- Transposition of the Great Vessels Repair – atrial switch operation</li> <li>d- Transposition of the Great Vessels Repair – atrial switch (Senning/Mustard)</li> <li>Truncus Arteriosus Repair</li> <li>Complete AV Septal Defect Repair</li> <li>AP Shunt</li> <li>ASD Repair</li> <li>Damus Kaye Stansel (DKS)</li> <li>Other, specify</li> </ul>
Admitting Diagnosis or Planned Implant	<ul> <li>Heart failure</li> <li>Cardiac surgery</li> <li>Non-cardiac medical problem</li> <li>Non-cardiac surgery</li> <li>VAD Placement</li> <li>TAH Placement</li> <li>Other cardiology</li> <li>Acute MI</li> <li>Unknown</li> <li>GI (Nausea, vomiting, diarrhea)</li> <li>Respiratory (SOB, wheezing, respiratory failure)</li> <li>FTT</li> <li>Lethargy</li> <li>Other, specify:</li> </ul>

### Clinical Events and Interventions this hospitalization (Pre-implant)

- CABG
- Aortic Valve replacement / repair
- Mitral valve replacement / repair
- Congenital cardiac surgery
- Other surgical procedures
- IABP
- ECMO
- LVAD
- RVAD
- TAH
- Dialysis
- Ultrafiltration
- Feeding tube
- Intubation
- Major MI
- Major infections / Positive blood cultures
- Unknown
- None
- Escalation to CPAP
- Arrythmia
- Previous ECMO
- Previous heart transplant
- Treatment of Rejection
- Peritoneal Drain
- Non-cardiac procedure

#### Select Type of infection:

- Bacterial
- Fungal
- Viral
- Protozoan
- Unknown

#### Select Location of infection:

- Blood
- Endocarditis, native
- Line Sepsis
- Mediastinum
- Pneumonia
- Urine
- Unknown
- Other

Congenital cardiac surgery, Select all that apply:	<ul> <li>Congenitally Corrected Transposition Repair (double switch)</li> <li>Congenitally Corrected Transposition Repair (classic)</li> <li>PA Banding</li> <li>TOV/DORV/RVOTO/Repair</li> <li>Ebstein's Anomaly Repair</li> <li>VSD Repair</li> <li>Norwood Stage I</li> <li>Glenn Procedure</li> <li>Fontan Procedure</li> <li>d- Transposition of the Great Vessels Repair – arterial switch operation</li> <li>d- Transposition of the Great Vessels Repair – atrial switch (Senning/Mustard)</li> <li>Truncus Arteriosus Repair</li> <li>Complete AV Septal Defect Repair</li> <li>Hybrid Repair</li> <li>AP Shunt</li> <li>ASD Repair</li> <li>Damus Kaye Stansel (DKS)</li> <li>Other, specify</li> </ul>
<b>Primary Reason:</b> Clinical manifestation of heart failure prompting VAD insertion according to the implanting physician:	<ul> <li>Decline in renal function</li> <li>Decline in hepatic function</li> <li>Decline in respiratory function</li> <li>Refractory fluid retention / volume overload</li> <li>Decline in cardiac output (by exam, mixed venous saturation, or cath) prior to onset of worsening acidosis/lactate</li> <li>Decline in nutrition / feeding intolerance</li> <li>Incessant severe sinus tachycardia</li> <li>Worsening tachyarryhythmia</li> <li>Other, please specify</li> <li>Not Reported</li> </ul>
Select all that apply:	<ul> <li>Emesis or inadequate calories (&lt;70% perscribed) requiring enteral feeding tube placement</li> <li>Recurrent emesis with adequate caloric intake despite feeding tube placement</li> <li>Inadequate caloric intake (with or without emesis) despite feeding tube placement</li> <li>Requiring parenteral (IV) nutrition</li> </ul>
Secondary Reason(s): Clinical manifestation of heart failure prompting VAD insertion according to the implanting physician:	<ul> <li>Decline in renal function</li> <li>Decline in hepatic function</li> <li>Decline in respiratory function</li> <li>Refractory fluid retention / volume overload</li> <li>Decline in cardiac output (by exam, mixed venous saturation, or cath) prior to onset of worsening acidosis/lactate</li> <li>Decline in nutrition / feeding intolerance</li> <li>Incessant severe sinus tachycardia</li> <li>Worsening tachyarryhythmia</li> <li>Other, please specify</li> <li>Not Reported</li> </ul>

Select all that apply:	<ul> <li>Emesis or inadequate calories (&lt;70% perscribed) requiring enteral feeding tube placement</li> <li>Recurrent emesis with adequate caloric intake despite feeding tube placement</li> <li>Inadequate caloric intake (with or without emesis) despite feeding tube placement</li> <li>Requiring parenteral (IV) nutrition</li> </ul>
IV inotrope therapy within 48 hours of implant	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
If Yes, IV inotrope therapy agents:	<ul> <li>Dobutamine</li> <li>Dopamine</li> <li>Milrinone</li> <li>Levosimendan</li> <li>Epinephrine</li> <li>Norepinephrine</li> <li>Isoproterenol</li> <li>Vasopressin</li> <li>Nitroprusside</li> <li>Fenoldopam</li> <li>Nesiriide</li> <li>Other, Specify</li> <li>Unknown</li> </ul>
Is this implant the primary MCSD	Yes

(LVAD or TAH) for this patient?

No

The INTERMACS® Patient Profiles are required at pre-implant and at all times when an implant occurs even if this is NOT the primary LVAD or TAH implant.

#### PEDIMACS® Patient Profile at time of implant

1 "Critical cardiogenic shock" describes a patient who is "crashing and burning", in which a patient has life-threatening hypotension and rapidly escalating inotropic pressor support (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

2 "Progressive decline" describes a patient who has been demonstrated "dependent" on inotropic support but nonetheless shows signs of continuing deterioration (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

3 "Stable but inotrope dependent" describes a patient who is clinically stable on mild-moderate doses of intravenous inotropes (or has a temporary circulatory support device) after repeated documentation of failure to wean without symptoms (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

4 "Resting symptoms" describes a patient who is at home on oral therapy but frequently has symptoms of congestion at rest or with ADL. (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

5 "Exertion Intolerant" describes a patient who is comfortable at rest but unable to engage in any activity, living predominantly within the house or household (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

6 "Exertion Limited" also describes a patient who is comfortable at rest without evidence of fluid overload, but who is able to do some mild activity (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

7 "Advanced NYHA Class 3" or "Ross Class III" describes a patient who is clinically stable with a reasonable level of comfortable activity, despite history of previous decompensation that is not recent (see the Site Users Guide, Section II. 2.4 Pre-Implant Form, PEDIMACS Patient Profiles for more details)

#### **MODIFIERS of the PEDIMACS® Patient Profiles**

	atient Promes
A - Arrhythmia.	<ul><li>Yes</li><li>No</li></ul>
	Unknown
TCS – Temporary Circulatory	• Yes
Support.	<ul> <li>No</li> <li>Unknown</li> </ul>
	Gindown
FF – Frequent Flyer.	• Yes
	No
	Unknown
Best Functional Capacity within 24	l hours of Implant
Sedated	• Yes
	No
	Unknown
Paralyzed	<ul> <li>Unknown</li> <li>Yes</li> </ul>
Paralyzed	
Paralyzed	• Yes
Paralyzed	<ul><li>Yes</li><li>No</li></ul>
	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>

	Unknown
Ambulating	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>
Primary Nutrition	<ul> <li>Orally</li> <li>Per feeding tube</li> <li>TPN</li> <li>Not Applicable</li> </ul>

Hemodynamics		
Systolic blood pressure		mmHg
	ST= OUnknown	
	Not done	
Diastolic blood pressure		mmHg
	ST= Unknown	
	Not done	
Peripheral edema	• Yes	
	No	
	Unknown	
Ascites	O Yes	
	No	
	Unknown	
ECG rhythm	Sinus	
-	Atrial fibrillation	
	Atrial Flutter	
	Paced: Atrial pacing	
	Paced: Ventricular pacing	
	Paced: Atrial and ventricul	ar pacing
	Unknown	
	Not done	
	Other, specify	
Echo Findings		
Systemic AV Regurgitation	0 (none)	
	1 (mild)	
	2 (moderate)	
	3 (severe)	
	Not Recorded or Not Docu	imented
Right AV Regurgitation	0 (none)	
	<ul> <li>1 (mild)</li> </ul>	
	<ul> <li>2 (moderate)</li> </ul>	
	<ul> <li>3 (severe)</li> </ul>	
	Not Recorded or Not Docu	imented
	Not Applicable	

PreImplant - Hemodynamics

mplant - Hemodynamics	version date: 9/27/20		
Aortic regurgitation	<ul> <li>0 (none)</li> <li>1 (mild)</li> <li>2 (moderate)</li> </ul>		
	<ul> <li>3 (severe)</li> <li>Not Recorded or Not Documented</li> </ul>		
System Ventricle Ejection Fraction	○ > 50 (normal)		
	40-49 (mild)		
	○ 30-39 (moderate)		
	20-29 (moderate/severe)		
	< 20 (severe) Not Recorded or Not Documented		
Left Ventricular Shortening Fraction	Normal		
	Mild		
	<ul> <li>Severe</li> <li>Not Done or Not Available</li> </ul>		
LVEDD	cm		
	ST= Not Recorded or Not Documented		
RVEF	Normal		
	Mild		
	Moderate		
	Severe		
	<ul> <li>Not Done</li> <li>Not Applicable</li> </ul>		
	Unknown		
	ers, as it is difficult to quantify. It may be described as "right ventricular function" or "right educed, or mild decrease" would all be characterized as "mild". Again, mild-moderate would be Id be recorded as "severe".		
Was there a thrombus identified by Echo?	<ul><li>Yes</li><li>No</li></ul>		
Select all that apply:	<ul> <li>RA - Right Atrium</li> <li>RV - Right Ventricle</li> </ul>		
	LA - Left Atrium		
	LV - Left Ventricle		
	<ul> <li>SVC - Superior Vena Cava</li> <li>IVC - Inferior Vena Cava</li> </ul>		
	Unknown		
Invasive Hemodynamics			
Date of measurement:			
	ST= Unknown Not Done		
	Not Dolle		

PreImplant - Hemodynamics

version date: 9/27/2017

Heart rate		beats per minute
	ST= Ounknown	
	Not Done	
Pulmonary Artery Systolic Pressure		mmHg
	ST= Unknown	
	Not Done	
Pulmonary Artery Diastolic		mmHg
Pressure	ST= Unknown	
	Not Done	
RA Pressure		mmHg
	ST= Unknown	
	Not Done	
PVR		wood units
	ST= Unknown	
	Not Done	
Pulmonary wedge pressure		mmHg
	ST= Olnknown	
	Not Done	
Cardiac index		L/min/m <sup>2</sup>
	ST= Unknown	
	Not Done	
Was Cardiac Index Measured by	• Yes	
Fick or Thermodilution?	No	
	Unknown	
Choose Method	Fick	
	Thermodilution	

Image: SGPT/ALT (alanine aminotransferase/ALT)   ST=   Unknown   Not done     Blood urea nitrogen   mg/dL   mmol/L   ST=   Unknown   Not done     Mg/dL   mmol/L   ST=   Unknown   Not done     Mg/dL   uminotransferase/ALT)   ST=   Unknown   Not done     U/L   ST=   Unknown   Not done     Unknown   Not done     Total bilirubin     mg/dL	Sodium		mEq/L
ST= Unknown   Not done     Potassium   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)   ST=   Unknown   Not done     Unknown   Not done     LDH   T=   Unknown   Not done     LDH     T=   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		ST= Unknown	
Blood urea nitrogen mmol/L   ST= Unknown   Not done mull   SGPT/ALT (alanine aminotransferase/ALT) u/L   SGOT/AST (aspartate aminotransferase/ALT) u/L   SGOT/AST (aspartate aminotransferase/ALT) u/L   ST= Unknown   Not done u/L   ST= Unknown   Not done Not done		Not done	
ST=       Unknown         Not done       mg/dL         Blood urea nitrogen       mg/dL         ST=       Unknown         Not done       mg/dL         ST=       Unknown         Not done       mg/dL         ST=       Unknown         Not done       umol/L         ST=       Unknown         Not done       u/L         ST=       Unknown         Not done       Not done         LDH       units/L, U/L, ukat/L         ST=       Unknown         Not done       Not done	Potassium		mEq/L
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			mmol/L
ST= Unknown   Not done     Creatinine   mg/dL   umol/L   ST=   Unknown   Not done     SGPT/ALT (alanine aminotransferase/ALT)   ST=   Unknown   Not done     SGOT/AST (aspartate aminotransferase/AST)   ST=   Unknown   Not done     LDH   Unknown   Not done     ST=   Unknown   Not done			
ST= Unknown   Not done     Creatinine   mg/dL   umol/L   ST=   Unknown   Not done     SGPT/ALT (alanine aminotransferase/ALT)   ST=   Unknown   Not done     SGOT/AST (aspartate aminotransferase/AST)   ST=   Unknown   Not done     LDH   Unknown   Not done     LDH   ST=   Unknown   Not done	Blood urea nitrogen		mg/dL
<ul> <li>Not done</li> <li>Creatinine</li> <li>mg/dL umol/L</li> <li>ST= Unknown</li> <li>Not done</li> </ul>			mmol/L
SGPT/ALT (alanine aminotransferase/ALT)   SGOT/AST (aspartate aminotransferase/AST)   ST=   Unknown   Not done     U/L   ST=   Unknown   Not done     LDH   LDH   ST=   Unknown   Not done			
ST= Unknown   Not done     SGPT/ALT (alanine aminotransferase/ALT)   ST=   Unknown   Not done     SGOT/AST (aspartate aminotransferase/AST)   ST=   Unknown   Not done     LDH   Unknown   Not done     LDH   Unknown   Not done	Creatinine		mg/dL
<ul> <li>Not done</li> <li>SGPT/ALT (alanine aminotransferase/ALT)</li> <li>ST = Unknown         <ul> <li>Not done</li> <li>Not done</li> </ul> </li> <li>SGOT/AST (aspartate aminotransferase/AST)</li> <li>ST = Unknown         <ul> <li>Not done</li> </ul> </li> <li>LDH</li> <li>LDH</li> <li>ST = Unknown         <ul> <li>Not done</li> </ul> </li> </ul>			umol/L
SGPT/ALT (alanine aminotransferase/ALT)   ST=   Unknown   Not done     SGOT/AST (aspartate aminotransferase/AST)   ST=   Unknown   Not done     LDH   ST=   Unknown   Not done     LDH   ST=   Unknown   Not done		ST= Unknown	
aminotransferase/ALT)   ST=   Unknown   Not done     SGOT/AST (aspartate aminotransferase/AST)   ST=   Unknown   Not done     LDH   Interference   LDH   Interference   Interference   Interference     Interference     Not done     Interference     Interference <td></td> <td>Not done</td> <td></td>		Not done	
SGOT/AST (aspartate aminotransferase/AST) LDH LDH ST= Unknown Not done units/L, U/L, ukat/L ST= Unknown Not done	SGPT/ALT (alanine		u/L
aminotransferase/AST) ST= Unknown Not done LDH ST= Unknown Not done			
ST= Unknown Not done LDH units/L, U/L, ukat/L ST= Unknown Not done	SGOT/AST (aspartate		u/L
LDH units/L, U/L, ukat/L ST= Unknown Not done	aminotransferase/AST)	ST= Unknown	
ST= Unknown Not done		Not done	
Not done	LDH		units/L, U/L, ukat/L
<b>-</b>			
Total bilirubin mg/dL		Not done	
	Total bilirubin		mg/dL
umol/L			umol/L
ST= OUnknown Not done			
Bilirubin direct mg/dL	Bilirubin direct		mg/dL
umol/L			umol/L

PreImplant - Laboratory

Bilirubin indirect		mg/dL
		umol/L
	ST= Olnknown	
	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= 0 < 50 mg/dL	
	Unknown	
	Not done	
Brain natriuretic peptide BNP		pg/mL
		ng/L
	ST= 0 > 7500 pg/mL	
	Unknown	
	Not done	
NT pro brain natriuretic peptide Pro- BNP		pg/mL
BA		ng/L
	ST= Unknown	
	Not done	
White blood cell count		x10 <sup>3</sup> /uL
		×10 <sup>9</sup> /L
	ST= Unknown	
	Not done	
Reticulocyte count		%
	ST= Unknown	
	Not Done	
Hemoglobin		g/dL
		g/L
		mmol/L
	ST= Unknown	
	Not done	

Hemoglobin A1C		%
		mmol/mol
Estimated Average Glucose (eAG):		
		mg/dL
		mmol/L
	ST= Unknown	
	Not Done	
Platelets		x10 <sup>3</sup> /uL
		x10 <sup>9</sup> /L
	ST= Unknown	
	Not done	
INR		international units
	ST= Unknown	
	Not done	
Uric acid		mg/dL
		umol/L
	ST= 0<1 mg/dL	
	Unknown	
	Not done	
Lymphocyte Count		~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~
		x10 <sup>3</sup> cells/µL
		x10 <sup>9</sup> cells/liter
	ST= Ounknown	
	Not done	
	○ <2%	
Lupus Anticoagulant		
	<ul><li>Negative</li><li>Unknown</li></ul>	

### **Concerns and Contraindications**

Concerns / Contraindications	ls co	ondition present?	Limi	tation for transplant listing?
Overall Status	Yes	Νο	Yes	No
Patient does not want transplant		0		
Musculoskeletal limitation to ambulation		$\bigcirc$		
Contraindication to immunosuppression		$\bigcirc$	$\bigcirc$	
Allosensitization	$\bigcirc$	$\bigcirc$	$\bigcirc$	
Frailty		0		0
Chronic Renal Disease	$\bigcirc$	$\bigcirc$	0	
Cardiothoracic issues	Yes	No	Yes	No
Frequent ICD Shocks	$\bigcirc$	0	0	0
Pulmonary Disease		$\bigcirc$		
Pulmonary Hypertension		$\bigcirc$		
Recent Pulmonary Embolus		$\bigcirc$		
History Of Atrial Arrhythmia		0		
Unfavorable Mediastinal Anatomy (includes sternotomies, sternal resection, radiation, flail chest, etc)				
Thoracic Aortic Disease		$\bigcirc$	$\bigcirc$	$\bigcirc$
Tracheostomy	$\bigcirc$	$\bigcirc$	$\bigcirc$	
Plastic Bronchitis				
Nutritional/GI	Yes	No	Yes	No
Large BMI	$\bigcirc$	0	0	0
Severe Diabetes	$\bigcirc$	$\bigcirc$	$\bigcirc$	
Malnutrition Cachexia		$\bigcirc$		
History Of GI Ulcers		$\bigcirc$		
History Of Hepatitis		$\bigcirc$		
Liver Dysfunction		$\bigcirc$	$\bigcirc$	
Anasarca	$\bigcirc$	$\bigcirc$	$\bigcirc$	
Protein Losing enteropathy		$\bigcirc$		0
Genetic Syndrome	$\bigcirc$	0		$\odot$
Vascular issues	Yes	Νο	Yes	No
Heparin Induced Thrombocytopenia	0	0	0	0
Chronic Coagulopathy		0		
Major Stroke				

nplant - Concerns and Contraindications						version date: 9/27/
Other Cerebrovascular Disease		$\bigcirc$				
Peripheral Vascular Disease		$\bigcirc$			$\bigcirc$	
Oncology/infection issues	Yes	No	Unknown	Yes	No	
History Of Solid Organ Cancer	$\bigcirc$	$\bigcirc$		0	$\bigcirc$	
History Of Lymphoma Leukemia						
History Of Bone Marrow Transplant BMT		$\bigcirc$		$\bigcirc$	$\bigcirc$	
History Of HIV	$\bigcirc$	$\bigcirc$				
Chronic Infectious Concerns	$\bigcirc$	$\bigcirc$				
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	$\bigcirc$	$\bigcirc$	0	$\bigcirc$	$\bigcirc$	
Limited Social Support					$\bigcirc$	
Repeated Noncompliance	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
History Of Illicit Drug Use		$\bigcirc$				
History Of Alcohol Abuse		$\bigcirc$			$\bigcirc$	
Narcotic Dependence	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
History Of Smoking		$\bigcirc$				
Currently Smoking		$\bigcirc$				
Severe Depression		$\bigcirc$				
Other Major Psychiatric Diagnosis		$\bigcirc$		$\bigcirc$		
Neurological // developmental abnormalities		$\bigcirc$				
Other Comorbidity	$\bigcirc$	$\bigcirc$				
HIV History						
HIV Diagnosis Date						
			Unknown Done			
Plasma HIV-1 RNA (Viral load) - Closest to implant	SI	= 0	Not Done	copies	/ml	
CD4 T-Cell Count - Closest to implant	S1	= 0	Not Done	cells/n	1m3	
Erythrocyte Sedimentation Rate (ESR)	ST	= 0	Not Done	mm/hr		
C-Reactive Protein (CRP)				mg/L		

PreImplant - Concerns and Contraindications		version date: 9/27/2017
PreImplant - Concerns and Contraindications Antiretroviral Therapy	<ul> <li>Abacavir (ABC) / Ziagen</li> <li>Atripla (FTC/EDV/TDF)</li> <li>Atazanavir (ATV) / Reyataz</li> <li>Combivir (3TC/ZDV)</li> <li>Complera (FTC/RPV/TDF)</li> <li>Darunavir (DRV) / Prezista</li> <li>Delavirdine (DLV) / Rescriptor</li> <li>Didanosine (ddl) / Videx EC</li> <li>Dolutegravir / Tivicay</li> <li>Efavirenz (EFV) / Sustiva</li> <li>Emtricitabine (FTC) / Emtriva</li> <li>Enfuvirtide (T20) / Fuzeon</li> <li>Epzicom (3TC/ABC)</li> <li>Etravirine (ETR) / Intelence</li> <li>Fosamprenavir (FPV) / Lexiva</li> <li>Indinavir (IDV) / Crixivan</li> <li>Kaletra (LPV/r)</li> <li>Lamivudine (3TC) / Epivir</li> <li>Maraviroc (MVC) / Selzentry</li> <li>Nelfinavir (NFV) / Viracept</li> <li>Nevirapine (NVP) / Viramune / Viramune XR</li> <li>Raltegravir (RAL) / Isentress</li> <li>Rilpivirine (RTV) / Norvir</li> <li>Saquinavir (SQV) / Invirase</li> <li>Stavudine (d4T) / Zerit</li> <li>Stribild (FTC/EVG/COBI/TDF)</li> </ul>	version date: 9/27/2017
	<ul> <li>Tenofovir Disoproxil Fumarate (TDF) / Viread</li> <li>Tipranivir (TPV) / Aptivus</li> <li>Trizivir (3TC/ZDV/ABC)</li> <li>Truvada (FTC/TDF)</li> <li>Zidovudine (ZDV) / Retrovir</li> <li>Unknown</li> <li>None</li> </ul>	
Infection Prophylaxis	<ul> <li>Atovaquone</li> <li>Azithromycin</li> <li>Dapsone</li> <li>Fluconazole</li> <li>Pentamidine, aerosolized</li> <li>Trimethroprim-sulfamethoxazole (TMP-SMX)</li> <li>Unknown</li> <li>None</li> </ul>	
History of Opportunistic Infection	<ul> <li>Cryptococcosis</li> <li>Cytomegalovirus (CMV)</li> <li>Epstein Barr virus (EBV)</li> <li>Esophageal candidiasis</li> <li>Histoplasmosis</li> <li>Kaposi's sarcoma</li> <li>Mycobacterium avium complex (MAC), dissemin</li> <li>Pneumocystis jiroveci (carinii) pneumonia (PCP)</li> <li>Toxoplasmosis</li> <li>Tuberculosis</li> <li>None</li> </ul>	
History of Hepatitis B	<ul> <li>Positive</li> <li>Negative</li> <li>ST= Unknown</li> </ul>	

	Not Done
History of Hepatitis C	<ul><li>Positive</li><li>Negative</li></ul>
	ST= OUnknown Not Done

Medications		
Loop diuretics	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	
lf yes, enter dosage	ST= OUnknown	mg/day
Type of Loop Diuretic:	<ul><li>Furosemide</li><li>Torsemide</li><li>Bumetanide</li><li>Other</li></ul>	
Cardiac Resynchronization Therapy (CRT)	<ul><li>Yes</li><li>No</li><li>Unknown</li></ul>	

Iality Of Life QOL surveys cannot be administered after th	e 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	
	<ul> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul>	
	• Unknown of 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	● 0 - Not at all	
exercise:	2 - Sometimes	
	• 4 - A lot	
	Unknown or Not Documented	
It is hard for you to pick up big	◯ 0 - Not at all	
things:	2 - Sometimes	
	• 4 - A lot	
	Unknown or Not Documented	
It is hard for you to take a bath or	◯ 0 - Not at all	
shower:	<ul> <li>2 - Not at all</li> <li>2 - Sometimes</li> </ul>	
	• 4 - A lot	
	<ul> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul>	
It is hard for you to do chores (like	◯ 0 - Not at all	
pick up your toys):	2 - Sometimes	
	4 - A lot	
	Unknown or Not Documented	
Do you have hurts or aches:	○ 0 - Not at all	
	<ul> <li>2 - Not at all</li> <li>2 - Sometimes</li> </ul>	
	• 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	

Where?	
Do you ever feel too tired to play:	◎ 0 - Not at all
,,.,.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	2 - Sometimes
	• 4 - A lot
	Unknown or Not Documented
MOTIONAL FUNCTIONING (problems w	<i>i</i> ith)
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	◯ 0 - Not at all
happen to you:	2 - Sometimes
	4 - A lot
	Unknown or Not Documented
OCIAL FUNCTIONING (problems with	)
ls it hard for you to get along with other kids:	○ 0 - Not at all
other Md3.	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
to play with you.	2 - Sometimes
	• 4 - A lot
	Unknown or Not Documented
Do other kids tease you:	○ 0 - Not at all
	2 - Sometimes
	<ul> <li>4 - A lot</li> <li>Unknown or Not Documented</li> </ul>

ripiant - Quanty of Life Offild (5-7 yrs)	Version date. 3/2	
	◯ 0 - Not at all	
	2 - Sometimes	
	$\sim$ 4 - A lot	
	Unknown or Not Documented	
It is hard for you to keep up when	◯ 0 - Not at all	
you play with other kids:	2 - Sometimes	
	• 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
SCHOOL FUNCTIONING (problems with.		
Is it hard for you to pay attention in		
class:	○ 0 - Not at all	
014001	2 - Sometimes	
	4 - A lot	
	Unknown or Not Documented	
Do you forget things:	◯ 0 - Not at all	
	○ 2 - Sometimes	
	• 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
	• Unknown of Not Documented	
Is it hard to keep up with	◯ 0 - Not at all	
schoolwork:	2 - Sometimes	
	4 - A lot	
	Unknown or Not Documented	
Do you miss school because of not	◯ 0 - Not at all	
feeling good:	○ 2 - Sometimes	
	4 - A lot	
	Unknown or Not Documented	
Do you miss school because you	◯ 0 - Not at all	
have to go to the doctor's or	2 - Sometimes	
hospital:		
	• 4 - A lot	
	<ul> <li>Unknown or Not Documented</li> </ul>	
If No, Please select a reason why	Too sick	
the PedsQOL was not completed:	<ul> <li>Administrative</li> </ul>	
If Administrative: Select a specific	<ul> <li>Urgent implant, no time</li> </ul>	
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>	
	<ul> <li>Unable to contact patient</li> </ul>	
	Other reason (specify)	
ality Of Life		
----------------------------------------------	------------------------------------------------------------------------------------	--
QOL surveys cannot be administered after the	e 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 ACTIVITES (pro	oblems with)	
It is hard for me to walk more than	0 - Never a problem	
one block:	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	
	<ul> <li>1 - Almost never a problem</li> </ul>	
	<ul> <li>2 - Sometimes a problem</li> </ul>	
	<ul> <li>3 - Often a problem</li> </ul>	
	<ul> <li>4 - Almost always a problem</li> </ul>	
	Unknown or Not Documented	
It is hard for me to do sports activity	0 Nover e problem	
or exercise:	0 - Never a problem	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Comparing a problem</li> </ul>	
	2 - Sometimes a problem	
	<ul> <li>3 - Often a problem</li> <li>4 - Almost shugun a problem</li> </ul>	
	<ul> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
It is hard for me to lift something	0 - Never a problem	
heavy:	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	◯ 0 - Never a problem	
shower by myself:	1 - Almost never a problem	
	2 - Sometimes a problem	
	◯ 3 - Often a problem	
	4 - Almost always a problem	
	Unknown or Not Documented	

#### PreImplant - Quality of Life Child (8-12 yrs)

It is hard for me to do chores around the house:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I hurt or ache: Where?	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I have low energy:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
ABOUT MY FEELINGS (problems with)		
l feel afraid or scared:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel sad or blue:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel angry:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I have trouble sleeping:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	

#### PreImplant - Quality of Life Child (8-12 yrs)

I worry about what will happen to	○ 0 - Never a problem
me:	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 (prob	plems with)
I have trouble getting along with	◯ 0 - Never a problem
other kids:	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	○ 0 - Never a problem
friend:	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
	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	○ 3 - Often a problem
	4 - Almost always a problem
	Unknown or Not Documented
I cannot do things other kids my	◯ 0 - Never a problem
age can do:	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	○ 4 - Almost always a problem
	Ounknown or Not Documented
It is hard to keep up when I play	○ 0 - Never a problem
with other kids:	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	<ul> <li>4 - Almost always a problem</li> </ul>
	<ul> <li>Unknown or Not Documented</li> </ul>
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
	<ul> <li>Unknown or Not Documented</li> </ul>

I forget things:

	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
I have trouble keeping up with my schoolwork:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
I miss school because of not feeling well:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
l miss school to go to the doctor or hospital:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
If No, Please select a reason why the PedsQOL was not completed:	<ul> <li>Too sick</li> <li>Administrative</li> </ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

ality Of Life		
QOL surveys cannot be administered after the	e 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 ACTIVITES (pro	oblems with)	
It is hard for me to walk more than	0 - Never a problem	
one block:	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	
	<ul> <li>1 - Almost never a problem</li> </ul>	
	<ul> <li>2 - Sometimes a problem</li> </ul>	
	<ul> <li>3 - Often a problem</li> </ul>	
	<ul> <li>4 - Almost always a problem</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
It is hard for me to do sports activity		
or exercise:	0 - Never a problem	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Semetimes a problem</li> </ul>	
	2 - Sometimes a problem	
	<ul> <li>3 - Often a problem</li> <li>4 - Alward always a machine</li> </ul>	
	4 - Almost always a problem	
	Unknown or Not Documented	
It is hard for me to lift something	◯ 0 - Never a problem	
heavy:	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	○ 0 - Never a problem	
shower by myself:	1 - Almost never a problem	
	2 - Sometimes a problem	
	3 - Often a problem	
	4 - Almost always a problem	
	Unknown or Not Documented	

#### PreImplant - Quality of Life Child (13-18 yrs)

It is hard for me to do chores		
	0 - Never a problem	
around the house:	1 - Almost never a problem	
	○ 2 - Sometimes a problem	
	-	
	3 - Often a problem	
	4 - Almost always a problem	
	Unknown or Not Documented	
	Onknown of 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	
	Often a problem	
	4 - Almost always a problem	
	<ul> <li>Unknown or Not Documented</li> </ul>	
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	
	Children of Not Documented	
I feel sad or blue:	0 - Never a problem	
	-	
	1 - Almost never a problem	
	-	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> </ul>	
l feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
I feel angry:	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost always a problem</li> <li>1 - Almost never a problem</li> <li>1 - Almost never a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost always a problem</li> <li>1 - Almost never a problem</li> <li>1 - Almost never a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>Unknown or Not Documented</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>1 - Almost never a problem</li> <li>3 - Often a problem</li> </ul>	
	<ul> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>Unknown or Not Documented</li> </ul>	

#### PreImplant - Quality of Life Child (13-18 yrs)

I worry about what will happen to	0 - Never a problem
me:	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 (prob	plems with)
I have trouble getting along with other teens:	○ 0 - Never a problem
other teens.	1 - Almost never a problem
	2 - Sometimes a problem
	<ul> <li>3 - Often a problem</li> <li>4 - Almost shugue a machine</li> </ul>
	<ul> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
Other teens do not want to be my	○ 0 - Never a problem
friend:	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	○ 0 - Never a problem
age can do:	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	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
····· ••••••••••••••••••••••••••••••••	<ul> <li>1 - Almost never a problem</li> </ul>
	<ul> <li>2 - Sometimes a problem</li> </ul>
	<ul> <li>3 - Often a problem</li> </ul>
	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:

	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
l have trouble keeping up with my schoolwork:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
l miss school because of not feeling well:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
l miss school to go to the doctor or hospital:	<ul> <li>0 - Never a problem</li> <li>1 - Almost never a problem</li> <li>2 - Sometimes a problem</li> <li>3 - Often a problem</li> <li>4 - Almost always a problem</li> <li>Unknown or Not Documented</li> </ul>
If No, Please select a reason why the PedsQOL was not completed:	<ul> <li>Too sick</li> <li>Administrative</li> </ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

ality Of Life (Parent)		
OL surveys cannot be administered after th	e visit date)	
edsQL		
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)	
HYSICAL FUNCTIONING (problems with	h)	
Walking: Walking more than one	◯ 0 - Never	
block:	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	0 - Never	
exercise: Participating in sports	1 - Almost never	
activity or exercise:	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Lifting something heavy: Lifting something heavy:	0 - Never	
something heavy.	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Bathing: Taking a bath or shower by	O - Never	
him or herself:	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:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Having hurts or aches: Having hurts or aches:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Low energy level: Low energy level:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
EMOTIONAL FUNCTIONING (problems w	ith)
Feeling afraid or scared: Feeling afraid or scared: Feeling sad or blue: Feeling sad or blue:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> </ul>
	Unknown or Not Documented
Feeling angry: Feeling angry:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Trouble sleeping: Trouble sleeping:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Worrying: Worrying about what will happen to him or her:	<ul><li>0 - Never</li><li>1 - Almost never</li></ul>

(z - y)	Version da	(0.0/21/20)
	◯ 2 - Sometimes	
	3 - Often	
	<ul> <li>● 4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
SOCIAL FUNCTIONING (problems with)	)	
Playing with other children: Getting	0 - Never	
along with other teens:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Ounknown or Not Documented	
Other kids not wanting to play with him or her: Other teens not wanting	0 - Never	
to be his or her friend:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Getting teased by other children:	© 0. Nover	
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	0 - Never	
children his or her age can do: Not	1 - Almost never	
able to do things that other teens	© 2 - Sometimes	
his or her age can do:	○ 3 - Often	
	<ul> <li>● 4 - Almost always</li> </ul>	
	Unknown or Not Documented	
M		
Keeping up when playing with other children: Keeping up when playing	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>	
with other teens:		
	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	
Forgetting things:	0 - Never	
Forgetting things:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> </ul>	

	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Doing the same school activities as	0 - Never	
peers: Keeping up with schoolwork:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Missing school/daycare because of	0 - Never	
not feeling well: Missing school because of not feeling well:	1 - Almost never	
because of not leening wen.	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Missing school/daycare to go to the	0 - Never	
doctor or hospital: Missing school to go to the doctor or hospital:	1 - Almost never	
to go to the doctor or hospital.	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
If No, Please select a reason why	Too sick	
the PedsQOL was not completed:	Administrative	
If Administrative: Select a specific	Urgent implant, no time	
reason:	<ul> <li>Coordinator too busy or forgot</li> </ul>	
	<ul> <li>Unable to contact patient</li> </ul>	
	Other reason (specify)	

Jality Of Life (Parent) (QOL surveys cannot be administered after the visit date) PedsQL		
Did the parent complete a form?	• Yes	
Did the parent complete a form?	<ul> <li>No</li> </ul>	
	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	h)	
Walking more than one block:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Running:	O - Never	
	1 - Almost never	
	2 - Sometimes	
	O 3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Participating in sports activity or	● 0 - Never	
exercise:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Lifting something heavy:	0 - Never	
	<ul> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Taking a bath or shower by him or	0 - Never	
herself:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	

Doing chores, like picking up his or her toys:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Having hurts or aches:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Low energy level:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
EMOTIONAL FUNCTIONING (problems w	vith)
Feeling afraid or scared:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling sad or blue:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Feeling angry:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Trouble sleeping:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Worrying about what will happen to him or her:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>

plant - Quality of Life Parent (5-7 yrs)		
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
OCIAL FUNCTIONING (problems with)		
Getting along with other children:	◯ 0 - Never	
	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Our Unknown or Not Documented	
Other kids not wanting to be his or	© 0 - Never	
her friend:	<ul> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	○ 4 - Almost always	
	Unknown or Not Documented	
Getting teased by other children:	© 0 - Never	
	1 - Almost never	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Not able to do things that other		
children his or her age can do:	0 - Never	
6	<ul> <li>○ 1 - Almost never</li> </ul>	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Keeping up when playing with other	0 - Never	
children:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	<ul> <li>Unknown or Not Documented</li> </ul>	
CHOOL FUNCTIONING (problems with		
Paying attention in class:	0 - Never	
r aying attention in class.	<ul> <li>0 - Nevel</li> <li>1 - Almost never</li> </ul>	
	<ul> <li>2 - Sometimes</li> </ul>	
	<ul> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>	
Forgetting things:	◯ 0 - Never	
Forgetting things:	<ul><li>0 - Never</li><li>1 - Almost never</li></ul>	

	<ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Keeping up with school activities:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> </ul>
	<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Missing school because of not feeling well:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
Missing school to go to the doctor or hospital:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
If No, Please select a reason why the PedsQOL was not completed:	<ul> <li>Too sick</li> <li>Administrative</li> </ul>
If Administrative: Select a specific reason:	<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

ality Of Life (Parent)		
QOL surveys cannot be administered after th	e 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	h)	
Walking more than one block:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	O 3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Running:	◯ 0 - Never	
Kunnig.	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	3 - Often	
	<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>	
	Onknown of Not Documented	
Participating in sports activity or	0 - Never	
exercise:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Lifting something heavy:	◯ 0 - Never	
	<ul> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	© 3 - Often	
	4 - Almost always	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Taking a bath or shower by him or		
herself:	0 - Never	
	<ul> <li>1 - Almost never</li> <li>2 - Sometimes</li> </ul>	
	<ul> <li>2 - Sometimes</li> <li>3 - Often</li> </ul>	
	<ul> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>	

Doing chores around the house:	<ul><li>○ 0 - Never</li><li>○ 1 - Almost never</li></ul>
	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 w	vith)
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
	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	◎ 0 - Never
him or her:	<ul> <li>1 - Almost never</li> </ul>

ipiant - Quanty of Life Farent (0-12 yis)	Version da	
	© 2 - Sometimes	
	3 - Often	
	<ul> <li>● 4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
SOCIAL FUNCTIONING (problems with)	)	
Getting along with other children:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	O 3 - Often	
	○ 4 - Almost always	
	Our Unknown or Not Documented	
Other kids not wanting to be his or	0 - Never	
her friend:	<ul> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	3 - Often	
	○ 4 - Almost always	
	Unknown or Not Documented	
Getting teased by other children:	◯ 0 - Never	
	0 1 - Almost never	
	2 - Sometimes	
	3 - Often	
	<ul> <li>● 4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Not able to do things that other	0 - Never	
children his or her age can do:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Keeping up when playing with other children:	0 - Never	
cimaren.	1 - Almost never	
	2 - Sometimes	
	O 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	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Forgetting things:		
Forgetting things:	0 - Never	
Forgetting things:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> </ul>	

<ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>Too sick</li> <li>Administrative</li> </ul>
<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

ality Of Life (Parent)		
QOL surveys cannot be administered after th	e 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	h)	
Walking more than one block:	0 - Never	
	1 - Almost never	
	2 - Sometimes	
	O 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	0 - Never	
exercise:	1 - Almost never	
	2 - Sometimes	
	3 - Often	
	4 - Almost always	
	Unknown or Not Documented	
Lifting something heavy:	© 0 - Never	
Lining something neavy.	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>	
	<ul> <li>2 - Sometimes</li> <li>3 - Often</li> </ul>	
	<ul> <li>● 4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
Taking a bath or shower by him or herself:	◯ 0 - Never	
nersell.	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
	Ounknown or Not Documented
Low energy level:	0 - Never
	<ul> <li>1 - Almost never</li> </ul>
	2 - Sometimes
	<ul> <li>3 - Often</li> </ul>
	<ul> <li>4 - Almost always</li> </ul>
	<ul> <li>Unknown or Not Documented</li> </ul>
EMOTIONAL FUNCTIONING (problems v	vith)
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
	<ul> <li>2 - Sometimes</li> </ul>
	© 3 - Often
	<ul> <li>4 - Almost always</li> </ul>
	Unknown or Not Documented
<b>-</b> - 1 <b>1</b>	_
Feeling angry:	0 - Never
	1 - Almost never
	2 - Sometimes
	0 3 - Often
	4 - Almost always
	Unknown or Not Documented
Trouble sleeping:	◯ 0 - Never
	1 - Almost never
	○ 2 - Sometimes
	3 - Often
	4 - Almost always
	<ul> <li>Unknown or Not Documented</li> </ul>
Worrying about what will happen to	○ 0 - Never
him or her:	1 - Almost never

inplant - Quality of Life Farent (15-10 yrs)		
	2 - Sometimes	
	3 - Often	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
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	0 - Never	
her friend:	<ul> <li>1 - Almost never</li> </ul>	
	2 - Sometimes	
	<ul> <li>3 - Often</li> </ul>	
	4 - Almost always	
	Unknown or Not Documented	
Getting teased by other teens:	© 0 - Never	
	1 - Almost never	
	2 - Sometimes	
	○ 3 - Often	
	<ul> <li>4 - Almost always</li> </ul>	
	<ul> <li>Unknown or Not Documented</li> </ul>	
	• Chikilowi di Not Documented	
Not able to do things that other	© 0 - Never	
teens his or her age can do:	1 - Almost never	
	○ 2 - Sometimes	
	3 - Often	
	○ 4 - Almost always	
	Unknown or Not Documented	
Keeping up when playing with other		
teens:	<ul> <li>0 - Never</li> <li>1 - Almost never</li> </ul>	
	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	
	<ul><li>1 - Almost never</li><li>2 - Sometimes</li></ul>	

<ul> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>0 - Never</li> <li>1 - Almost never</li> <li>2 - Sometimes</li> <li>3 - Often</li> <li>4 - Almost always</li> <li>Unknown or Not Documented</li> </ul>
<ul> <li>Too sick</li> <li>Administrative</li> </ul>
<ul> <li>Urgent implant, no time</li> <li>Coordinator too busy or forgot</li> <li>Unable to contact patient</li> <li>Other reason (specify)</li> </ul>

ST= Not done Not done: too sick	feet
Not done: too sick	feet
Not done: too sick	
Not done: other	
Not done: age inappropried to the second	riate
as possible during the 6 minutes. Id walk behind the patient to avoid	bly as long as possible to avoid frequent turns. Patients a They are advised that they may stop if necessary during I undue influence on the pace. The distance covered dur at 15 feet of the 6minute walk for the Gait speed test
	seconds
ST= ONot done	_
Not done: too sick	
Not done: other	
Not done: age inappropried to the second	riate
	mL/kg/min
ST= ONot done	_
Not done: too sick	
Not done: other	
Not done: age inappropried to the second	riate
alues recorded during the bicycle a	nl/kg/min of oxygen consumed during symptom-limited are usually 1-2 ml/min lower than for the treadmill, but it i cycle is preferable as the mode easiest to standardize.
	7%
ST= Not done	_
Not done: too sick	
Not done: other	
Not done: age inappropried to the second	riate
ioxide production divided by oxygo considered to represent an adequ	en consumption, and is used as an index of how vigorous ate effort.
	as possible during the 6 minutes. Id walk behind the patient to avoid u may use the time from the first peed test below.) ST= Not done Not done: too sick Not done: other Not done: age inapprop the patient to walk the first 15 feet of footfall at 0 feet and ends with the rst 15 feet of the 6 minute walk ST= Not done ST= Not done Not done: too sick Not done: age inapprop uring exercise (mL/kg/min) is the r alues recorded during the bicycle a ment. If both are available, the bic ST= Not done ST= Not done Not done: too sick Not done: other Not done: age inapprop

<ul> <li>breath.</li> <li>Class III: Marked limitation of physical activity; comfortable at rest, but less than ordinary activity causes fatigue, palpitation or shortness of breath.</li> <li>Class IV: Unable to carry on minimal physical activity without discomfort; symptoms may be present at rest.</li> <li>Unknown</li> </ul>
<ul> <li>Ross Class I: No limitations or symptoms.</li> <li>Ross Class II: No growth failure.</li> <li>Ross Class III: Growth failure.</li> <li>Ross Class IV: Symptomatic at rest.</li> <li>Not applicable: &gt;= 2 years of age</li> <li>Unknown</li> </ul>
<ul> <li>Mild tachypnea with feeds in infant</li> <li>Mild diaphoresis with feeds in infant</li> <li>Dyspnea on exercise in older children</li> <li>Unknown</li> </ul>
<ul> <li>Marked tachypnea with exertion or with feeding</li> <li>Marked diaphoresis with exertion or with feeding</li> <li>Unknown</li> </ul>
<ul> <li>Tachypnea</li> <li>Retractions</li> <li>Grunting</li> <li>Diaphoresis</li> <li>Unknown</li> </ul>

Screening Log - Pedimacs		
Implant Date		
Inclusion: Patient must meet all inc	clusion criteria:	
	support device (MCSD) which is FDA approved 2 (The device does not need to be the first implant for the patient)	
Device type	<ul> <li>LVAD</li> <li>RVAD</li> <li>Both (LVAD + RVAD in the same OR visit)</li> <li>Total Artificial Heart</li> </ul>	
Device brand	<ul> <li>Berlin Heart EXCOR (paracorporeal)</li> <li>HeartWare HVAD</li> <li>HeartMate II LVAS</li> <li>HeartMate III</li> <li>HeartMate IP</li> <li>HeartMate VE</li> <li>HeartMate XVE</li> <li>Micromed DeBakey VAD - Child</li> <li>Novacor PC</li> <li>Novacor PCq</li> <li>Thoratec IVAD</li> <li>Thoratec IVAD</li> <li>Abiomed AB5000</li> <li>Abiomed BVS 5000</li> <li>Thoratec Centrimag (Levitronix)</li> <li>Thoratec Pedimag</li> <li>TandemHeart</li> <li>Biomedicus</li> <li>Maquet Rotaflow</li> <li>Sorin Revolution</li> <li>Abiomed Impella 2.5</li> <li>Abiomed Impella 5.0</li> <li>Abiomed Impella RP</li> <li>Other, Specify</li> </ul>	
Specify brand		

#### Screening Log

Device brand (RVAD)	
Specify brand (RVAD)	
Age Range	<ul> <li>0 to 2</li> <li>3 to 4</li> <li>5 to 9</li> <li>10 to 12</li> <li>13 to 15</li> <li>16 to 18</li> </ul>
Race	<ul> <li>American Indian or Alaska Native</li> <li>Asian</li> <li>African-American or Black</li> <li>Hawaiian or other Pacific Islander</li> <li>White</li> <li>Unknown / Undisclosed</li> <li>Other / none of the above</li> </ul>
Ethnicity: Hispanic or Latino	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
Gender	<ul> <li>Male</li> <li>Female</li> <li>Unknown</li> </ul>
Did death occur within 2 days post implant?	<ul><li>Yes</li><li>No</li></ul>
Is this VAD an investigational device?	<ul><li>Yes</li><li>No</li></ul>
Is patient involved in a VAD related study?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>
What is the name of the study?	
Is this an industry sponsored post approval study?	<ul> <li>Yes</li> <li>No</li> <li>Unknown</li> </ul>

Transfer Form - Pedimacs					
Transferred Care to another hospital Date transferred care	⊖ Yes ⊖ No				
Date transferred care	ST= Unknown				

#### Withdraw Consent - Pedimacs

Did the patient withdraw consent?

Yes	
No	

Date of withdrawn consent:
