

Data Collection Form

Timing of Stage 2 in the Critical Left Ventricular Outflow Tract Obstruction Cohort: Variables for Dynamic Risk Profiles

PART 1: Post Norwood, pre-Stage 2 Repeated Measures

Study # : _____

- O₂ saturations
 - O₂ saturation _____ %
 - Date of O₂ saturation (MM/DD/YY) _____

- Weights at clinic visits and interim procedures/hospitalizations
 - Weight _____ kg
 - Date weight obtained (MM/DD/YY) _____

- Lengths at clinic visits and interim procedures/hospitalizations
 - Length _____ cm
 - Date length obtained (MM/DD/YY) _____

- BSA at clinic visits and interim procedures/hospitalizations
 - BSA _____ cm²
 - Date BSA obtained (MM/DD/YY) _____

PART 2: Post-Norwood until Stage 2

Study # : _____

Post-Norwood course:

- Major non-cardiac operations between Stage 1-2
 - Name of operation _____
 - Date of operation (MM/DD/YY) _____
 - Indication for operation _____

- Nutritional information
 - Oral feeding
 - Enteral feeding

- Type of enteral access
 - Nasogastric tube
 - Nasoenteric tube (intestinal)
 - PEG (percutaneous endoscopic gastrostomy)
 - Jejunal tube

- Calorie plan/regimen
 - Goal kcal/day or kcal/feeding _____

- Non-operative cardiac readmissions pre-Stage 2
 - Date of hospitalization (MM/DD/YY) _____
 - Date of discharge (MM/DD/YY) _____
 - Indication for admission (e.g. for diuresis, failure, respiratory failure) _____

 - Required inotropes?
 - Yes
 - No
 - Type of inotrope _____

- Cardiac arrest
 - In hospital
 - Out of hospital
 - Date of arrest (MM/DD/YY) _____

- Chylothorax
 - Yes
 - No
 - Required operative intervention? _____

Interstage monitoring:

- Home monitoring after Norwood
 - Yes
 - No

- Not commented on
- Daily weights
 - Yes
 - No
 - Not commented on
- Pulse oximetry
 - Yes
 - No
 - Not commented on

Markers of non-cardiac organ dysfunction, pre-Stage 2:

- Pulmonary
 - o Tracheostomy
 - Yes
 - No
 - Date of tracheostomy (MM/DD/YY) _____
 - Date of decannulation (MM/DD/YY) _____
 - o CPAP
 - Yes
 - No
 - Date CPAP initiated (MM/DD/YY) _____
 - Date CPAP terminated (MM/DD/YY) _____
 - o Re-intubation following surgical extubation
 - Yes
 - No
 - Date of intubation (MM/DD/YY) _____
 - Date of extubation (MM/DD/YY) _____
- Renal
 - o Required for Renal Replacement Therapy in ICU
 - Yes
 - No
 - Date RRT initiated (MM/DD/YY) _____
 - Date RRT terminated (MM/DD/YY) _____
- Neuro
 - o Ischemic Stroke
 - Yes
 - No
 - Date of stroke (MM/DD/YY) _____
 - o Intracranial hemorrhage/hemorrhagic stroke
 - Yes

- No
- Date of hemorrhage (MM/DD/YY) _____
- Seizure
 - Yes
 - No
 - Date of seizure (MM/DD/YY) _____
- Infectious issues
 - Bloodstream infection as defined by + Blood cultures
 - Yes
 - No
 - Date of positive cultures (MM/DD/YY) _____
 - Viral or bacterial _____
 - Species of bacteria or virus _____
 - Sepsis
 - Yes
 - No
 - Date of diagnosis (MM/DD/YY) _____
 - Pneumonia
 - Yes
 - No
 - Bacterial or viral _____
 - Date of diagnosis (MM/DD/YY) _____
 - RSV/URI
 - Yes
 - No
 - Bacterial or viral _____
 - Date of diagnosis (MM/DD/YY) _____
 - UTI
 - Yes
 - No
 - Date of positive urine culture (MM/DD/YY) _____
 - Line-associated infections
 - Yes
 - No
 - Date of diagnosis (MM/DD/YY) _____
 - Meningitis
 - Yes
 - No
 - Date of diagnosis (MM/DD/YY) _____
 - Bacterial or viral _____
 - Date of diagnosis _____

PART 3: Post Stage 2

Study # : _____

Post-Stage 2 course:

- Major non-cardiac operations between Stage 2-Fontan
 - Name of operation _____
 - Date of operation (MM/DD/YY) _____
 - Indication for operation _____

- Nutritional information
 - Oral feeding
 - Enteral feeding

- Type of enteral access
 - Nasogastric tube
 - Nasoenteric tube (intestinal)
 - PEG (percutaneous endoscopic gastrostomy)
 - Jejunal tube

- Calorie plan/regimen
 - Goal kcal/day or kcal/feeding _____

- Non-operative cardiac readmissions pre-Fontan
 - Date of hospitalization (MM/DD/YY) _____
 - Date of discharge (MM/DD/YY) _____
 - Indication for admission (e.g. for diuresis, respiratory failure) _____

 - Required inotropes?
 - Yes
 - No
 - Type of inotrope _____

- Cardiac arrest
 - In hospital
 - Out of hospital
 - Date of arrest (MM/DD/YY) _____

- Chest tube duration
 - Date of insertion (MM/DD/YY) _____
 - Date of removal (MM/DD/YY) _____

Markers of non-cardiac organ dysfunction, pre-Fontan:

- Pulmonary
 - Tracheostomy
 - Yes
 - No
 - Date of tracheostomy (MM/DD/YY) _____

- Date of decannulation (MM/DD/YY) _____
 - CPAP
 - Yes
 - No
 - Date CPAP initiated (MM/DD/YY) _____
 - Date CPAP terminated (MM/DD/YY) _____
 - Re-intubation following surgical extubation
 - Yes
 - No
 - Date of intubation (MM/DD/YY) _____
 - Date of extubation (MM/DD/YY) _____
- Renal
 - Required for Renal Replacement Therapy in ICU
 - Yes
 - No
 - Date RRT initiated (MM/DD/YY) _____
 - Date RRT terminated (MM/DD/YY) _____
- Neuro
 - Ischemic Stroke
 - Yes
 - No
 - Date of stroke (MM/DD/YY) _____
 - Intracranial hemorrhage/hemorrhagic stroke
 - Yes
 - No
 - Date of hemorrhage (MM/DD/YY) _____
 - Seizure
 - Yes
 - No
 - Date of seizure (MM/DD/YY) _____
- Infectious issues
 - Bloodstream infection as defined by + Blood cultures
 - Yes
 - No
 - Date of positive cultures (MM/DD/YY) _____
 - Viral or bacterial _____
 - Species of bacteria or virus _____
 - Sepsis
 - Yes
 - No
 - Date of diagnosis (MM/DD/YY) _____
 - Pneumonia
 - Yes
 - No
 - Bacterial or viral _____
 - Date of diagnosis (MM/DD/YY) _____

- RSV/URI
 - Yes
 - No
 - Bacterial or viral _____
 - Date of diagnosis (MM/DD/YY) _____
- UTI
 - Yes
 - No
 - Date of positive urine culture (MM/DD/YY) _____
- Line-associated infections
 - Yes
 - No
 - Date of diagnosis (MM/DD/YY) _____
- Meningitis
 - Yes
 - No
 - Date of diagnosis (MM/DD/YY) _____
 - Bacterial or viral _____
 - Date of diagnosis _____