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
- 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