Clinical MCH-NICU Guideline

MCH Quick reference summary for guideline and management of newborns with congenital heart defect in the early post-natal life

INTRODUCTION

The following guideline is aimed to standardize the care of newborns with congenital heart defects admitted to the NICU at the Montreal Children's Hospital. Specifically, it targets tasks that should be accomplished by the interdisciplinary team caring for these infants in the immediate post-natal period, before surgical intervention.

THIS GUIDELINE APPLIES TO

- Newborns with one of the below cardiac diagnosis:
  - A) Congenital heart defect(s) requiring prostaglandin infusion (ductal-dependent for systemic flow, pulmonary flow or mixing)
  - B) Total anomalous pulmonary venous return
  - C) Severe variants of Tetralogy of Fallot that can lead to neonatal instability (MAPCAS or absent pulmonary valve)
- Professionals targeted: Nurses, neonatal nurse practitioners, neonatal nurse practitioner students, physicians (neonatologists, clinical assistants), residents, fellows, respiratory therapists, nutritionists, pharmacists, occupational therapists, physiotherapists.

TABLE OF CONTENTS

Team and

- NICU lead: Gabriel Altit (Neonatology)
- Cardiology lead: Claudia Renaud, Adrian Dancea (Cardiology)
- Nursing lead: Stephanie Mardakis and Elissa Remmer (RN-Educators, NICU)
- NNP lead: Sarah Asselin (Neonatology-NNP), Olga Kazantseva (Neonatology, NNP)
- Trainee representative: Punnanee Wutthigate (Neonatology – Fellow)

Content review:

- Richard Gosselin (Neonatology)
- Tanya Di Genova (Pediatric Intensive Care Unit)
- Pierre-Luc Bernier and Christo Tchervenkov (Pediatric Cardiac Surgery)
- Nora Ruo and Rodolphe Kenol-Maurrasse (Pharmacy)
- Elise Couture, Diane Martin and Patricia Grier (Neonatal Follow-up)
- Shani Lugasi (Nutrition)
- Michele Zegray (RN Cardiology)
- Bettina Mucha-Le Ny (Medical Genetics)
- Gianluca Bertolizio (Cardiac Anesthesia)
- Christine Labelle (Occupational Therapy)
- Shani Lugasi and Caroline Porraccio (Nutrition)
- Matthew Park and Marie Laberge (Social Services)

SECTION 1: Admission

Admission to the NICU

Vital signs and monitoring

- Put pre-ductal and post-ductal saturation monitoring in place, unless specifically ordered otherwise by cardiology / neonatology medical team
- Set monitor alarms to target oxygen saturation as per admission orders – should be discussed with the cardiology/NICU medical team.
    - Patients with single ventricular physiology, restricted pulmonary blood flow (pulmonary stenosis or atresia) or d-transposition of great arteries should be saturating > or = 75%.
    - Non-cyanotic heart defect newborns should have oxygen saturation targets corresponding to the OWL protocol.
- Put the Cerebral and Renal NIRS sensors (for at least the first 7 days of life). Advise medical team if values consistently below 50% for either. Consider alerting medical team if a drop by 30% or more in the past 4 hours.
- Oxygen supplementation should not go beyond 30% (if suspected component of lung disease) in newborns on PGE1 infusion, unless specified otherwise by the neonatal / cardiology teams.
- Right upper limb and post-ductal lower limb (or umbilical arterial line) blood pressure should be measured at every care if suspected/confirmed: coarctation of aorta, hypoplastic arch, other anomaly of the aorta (such as: interrupted aortic arch), hypoplastic left ventricle. *If umbilical arterial line in place, this represents the lower limb blood pressure since it is positioned in the post-ductal area.*

Already standard of care for all newborns:

- Cuff BP taken on all four limbs at admission
- Ensure nares are patent on both sides (rule out choanal atresia). If suspicion of choanal atresia – rule out CHARGE syndrome.

Prostaglandin E1 (Alprostadil):

- Prostaglandin E1 (PGE1 - Alprostadil) infusion requirements: refer to prenatal cardiology and neonatology consultations. If post-natal diagnosis / suspicion – decision to initiate PGE1 infusion should be made by medical team according to clinical status. Usually, dosages at initiation depend on time since birth and size of ductus.
- Dosages/Concentration:
    - If the ductus is known to be large (first hours of life), PGE1 therapy can be started at a low dose initially (0.01 mcg/kg/minute)
    - If the ductus is restrictive or the status of the ductus is unknown, the initial dose is 0.05 mcg/kg/minute.
    - Usual concentration: Prostaglandin E1 at 10 mcg/mL.
        - May be also prescribed occasionally as 2 mcg/mL by medical team.
        - 2 mcg/mL will usually lead to higher than necessary non-nutritional fluid intake
    - Dosage of PGE1 can be increased as needed to a usual maximum dose of 0.1 mcg/kg/minute. The risk of side effects (eg. Apnea, fever, hypotension & diarrhea etc.) increases with increasing dosages of PGE1.
    - Once stable oxygenation has been achieved, PGE1 dosage should be titrated down to the lowest effective dosage (with guidance of cardiology recommendations)
- Patients should be monitored closely for apnea and hyperthermia (rectal T > 38 °C) after PGE1 is started. Axillary temperature is monitored at every care and a rectal temperature is

done only if the axillary one is elevated. The medical team should be informed if either is noted.

- IMPORTANT: In case of hyperthermia, DO NOT ADMINISTER non-steroidal anti-inflammatory medications such as ibuprofen, as it may induce ductal constriction. The use of acetaminophen in that population is controversial, as there are reports that it may induce ductal constriction in premature infants non-exposed to PGE1. Its effect on ductal tissue exposed to PGE1 is unknown. Pharmacy representative advises against using high dose acetaminophen (i.e.: 15 mg/kg/dose q6hours) for prolonged periods of time for the very small theoretical risk of ductal closure.

Line placement

- *If the newborn is thought to need an atrial septostomy* – please refer to Septostomy protocol. The umbilical stump should not be touched until Cardiology has completed septostomy. *Once septostomy completed, umbilical lines to be inserted (double-lumen UVL and UAL).*
- If no need for septostomy: on admission, insertion of a <u>double</u> lumen UVL (or PICC if it is an admission for a later post-natal diagnosis) if starting PGE1 (or sedation/inotropes). A double-lumen should always be attempted when installing a UVL or PICC.
    - For certain cardiac conditions (non-PGE1 dependent), a peripheral intravenous line may be inserted according to the prenatal recommendation of NICU/Cardiology.
    - Regardless of the need for PGE1, a double lumen UVL and a UAL should also be placed in patients with anticipated need for neonatal cardiac intervention (catheterization or surgery in the first 14 days of life)
    - In newborns with a need for neonatal cardiac intervention or prolonged PGE1/inotropic infusion, a double-lumen PICC should be placed in the days following admission.
- UAL should be attempted in all patients started on PGE1 (or inotropes).
- Discuss timing of UVL or UAL removal with cardiac surgery team

Investigations

- On admission: CBC, blood gas (including lactate / glucose / electrolytes), type and screen and Coombs for all babies upon line placement
    - If palliative care is imminent or critically ill patient – consider saving one tube of EDTA blood (1-2 ml) for DNA extraction and consult medical genetics to provide test form(s)
    - *Extra attention for lymphopenia and normalized ionized calcium in cases where Di George (22q11.2 deletion) syndrome suspected. Di George may happen in any types of congenital heart defect, although it has been classically associated with conotruncal anomalies (truncus arteriosus, interrupted aortic arch, tetralogy of Fallot), as well as VSD and ASD. If Di George confirmed, consult systematically Immunology and Endocrinology.*
    - *If lymphopenia – ensure to follow CBC until normalization of absolute lymphocyte count – otherwise, involve Immunology. Lymphopenia in a newborn if absolute value* $< 2.5 \times 10^9$*/L. Considered severe if* $<1.5 \times 10^9$*/L.*
    - *If hypocalcemia – ensure to follow calcium, albumin and total calcium – Consider endocrinological evaluation (PTH, Vit D 25-OH levels) and consultation. Red flag if iCa<1.00.*
- Chest/Abdominal radiography on admission. Abdominal radiographies (Anterior-Posterior and lateral shoot through for line placements)
    - *Extra attention for presence of thymus.*
    - *If absent thymus – consider the diagnosis of DiGeorge*
    - *If situs anomalies – consider the diagnosis of primary ciliary dyskinesia or other heterotaxy syndromes*
    - *If vertebral anomalies – consider VACTERL Association (diagnosis of exclusion)*

- Confirm presence or absence of thymus, situs and vertebral integrity in admission note

Nutrition and Fluid Balance

- Newborn should be re-weighted in NICU incubator upon admission to ensure an accurate "dry" birth weight is used for fluids and medications
- If not feasible, use a dry weight of the 50th percentile for gestational age at birth.

<u>Parenteral nutrition</u>

- Initiate fluids with early parenteral nutrition
  - Starter Amino Acids TPN
  - Start SMOF lipids at 1g/kg/day (Intralipids only if one lumen and on PGE1 due to compatibility issues). Indeed, SMOF (soybean oil, medium-chain triglycerides, olive oil, and fish oil) is not compatible with PGE1. PGE1 are not compatible with SMOF, therefore Intralipid has to be prescribed if ever PGE1 and lipids have to be infused in the same line (e.g. in the case of a single lumen available).
- Start total fluid intake as per gestational age recommendation. Usually:
  - 34 weeks to term: start on day 1 with 65 mL/kg/day
  - 29 weeks to 34 weeks: start with 80 mL/kg/day
  - <29 weeks: refer to ELGA protocol
  - Adjust total fluid intake according to discussion between medical team and cardiology team, medical condition, as well as age of infant at admission.
  - If admission at more than 72 hours of age, do not exceed 100 mL/kg/day.
  - 100 mL/kg/day by intravenous support with a central line is often enough fluid to provide caloric intake. Increasing fluids beyond should be done cautiously with guidance of nutrition.

<u>Enteral nutrition</u>

- All infants started on PGE1 infusion should be NPO
  - As soon as baby is stabilized, discuss introduction of enteral feeds with cardiology (joint decision between critical care team [NICU or PICU] and cardiology team)
- When colostrum is available, initiate oral immune therapy (OIT) – Refer to OIT Protocol
- Wait for Cardiology approval to start trophic (10-20 ml/kg/day) or nutritive feeds with **EBM or pasteurized human milk [67]**
- Early consult with lactation consultant

Services to be consulted upon admission:

- Cardiology (with Cardiology Nurse and Nurse Practitioner)
  - Cardiac surgery will be contacted by Cardiology - if operative management is thought to be urgent/imminent (example: obstructive TAPVR) – may be notified/consulted by NICU earlier.
- Genetic team (may request Ophthalmology evaluation)
- Social worker
- Lactation team
- Cardiac anesthesia should be involved if operative management anticipated or planned (cardiac surgery or catheterization). Email: aicmch@muhc.mcgill.ca to inform about consultation.
- Occupational therapy
- Music Therapy
- In certain circumstances: PACT and Spiritual Care

- Obtain consent at admission for:
  - Hospitalization and care (general consent form)
  - Transfusion

- Donor milk administration (eligibility will be confirmed by milk bank according to Hema Quebec's supplies)
- Hearing screen (consider cardiac intervention as risk factor)
- Double-lumen PICC line

SECTION 2: Preoperative hospitalization in NICU

Preoperative monitoring and care

- All CHD patients need to have functional intravenous access at all times (UVL, PICC or PIV) in the pre-interventional setting; if peripheral access is used for PGE1 or inotropes, a second PIV should be in place as back-up.

Respiratory care / monitoring

- Despite the cardiac defect, airway and breathing remain a priority - ABC
- Respiratory rate must be monitored continuously with cardiorespiratory monitors. Document hourly. If the patient is on PGE1, the respiratory rate alarm must be turned on.
- Assessment of respiratory system is required minimally with every care. This includes:
  - Respiratory rate
    - Presence of work of breathing, indrawing, grunting, tachypnea
    - Bradypnea/apnea: is the baby newly on PGE1 or on a higher dose of PGE1?
  - Overcirculation
    - Reflective of excessive blood flow reaching the lungs, leading to pulmonary edema
    - Will be reflected clinically by increased work of breathing, increased secretions, chest radiography changes, desaturations or oversaturation, tachypnea, positive fluid balance and/or peripheral edema.
    - If overcirculation is suspected, treatment with diuretics, such as furosemide, needs to be considered.
    - In those supported by mechanical ventilation: aim for some degree of permissive hypercapnia. This allows for higher PVR to decrease pulmonary flow and temper pulmonary over-circulation. Avoid pCO2 < 40 and aim for a pH between 7.30 and 7.40.
  - Work of breathing: retraction, tracheal tugging, head bobbling
  - Oxygen saturation
    - Pre- and post-ductal saturation should be monitored continuously. Saturation targets should be established after discussion with cardiology team and ordered.
    - If differential > 10% between pre and post-ductal saturations (after ensuring that the reading is adequate) advise medical team
  - Colour
    - Presence of central cyanosis? Or clinical systemic hypoperfusion (mottled skin, pallor, decreased urine output, increased lactate, acidosis, depressed level of consciousness or agitated)?
- In patients with signs of PPHN or suspected pulmonary hypertension, **discuss with cardiology before starting iNO** and get echocardiography to confirm physiology. iNO may worsen pulmonary edema in patients with structural heart lesions leading to pulmonary overcirculation. iNO may be considered (after discussion with cardiology) in:

        - TGA with reverse differential, or newborns with concomitant perinatal stressor / hypoxic ischemic insult with persistence of high pulmonary vascular resistances
    - In presence of respiratory compromise, advise medical team and consider:
        - Chest radiography
        - Blood gas with lactate level, electrolytes, and glucose
        - *Think of other possible etiologies: Arrhythmia / Bacteremia / Cardiac failure / Effusions / Clot.*

Hemodynamic monitoring

- The following must be monitored closely:
    - **Blood pressure** - minimum with every care; more frequently if concerns or invasive BP monitoring available (For reference values of normal blood pressure depending on gestational age, please refer to usual practice care by PALS guidelines; for premature newborns – mean blood pressure = or > than gestational age)
        - Umbilical arterial line is warranted in every baby with possible neonatal intervention (<2 weeks of age); invasive BP must be monitored and documented hourly
        - 2-limb blood pressure (right – arm and a post-ductal: UAL or lower-limb) at least twice a day (except if PICC line placed in right arm).
        - If differential > 10 mmHg of systolic BP between pre- and post-ductal blood pressure, advise medical team (especially in ductal dependent lesions for systemic perfusion, such as: HLHS, Coarctation, Interrupted Aortic Arch).
        - Advise medical team if presence of hypo- or hypertension at any time
    - **Heart rate** - continuously with cardiorespiratory monitors. Document heart rate hourly. If signs of arrhythmias or anomalies:
        - Advise medical team
        - Print the monitor strip reflecting the anomaly
        - Consider 12-lead electrocardiogram
        - Monitor hemodynamics closely
        - Bring the defibrillator close to the room
    - **Perfusion** – minimum with every care; details to note include:
        - Upper and lower limb pulses to be assessed with every care
        - Capillary refill to be assessed with every care: </= 3
        - Is the baby mottled or cyanotic?
- When PGE1 is infusing, monitor temperature continuously with incubator probe and q cares with axillary thermometer (document hourly)
    - If axillary temperature > 37°C, reassess via rectal route
    - In presence of hyperthermia (rectal T > 38 °C), advise medical team
    - If presence of apneas or desaturations, advise medical team
    - Prolonged PGE1 infusion may be associated with inflammatory bone changes and discomfort

Gastrointestinal monitoring

- Feeds will only be initiated once agreed between cardiology and NICU's assessment
- Patient may be NPO, on trophic feeds, partially fed or fully-fed based on the cardiovascular assessment / physiology as described by Cardiology. Certain malformations are associated with poor intestinal perfusion/oxygenation, and these patients are at higher risk for gastro-intestinal adverse events (such as necrotizing enterocolitis). Others are at higher risk for malrotation (heterotaxia syndromes).

- Examine abdomen systematically at every care, looking for signs of gastrointestinal compromise or intolerance such as:
  - Abdominal distention and visible bowel loops
  - Abdominal tenderness
  - Abnormal coloration of the abdominal wall
  - Vomiting
  - Bilious vomiting (ominous sign for: malrotation / volvulus)
  - Bloody stools
  - Absent or decreased bowel sounds
- If presence of any signs of gastrointestinal compromise or feeding intolerance:
  - Hold feeds
  - Advise medical team immediately
  - Consider abdominal radiography (AP and Lateral) +/- investigations (such as: CBC, blood and urine culture, gas for glucose, pH and lactate, CRP).

Renal monitoring

- Renal saturation by NIRS should be applied upon admission (refer to NIRS guidelines)
- Follow urine output every care as it is reflective of fluid balance and renal perfusion
  - Calculate fluid balance q 6 – 8 hours
  - Measure weight q 24 hours
- Follow renal function tests weekly or more often if concerns. Specifically, some of these newborns may be on high dose diuretics which may impact renal function. High urea level indicates potentially intra-vascular depletion and may put the patient at risk of pre-renal acute kidney injury.
  - Follow trends in urea and creatinine
  - Follow electrolyte balance (Na, K, Cl, bicarbonate)
  - Consider use of spironolactone in patients with diuretic-induced hypokalemia.

Neurologic monitoring

- Neurological assessment is required as it may reflect presence of potential complications such as decreased cerebral perfusion or stroke
- Monitoring of neurologic status includes:
  - Alertness
    - Assess for presence of lethargy or decreased spontaneous activity
  - Presence of seizures
- Cerebral saturation by NIRS should be applied starting admission (refer to NIRS guidelines)
- Cerebral imaging is indicated before surgery
  - Cerebral magnetic resonance imaging (MRI) is the gold standard. Should be ordered on admission in order to optimize organization with the radiology team.
  - If MRI is not feasible or not requested by cardiovascular surgery team, brain ultrasound may be considered as a replacement of MRI to ensure no large bleed before possible cardiac intervention (especially if requiring cardiopulmonary bypass and anticoagulation).

Investigations

- CHD patients require laboratory monitoring
  - Patients started on PGE1 should have blood gas (including lactate / glucose / electrolytes) evaluation at least q12 hours for the first 48 hours of life and then daily for the first week of life
  - Liver profile (ALT, Alkaline phosphatase, GGT), neonatal bilirubin (Total / Direct), urea, creatinine and TPN bloodwork (triglycerides, magnesium, phosphate) on the same tube at 24-hour of life

- Weekly: renal function (creatinine, urea), hepatic function and enzymes (ALT, GGT, alkaline phosphatase [also important for the monitoring of inflammatory bone changes in chronic PGE1 infusion], albumin, glucose), complete blood count, total parenteral nutrition labs (Mg, triglycerides, phosphate)
- Pre-intervention (surgery or catheterization): baseline cortisol value, coagulation profile, Sars-CoV-2 screen in the 24 hours prior to intervention. Type and screen should be ensured to be valid.

- Order 12-leads electrocardiogram in the first 24 hours of life (if admitted on a week-end day, do a 12-leads ECG by the NICU team and order one by the cardiology team for the next working day)
- Abdominal ultrasound for anomaly screen (special attention to renal anatomy) – to be organized ideally before the first intervention or discharge.
- Brain MRI should be requested on admission with pre-assessment form for newborns with anticipated neonatal cardiac intervention. If not feasible prior to intervention, ensure to have at least one brain ultrasound to ensure the absence of any gross intra-cranial bleed before surgery. For those without the need for neonatal cardiac intervention, a brain MRI is unnecessary unless specifically requested by cardiology or cardiac surgery.
- Ensure all necessary genetic testing has been sent before removing the central lines (UVL or UAL)

Nutrition and Fluid Balance

- Optimize parenteral and enteral nutrition as soon as possible after birth
- Weigh the baby minimally q 24 hours
- Measure head circumference and length on weekends every week
  - Plot measures on appropriate growth curves

- As soon as baby is stabilized, discuss introduction of enteral feeds with cardiology
  - PGE1 and umbilical arterial access are not contraindications to enteral feeds
- When colostrum is available, initiate oral immune therapy (OIT) – Refer to OIT protocol
- When Cardiology agrees, start trophic feeds with **EBM or pasteurized human milk [67]** ~ 20 ml/kg/day, with close monitoring
  - Progress feeds as tolerated depending on clinical stability **and cardiology's approval**
  - Early consult with lactation consultant
  - Do not use formula for trophic feeds
- Prioritize mother's milk when available
  *If not, administer pasteurized human milk after obtaining parental consent; **avoid** formula. PHM eligibility is until 3 weeks after reaching full enteral feeds. After which, if still not enough EBM (or mother not breastfeeding), the infant needs to be changed to their "population" appropriate formula.*
- If requiring gavage, prioritize bolus feeds if tolerated.
- Discontinue feeds if any signs of feeding intolerance or hemodynamic instability
- If growth remains suboptimal, consider fortification when feeds are well tolerated at full intake
- Encourage feeds by mouth when clinical stability and respiratory status allow it. Encourage direct breastfeeding
- Probiotics are not indicated for this population

Fluid balance

- Measure fluid balance q 6-8 hours with strict input and output, including urine output monitoring.

- Measure urine output with each diaper change, or hourly if Foley catheter in place. Calculate urine output per kg per hour at each care (advise medical team if less than 1 mL/kg/hr).
- Consider diuretics when excessive positive balance and/or excessive weight gain
- Aim to provide optimal nutrition. Excessive fluid restriction may lead to sub-optimal pre-operative growth and nutritional status. A balance between judicious use of diuretics and careful fluid restriction may be more appropriate than aiming a single strategy.

Medication

- Use dilution with dextrose for continuous infusions when possible
- If ever nutritive requirements really cannot be met, evaluation with pharmacy (and nutrition) for dilution of certain continuous infusions in D10% instead of D5% can be made

Sedation and analgesia

- Pay special attention to the effects of each sedative/analgesic agent on hemodynamics

- Consider sedation and analgesia for patients with:
  - Mechanical ventilation (especially if intubated for heart failure to diminish cardiac work)
  - Agitation complicating clinical stability
    - Non-pharmacological tools to be prioritized, including pacifier, positioning, music, skin-to-skin, voice recordings from parents
  - Pain secondary to the presence of invasive medical device(s)
  - Pain from other sources
  - Suspected significant acute pulmonary hypertension (secondary to suspected high pulmonary vascular resistance)

- The preferred agents for patients with congenital heart defect
  - Discuss on a case-by-case basis with pharmacists
  - For analgesia:
    - For an infusion: consider fentanyl
    - For intermittent dosages: consider morphine
  - Sedation:
    - For an infusion: consider dexmedetomidine (however, beware of hypotension and bradycardia)
    - For intermittent dosages: consider midazolam

Family integrated care and developmental care

- Offer skin to skin in the delivery room for newborns who do not need emergent NICU admission (under surveillance of the resuscitation team). Those with a recommendation for PGE1 infusion should be considered as an emergent need for NICU admission.
- The accompanying parent should be invited to follow their infant from the delivery room to the NICU.
- Provide family with welcome package and pamphlets regarding neonatal unit.
- Encourage parental presence at the bedside
- Explain structure of rounds and care to parents at arrival in the NICU. Encourage parental participation in rounds and cares. Explain the use of NeoConnect and voice recording on admission to parents.

• Present and explain roles of various health care professionals involved in the care of the family
• Encourage reading and speaking to their baby to promote language acquisition (at least 1 hour per day) and inform parents about Books for Babies. Encourage parents to bring books in their own language. Encourage use of voice recorder for when not at bedside.
• Involve music therapist when possible • For all CHD patients with prolonged hospitalization (> 2 months) or developmental concerns, discuss with bridge team and consider consult. First assessment of neonatal follow-up is usually at 4 months of age in the outpatient setting. • All CHD patients should be assessed by OT for global evaluation and oral skills – this should be done as soon as possible to preserve oral skills when NPO and provide neuro-stimulation information to the parents. Consider physiotherapy consultation.
• When doing potentially painful or uncomfortable procedure, offer non-pharmacological (sucrose, breast feeding or non-nutritive sucking, positioning, skin-to-skin, music therapy) and pharmacological interventions (enteral/intravenous/submucosal/intranasal/subcutaneous medications [depending clinical context], as well as topical anesthesia, when indicated) for pain control.
• Kangaroo care (Skin to Skin care) or modified Kangaroo care (depending on clinical status and contraindications) to be encouraged • Encourage breastfeeding and/or oral feeds when clinical status allows it *All CHD patients need an OT assessment for oral skills and global neurodevelopmental assessment during hospitalization*
• Inform family about the services of En-Coeur foundation (Contact Social Services).

SECTION 3: Discharge planning

Discharge Planning

Developmental follow-up
• ***For CHD patients with open-heart surgery occurring at less than 3 months of age***
  o Consult occupational therapist for global neurodevelopmental assessment prior to discharge
  o Consultation with neonatal follow-up clinic (1st appointment at 4 months)
  o If patient is still hospitalized at 4 months, consult bridge team for inpatient assessment
• ***For CHD patients <u>without neonatal open-heart surgery</u> (not before discharge or > 3 months)***
  o Consult occupational therapist for assessment prior to discharge
  o If prolonged hospitalization (> 2 months) and/or concerns about neurodevelopment, consult bridge team
  o If patient has a cardiac anomaly associated with a diagnosed syndrome, refer to neonatal follow-up clinic (except Down syndrome)
  o If specific condition and/or instability during hospitalization or other concerns justifying closer developmental follow-up, discuss with neonatal follow-up clinic team for referral. *Patients with ASD and/or VSD are not expected to have assessment by OT before discharge nor to be referred to the neonatal follow-up clinic.*
• Hearing screen to be done before discharge for all patients
  o If required, referral in audiology clinic at 10 months

Nutrition

- Assess presence of risk factors for growth failure after discharge and ensure appropriate follow-up with nutrition in the outpatient community, as well as close follow-up with community pediatrician (or family doctor) identified before discharge:
  - Persistent congestive heart failure
  - Neurologic injury
  - Genetic abnormalities
  - Gastrointestinal malabsorption
  - Vocal cord dysfunction → Requires ENT consultation and feeding safety assessment.
  - Dysphagia
  - Oral aversion
  - Gastroesophageal reflux disease
- Assessment by occupational therapist (OT) to ensure safe oral feeds is required before discharge
  - After OT assessment, consider videofluoroscopy if there are remaining doubts about aspiration and/or penetration while feeding orally.
- If patient is discharge with home gavage, refer to neonatal follow-up clinic.
- Consider gastrostomy if thought to require long term home gavage (consultation with gastroenterology and pediatric surgery)

Cardiology

- Inform (or notify) cardiology nurse when discharge is approaching
  - Specific cardiology teaching to be giving by cardiology nurse if required
- RSV prophylaxis (Synagis) during viral season if patient meet criteria (assessment by Cardiology RN for outpatient setting)
  - During hospitalization, Synagis RN in the NICU should evaluate for Synagis eligibility.

Pharmacy/Medications:

- All outpatient prescriptions to be given to parents at discharge (i.e., vitamin D and iron if indicated)
  - Ensure that all cardiac medications are available at the family's pharmacy before discharge (notify NICU pharmacist)
- Pharmacy needs to be notified days in advance, given the general delays for external pharmacies to order uncommon prescriptions.

Newborn Care

- Identify a community pediatrician (or family doctor) in charge of newborn before discharge
- Family to receive routine discharge teaching by the bedside nurse. The cardiology nurse will provide any specialized teaching required (eg. monitoring for heart failure, counting of heart rate at home, gavage feeding, etc.)
- Follow-up ideally within the first 2 weeks after discharge by the pediatrician or family doctor

Other

- Notify medical genetics prior to discharge: for repeat physical evaluation, chart review, possible additional genetic testing prior to discharge and organization of out-patient follow-up.