

# NICU Congenital Diaphragmatic Hernia (CDH) Care Guideline

## Delivery Room Resuscitation

- Immediate intubation
- Place 10 fr salem sump orogastric or nasogastric tube to low continuous suction
- Pre-ductal pulse oximeter
- Begin O<sub>2</sub> at 50%, may increase to 100% if infant remains bradycardic
- Goal saturations >65% at 5 minutes, > 75% at 10 minutes of life

## NICU Admit

### Monitoring and Diagnostics

- Cardiac monitoring with pre and post ductal saturations, Tcom, and end tidal Co<sub>2</sub>
- Transport workup, blood culture, CBC, microarray
- CXR, head ultrasound, ECHO on arrival
- Consult pediatric surgery and genetics

### Ventilation and Oxygenation

- Vent settings: SIMV rate 30-40, PIP ≤25, inspiratory time 0.35, tidal volume <5cc/kg
- O<sub>2</sub> @50%, may wean at 6hrs of life if stable with preductal sats >85%, hold weaning at 30% until stable high O<sub>2</sub> saturations
- MAP goal 40-50mmHg

### IV Access/Fluids/Medication

- UVC or PICC and UAC or PAL
- Maintenance fluid ≤ 80mL/kg/day including all current infusions
- Sedation as clinically indicated
- Consider antibiotic x 48 hours in presence of prenatal risk factors or symptoms

### Other Treatment

- Inhaled Nitric Oxide (iNO) for pulmonary hypertension only after echocardiogram and discussion with NICU red team and cardiology
- ECMO if meets clinical indications and inclusion criteria

### Considerations:

- Use of high frequency oscillatory ventilation (HFOV) may be indicated if increased conventional ventilator settings are required
- Sedation: utilize intermittent doses of narcotics prior to initiating infusion; morphine or fentanyl infusion, versed PRN if indicated. Avoid paralysis. If infusions required preoperative, utilize increased doses as needed to control postoperative pain
- Pulmonary Hypertension:
- iNO contraindicated in LV dysfunction, LA enlargement, small left sided structures.
- Prostaglandins exhibit benefit in impaired LV function and select congenital heart diseases.

## Postoperative Care

- Schedule OR when exhibits evidence of physiologic stability
- Preoperative labs: CBC w/ diff, BMP, blood case, T&C, and DIC (if on ECMO)
- Postoperative VS per policy, monitor for signs and symptoms of compartment syndrome
- Goal O<sub>2</sub> sat ≥ 90%
- NPO with 10 fr salem sump
- CXR and blood gas
- CBC and CMP in AM postoperative day #1
- Pain/sedation as clinical appropriate
- Utilize cefazolin for antibiotic prophylaxis per repair type

Reassess the appropriateness of Care Guidelines as condition changes. This guideline is a tool to aid clinical decision making. It is not a standard of care. The provider should deviate from the guideline when clinical judgment so indicates.

### Discharge Criteria

- Weight, length, head circumference updated
- Immunizations, hearing evaluation, EDAC screening completed
- Immunizations, hearing evaluations, ST evaluation, CXR, Echo, head CT or MRI (if abnormal finding on HUS/seizures/abnormal neurologic findings/ECMO/patch repair)
- Follow up arranged for: RSV, Cardiology, Pediatric Surgery, and outpatient ST.

**CDH Parent/  
Family Education:**  
See attached copy at end of this guideline

## Congenital Diaphragmatic Hernia (CDH) Clinical Guideline

### Inclusion Criteria:

- All infants born with congenital diaphragmatic hernia

### Available Resources:

- CDH order set
- CDH Parent/Family Education:

### Prenatal Recommendations:

#### Antepartum Care:

- Ultrasound suspicious for CDH: refer to Maternal Fetal Medicine for detailed ultrasound exam
  - MFM ultrasound to include evaluation for other abnormalities, LHR and O/E ratios, description of liver involvement, and preliminary counseling/consultation
  - May also consider fetal MRI
- Referral to Pediatric Cardiology for fetal echocardiogram @ approximately 22 weeks.
- Genetics consultation with discussion of amniocentesis for microarray
- Referral to Pediatric Surgery
- Ongoing fetal surveillance to include ultrasound approximately every 2 weeks to evaluate fetal status, fluid and growth as appropriate.
- Initiation of antepartum fetal monitoring with twice weekly NST/weekly AFI at 33-34 weeks or sooner if other co-morbidities (for example IUGR) are noted.
- Multidisciplinary care meeting to involve OB, MFM, Neonatology, Genetics and Pediatric Surgery

#### Delivery:

- Recommended delivery at a tertiary medical center with ECMO capabilities
- Routine caesarean section is *not* recommended
- Discussion of possibility of induction of labor at fetal consultation
- Encouragement of full term delivery (39 weeks) but delivery may be warranted earlier for fetal and/or maternal indications
- Use of antenatal steroids may be indicated in infants less than 37 weeks gestation with concern for preterm delivery

### Delivery Room Anticipation and Resuscitation:

#### Pre-briefing:

- Team huddle with discussion of plan of care and clearly defined team member roles
- Advanced preparation of supplies including equipment for intubation, 10 fr salem sump, potential normal saline fluid boluses and resuscitative medications. Have CODE cart immediately available.

#### Delivery/ Resuscitation:

- Delayed cord clamping is currently not recommended
- Immediate intubation to avoid the use of bag mask ventilation and blow by fiO2 to avoid gastric distention and lung compression
  - *Avoid* use of high peak inspiratory pressure (PIP). PIP *not* to exceed 20-25
- Placement of 10 fr salem sump orogastric or nasogastric tube to low continuous suction
- No use of paralytic medications
- Placement of *pre-ductal* pulse oximeter

#### Initial Saturation and Oxygen Use Goals:

- Inspired oxygen is started at 50%
- Pre ductal saturation *greater than 65% at 5 minutes of life; greater than 75% at 10 minutes of life*
- In the event the infant remains bradycardic, may increase the oxygen concentration to 100%

## Neonatal Intensive Care Interventions:

### Monitoring:

- NICU monitors with pre and post ductal saturations
- Tcom and end tidal monitoring
- May place NIRS cerebral monitoring

### Diagnostic Studies/Labs:

- Admission labs: Transport work up, blood culture, CBC, Microarray
- CXR on admission and as indicated
- Baseline Head ultrasound on arrival
- ECHO on admission
- Consults: Pediatric surgery, Genetics

### Ventilation:

Goal of gentle ventilation by means of permissive hypercapnia to provide low pressures while maintaining adequate lung aeration

- Acceptable PaCO<sub>2</sub> range: ≤ 65
- Acceptable pH range: ≥ 7.25
- Ventilator settings: SIMV preferred, Rate 30-40, PIP not to exceed 25, inspiratory time 0.35, goal tidal volume less than 5 cc/kg
  - Consider the use of High frequency oscillatory ventilation (HFOV) if increased settings are required

### Oxygenation:

- Pre-ductal saturation goal: greater than 85%
- *Oxygen is started at 50%; weaning can begin at 6 hours of life if stable, hold weaning at 30% until infant has demonstrated stability and consistent high oxygen saturations*
  - *Wean O<sub>2</sub> by 3% every hour for pre-ductal saturations greater than 85%*
  - *Do not titrate FIO<sub>2</sub> based on PaO<sub>2</sub> or oxygen index (OI)*
  - *If pre ductal saturations are less than 85%, increase O<sub>2</sub> gradually as needed*
- Initiation of Inhaled Nitric Oxide (iNO) and indications of use: (see also considerations for management section for more information)
  - Echocardiogram demonstration of pulmonary hypertension that is unresponsive to other management options *and* infant is requiring greater than 60% oxygen
  - ECMO and surgical teams should be made aware of patient if starting iNO

### IV Access/ Fluid Management:

- UAC/UVC or peripheral arterial line and PICC line
  - Placement of umbilical venous and arterial lines: if liver is in thoracic cavity, the UV catheter often does not travel thru the ductus venosus and alternative venous access should be obtained when patient is stable
- Maintenance fluid ≤ 80 ml/kg/day including all current infusions

## Continued Neonatal Intensive Care Interventions:

### Hemodynamic management:

- Target goal mean blood pressure of 40-45 mmHg (low normal) in term infants
- Initiation of infusions
  - Dopamine use as first line agent
  - Consideration of a second agent in management of pulmonary hypertension after speaking with Red Team attending and surgical team
  - Consider repeat echocardiogram
  - Consult ECMO team in the event of continued hypotension
  - Consider use of steroids in presser-resistant hypotension

### Antibiotics:

- Clinical use of antibiotics not empirical
  - May consider 48 hr antibiotic treatment in presence prenatal risk factors or symptomatic patient

### Sedation:

- As clinically indicated
  - Use of intermittent dosing first
  - Morphine or fentanyl infusion, versed PRN if indicated
- Avoid paralysis

### Pulmonary Hypertension:

- Prevention is best
- ECHO findings suggestive of systemic or suprasystemic pulmonary hypertension
- Evaluation of pre and post saturations
- Inhaled Nitric Oxide (iNO): consider only after echocardiogram and discussions with NICU Red Team and Cardiology. Contraindications include use in LV dysfunction, LA enlargement, small left sided structures
- Prostaglandins: benefit exhibited in impaired left ventricular function and select congenital heart diseases. Talk to NICU Red Team prior to starting.

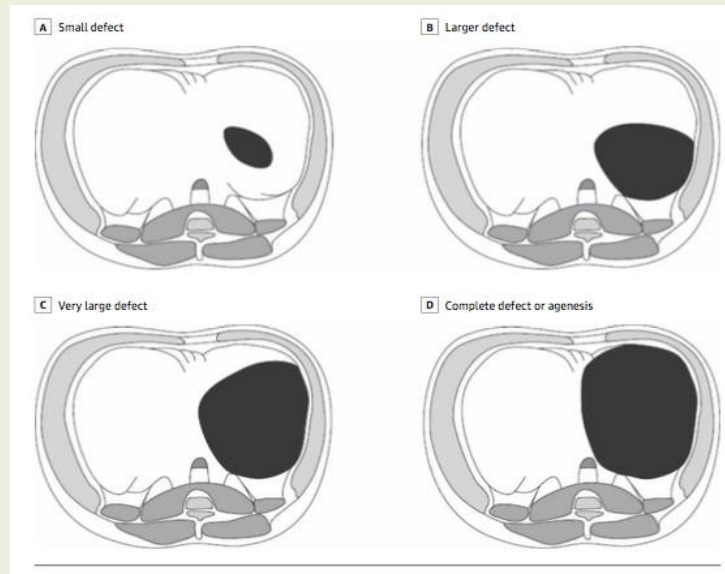
### ECMO:

- Indications:
  - Inability to maintain preductal saturations >85% *relative to clinical scenario*
  - Increased PaCO<sub>2</sub> and respiratory acidosis with pH <7.15 despite efforts to optimize ventilator management
  - Ventilator requirements of peak inspiratory pressure ≥ 28 cm H<sub>2</sub>O or mean airway pressure ≥ 15 cm H<sub>2</sub>O is required to achieve saturations >85%
  - Inadequate oxygen delivery with metabolic acidosis as evidenced by lactate >5 and pH <7.15
  - Systemic hypotension resistant to therapy
- Inclusion criteria: each patient will be evaluated on a case by case basis but general inclusion criteria are listed below
  - Weight > 2 kg
  - Gestational age >34 weeks
  - Absence of multiple or severe congenital anomalies or chromosomal anomalies
  - Current head ultrasound with evidence of intraventricular hemorrhage ≤ Grade I

## Perioperative

**Surgical Repair:** to be done at the bedside in the NICU in severely ill patients. OR may be considered on an individual case basis in stable patients. Scheduling of cases early in the day allows for adequate support intra-operatively and post-operatively.

- Patient exhibits evidence of physiologic stabilization, improvement of pulmonary hypertension. Surgeons to document classification of defect size (A,B, C, D) in operative note (see below diagram)



## Surgical Preparation:

- Pre-operative labs completed within 24 hours prior to surgery and evaluated:
  - CBC with differential
  - BMP
  - Blood gas
  - Type & Cross (if not already completed)
  - If on ECMO, DIC profile required
- Pre-operative echocardiogram within 24-48 hours of surgical date
- Order desired blood products to be in the OR or NICU at bedside during the procedure
  - Packed red blood cells, platelets, FFP ( 20 ml/kg of each)
- Clear space in patient room for anesthesia and surgery by removing nonessential equipment and staff
- Ensure adequate IV access (2 PIV's or 1 PIV and 1 PICC) for administration of blood products and medications.
- Consider arterial access for monitoring of blood pressure
- Replace TPN with D10 ½ NaCl to avoid electrolyte imbalances.
- Anesthesia to administer pre-operative antibiotics within 1 hour of incision
- Make appropriate post-operative pain control plan and pre- order appropriate medications
- May consider use of Amicar: in CDH repairs done *on ECMO* (consult with Neonatology attending and Surgeon prior to ordering/ dosing instructions included in considerations for management section)

**Post-Operative Care Management:** remember to complete the VON QI OR Handoff Tool

Monitoring:

- Monitor post-operative vital signs per policy
- Monitor for signs and symptoms of compartment syndrome: decreased distal pulses, abdominal distention, decreased urine output, skin discoloration

Gastric Decompression

- 10 fr salem sump orogastric or nasogastric tube to low continuous suction
- NPO with salem sump until full return of bowel function

Diagnostic Studies/ Labs:

- CXR immediately post-operative
- Blood gas immediately post-operative
- CBC/BMP in the AM post-operative day #1
  - Or earlier if clinically warranted

Oxygenation:

- Goal O2 Saturations  $\geq 90\%$
- Continue pre and post ductal saturation monitoring

Ventilation:

Fluid Management:

- Continue pre-operative management of fluids and initiation of TPN after first post-operative void

Hemodynamic Management:

- Closely monitor blood pressure
- Consider fluid administration or vasopressor support as needed

Antibiotics:

- Routine repair with no patch- Ancef for 24 hours; additional doses per surgeon discretion
- Patch repair- Ancef for 24 hours post-operative; additional doses per surgeon discretion
- Open abdomen- utilize Ancef until abdominal closure
- Chest tube with patch- utilize Ancef until discontinuation of chest tube

Sedation:

- As clinically indicated
  - May consider use of scheduled IV Tylenol for pain control
  - Utilize intermittent dosing of narcotics prior to initiating narcotic infusion
    - Morphine or fentanyl infusion, versed PRN if indicated
- If infusions required pre-operative, utilize increased doses as needed to control post-operative pain

Skin care:

- Notify surgery of any signs of erythema, drainage, bleeding, or wound concerns
- If sutures are placed, contact surgery for removal plan/date
- After sutures removed or surgical site has healed:
  - Apply Mepitel One (preemies)/ Mepitac (post-term) to surgical sites once healed for scar therapy
  - Change or re-apply after each bath



### Considerations for Management:

- CDH occurs when the diaphragm allows abdominal contents to herniate into the chest. It occurs in an estimated 1 out of 2500-4000 births.
- Liver position is the most reliable predictor of severity and mortality in CDH.
  - CDH associated with another major congenital anomaly has a very poor prognosis
- LHR (lung area to head circumference ratio) values are also used to predict prognosis and are a reliable indicator when value is accurate. It is an ultrasound measurement of the contralateral lung at level of the heart standardized to the head circumference. (Partridge et al)  
Predicated survival LHR values:
  - LHR < 1 = increased incidence of ECMO and lower survival
  - LHR > 1 = better survival rate and decrease incidence of ECMO
- Given limitations in the LHR measurement, some studies suggest the LHR should be expressed as a function of gestational age [observed (O)/ expected (E) LHR] which is calculated using a specific formula. (Weems et al)
  - O/E LHR < 25% severe pulmonary hypoplasia, predicted survival < 30%
  - O/E LHR > 46% mild hypoplasia, predicted good survival rate greater than 85%
- MRI offers visualization of the fetal lung and liver that is less dependent on maternal and fetal positioning. It is an accurate way to calculate total fetal lung volume. (Weems et al)
  - O/E total lung volume less than 25%, predictive survival < 15%
  - O/E total lung volume greater than 35%, predictive survival may be greater than 80%
- Most significant post natal factors affecting survival: pulmonary hypoplasia, persistent pulmonary hypertension.
- Pulmonary HTN in infants with CDH is multifactorial. Echocardiograms should be used to assess for PHTN. It is related to:
  - structural abnormalities of CDH causing pulmonary hypoplasia and decreased airway and alveolar development
  - imbalanced innervation of smooth muscles
  - increased reactivity to stimuli: agitators: ETT suctioning, baths, procedures, noise (noxious stimuli)
  - lung injury caused by assisted ventilation
  - metabolic disturbances
  - decreased response to vasodilators
- Inhaled Nitric Oxide causes vasodilation of the pulmonary vasculature and decreased ventilation perfusion mismatching. Although often used in the CDH population, no benefit to iNO use in the CDH population has been demonstrated in recent research.  
*Contraindicated in patients with suspected LV dysfunction, LA enlargement, small left sided structures*
- CDH Surgical Repair: Traditional approach consists of repair through laparotomy, however the thoracoscopic repair is an increasingly used approach associated with potentially fewer postoperative ventilator days, smaller size of incision and decreased analgesic use. Iatrogenic pneumoperitoneum is to be expected post-op.
  - If utilizing Amicar, see below dosing recommendations (J. of Ped Surgery, 2003;Vol 38(8):1212-6).
    - administered 1 hr prior to case
    - Amicar bolus dose 100 mg/kg directly to the patient
    - Decrease heparin drip
    - Increase ECMO circuit flow as needed to minimize clotting
    - If severe or uncontrolled bleeding develops intra-op or post-op, may begin Amicar drip of 30 mg/kg/hr
    - 4 hours after case, if no significant bleeding, may resume heparin drip. Once therapeutic per ECMO protocol, decrease ECMO flow back to baseline.

	Before Discharge	1-3 Months Of Age	4-6 Months Of Age	9-12 Months Of Age	15-18 Months Of Age	Annually Thru Age 16
Weight, length, head circumference	X	X	X	X	X	X
Chest X-ray	X	If patch present	If patch present	If patch present	If patch present	If patch present
Pulmonary function tests (Pulmonary consult and long-term f/up)			If indicated		If indicated	If indicated
Childhood Immunizations	X	X	X	X	X	X
RSV Prophylaxis (RSV Clinic CHOC)	RSV season during 1 <sup>st</sup> 2 yrs of life (during RSV season the first dose is given prior to discharge or on the day of discharge)					
Echocardiogram and cardiology follow-up	X	If previously abnormal or on supplemental oxygen	If previously abnormal or on supplemental oxygen	If previously abnormal or on supplemental oxygen	If previously abnormal or on supplemental oxygen	If previously abnormal or on supplemental oxygen
MRI	Head CT or MRI if there was an abnormal finding on head ultrasound; or seizures/abnormal neurologic findings; or ECMO or patch repair	As indicated	As indicated	As indicated	As indicated	As indicated
Hearing evaluation	X	X	X	X	X	Every 6 mo to age 3, then annually to age 5
Developmental/ Neurodevelopmental screening evaluation (EDAC)	X	X	X	X		Annually to age 5
Assessment for oral feeding difficulties (outpatient speech therapy )	X	X	If indicated	If indicated	If indicated	If indicated
Upper GI and/or pH probe (GI Consult for reflux management)	Consider at any time/ age for all patients if symptomatic					
Scoliosis and chest wall deformity screening (physical exam, chest X-ray, chest CT) (Pediatric Surgery and Pediatrician f/up)				X		X
Pediatric Surgery Outpatient Follow-up	First outpatient visit scheduled for 2-3 weeks after discharge	X	X	X	X	X



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## **Congenital Diaphragmatic Hernia**

### **What is Congenital Diaphragmatic Hernia?**

The diaphragm is a muscle that separates the chest from the abdomen. A congenital diaphragmatic hernia (CDH) happens when this muscle does not close. This allows the organs from the abdomen to move into the chest through this hole. This defect occurs when the baby is developing before birth. It can happen on either the right or left side. In extremely rare cases it can happen on both sides.

The organs that belong in the abdomen move into the chest space and leave less room for the lungs to grow normally. This causes the lungs to be small. After the baby is born there is less blood flow to the lungs and high blood pressure in the blood vessels leading to the lungs. This makes breathing after birth very difficult. It can be life-threatening.

### **Who gets Congenital Diaphragmatic Hernia?**

There is no single known cause of CDH. It tends to happen more in males than females. It is not related to anything a mother did or did not do during the pregnancy. There is also recent evidence that genetics may be related to CDH. Parents who have had one child with CDH are at increased risk to have another child with the same problem.

### **What are the symptoms?**

- Difficulty breathing
- Inability to breathe on their own
- Fast heart rate
- Fast breathing
- Bluish skin color
- Retractions—the muscles between and around the ribs are sucked in
- The abdomen may look flat or sunken in because abdominal organs are in the chest
- The chest may look more full or uneven on each side

### **What can I expect before surgery?**

Doctors and nurses will try to give you a moment to meet your baby for the first time at delivery, but they will be focused on helping him or her in the safest, quickest way possible. Soon after delivery, a doctor will insert a breathing tube (also known as an endotracheal tube) into your baby's mouth and a machine called a ventilator can help your baby breathe. A tube will be inserted into your baby's nose and threaded through the esophagus into the stomach. It will keep your baby's stomach empty so that the baby's lungs have as much room in the chest as possible to expand.

Once the baby is as stable as possible, NICU physicians, nurses, and respiratory therapists will bring him or her back to our NICU where the baby will remain for the rest of your stay at CHOC.

The diaphragmatic hernia will be surgically repaired once your surgeon and the NICU team feel the baby can safely have the procedure, and they feel the benefits of the surgery are greater than the risks.

### **After the Surgery:**

Your baby will remain on a ventilator until the NICU team decides that he or she can safely breathe on his or her own. During the surgery the abdominal organs were moved from the chest area to the abdomen, so the baby's abdomen may appear full and tight.

Once the team feels the baby is ready, the baby will be fed very small amounts of breastmilk (it is strongly preferred over formula). If the baby is still on a ventilator when it is time to feed, it will be fed through a small tube placed into the stomach through the nose. This is called a nasogastric feeding tube or "NG tube". If the baby is not on a ventilator, we will begin bottle feeding under close supervision of our feeding team. Since your baby's stomach and intestines have never been fed, we watch the baby closely while we start feedings. We will slowly increase the amount as your baby tolerates. IV nutrition will be necessary until your baby reaches a full feeding amount.

### **What are the long-term concerns? Will this affect growth and development?**

Outcomes are usually better in cases where the liver remains down in the abdomen when the defect forms before birth. Babies can have different types of problems requiring long term care and follow up. Many babies will have chronic lung disease and may require oxygen or medications to help them breathe long term. Gastroesophageal reflux is a common problem. This is when acid and fluids from the stomach move out of the stomach and up into the esophagus. This can cause irritation, vomiting, feeding problems, lung problems and growth difficulties. Some babies have developmental delays and may not roll over, sit, crawl, stand or walk at the same time as healthy babies. Developmental therapy is an important part of long term care. Physical therapy, speech therapy and occupational therapy are offered in the hospital and as a part of the discharge plan to help babies achieve their greatest potential.

### **When should we see a doctor after discharge?**

Patients with CDH need long-term follow up with multiple different doctors. Attached is a chart showing the follow up needed for a patient with CDH as they get older. When your baby is discharged you will have the following appointments:

- Pediatrician within 1-3 days after discharge.
- Surgeon 2-3 weeks after discharge from the hospital.
- If there are other specialists providing care for your baby, we will let you know when you will need to have further appointments with them.

You may call to make these appointments around the time of discharge. Some appointments have already been made for you. Your discharge instructions will have the phone number to call with all concerns and questions.

**Important Numbers:**

CHCO Main Hospital NICU (714) 509-8540 Call for updates on your baby while inpatient

CHOC PSF Surgical Office (714) 364-4050 Call for appointments and concerns after discharge

CHOC PSA Surgical Office (714) 361-4480 Call for appointments and concerns after discharge