

## CONGENITAL DIAPHRAGMATIC HERNIA FORM Version 4

### Postnatal (Main) Data Collection Sheet:

#### **Note:**

**\*\*\* Enter dates in the format which you commonly use in your country.**

**\*\*\* Enter times as military time (24-hour clock). (such that 1:30 PM is entered as 13:30)**

**\*\*\* Enter values for PO<sub>2</sub> and PCO<sub>2</sub> in mm Hg or kiloPascal- whichever unit you commonly use in your country.**

1. Center #: (Random center number assigned by Pam Lally, between 1 and 100)
2. Patient #: (Number patients consecutively for each year. A patient can then be identified as Year Birth and Patient number, e.g. 2015-01)
3. Patient Date of Birth: (Date patient was born)
4. Time of Birth: (Time patient was born)
5. Inborn/Outborn: (An inborn baby is born in the institution where definitive care for CDH will be provided. An outborn baby is delivered in a separate institution and a transport team is required to bring the baby to the center where definitive care for CDH will be provided. If the infant is born in a separate institution but is managed from birth by the same neonatal/surgical team, and requires only a brief transport to a separate institution, the infant should be considered inborn. We are thus differentiating outborn babies as those whose initial care is not under the control of the neonatal/surgical team who provides definitive care for CDH.)
6. Admission date: (Date an outborn patient was admitted- leave blank if infant is inborn)
7. Admission time: (Time an outborn patient was admitted- leave blank if infant is inborn)
8. Sex: M (male) / F (female)
9. Race: Asian / Black / Hispanic / Native American / White / Other (specify) (This category is included to help centers collate data for granting agencies)
10. EGA (at birth): (Gestational age at birth in weeks. Ignore "days" such that a baby born at 35 weeks and 6 days is 35 weeks EGA)
11. Birthweight (in kilograms)
12. Length (in cm)
13. Head circumference (in cm)
14. APGAR (record 1, 5, and 10 minute Apgar on a scale of 0-10, if an Apgar can be assigned; leave blank if there is/are no Apgar scores).
15. SNAP II score (if done)
16. CPR in Delivery Room: Was cardio-pulmonary resuscitation (chest compressions and/or medication such as epinephrine, bicarbonate, etc) given in delivery room? Yes or No
17. Method of delivery:
  - a. Vaginal (Spontaneous)
  - b. Vaginal (Induced- labor requires pitocin or other agents for initiation)
  - c. C-Section (Elective- planned C-section)
  - d. C-Section (Urgent or Non-Elective- other delivery such as spontaneous or induced vaginal delivery was attempted, or mother/baby presented in distress and required emergent delivery).

18. Prenatal diagnosis of CDH: Was CDH was diagnosed before delivery? Yes or No.
  - a. If yes, provide the gestational age in weeks when the diagnosis was made. (Ignore “days” such that a baby diagnosed at 30 weeks and 6 days is diagnosed at 30 weeks.)
  - b. If no, when was diagnosis of CDH made : date and time
19. Were prenatal steroids given? (Yes, No, Unknown, and if yes, # doses given)
20. Was surfactant given (after delivery)? (Yes, No, Unknown, and if yes, # doses given)
21. Was a karyotype sent? Yes or no, Result: normal, abnormal, pending/unknown (explain in next field)
22. Chromosomal anomalies: check if infant has a chromosomal anomaly (such as Trisomy 18, 21, or 13) or a syndrome (such as Fryns)- describe the anomaly (e.g. Trisomy 21, Fryns syndrome)
  - a. If karyotype abnormal, describe
  - b. If chromosomal anomaly/syndrome diagnosed or strongly suspected (even if karyotype not sent or pending), please describe
23. Other anomalies: check if any anomalies are noted on exam or evaluation (especially significant would be any anomalies that might complicate the infant’s care such as Omphalocele or other GI anomalies such as TEF, neural tube anomalies, vertebral anomalies, or pulmonary anomalies such as sequestrations). Any anomalies noted here will be included in the database and may help future identification of syndromes, etc that are associated with CDH.
24. Cardiac anomalies: check all cardiac anomalies noted (if the anomaly is not listed, describe it in the blank space after “Other:”)
25. Pulmonary hypertension-
 

**Record 3 echocardiograms if possible:**

**first echo** (earliest echo, ideally after birth/diagnosis/admission)

**second echo** (ideally closest to pre-op or repair)

**last echo** (ideally before discharge)

  - a. Enter date of first post-natal echocardiogram
  - b. Check the box that most closely describes the presence (or absence) of pulmonary hypertension noted:
    - i. None
    - ii. Elevated and < 2/3 systemic BP
    - iii. Elevated and between 2/3 systemic BP and systemic BP
    - iv. > systemic BP
  - c. PDA:
    - i. L to R: predominantly left to right
    - ii. Bidirectional
    - iii. R to L: predominantly right to left
    - iv. No shunt
    - v. Diameter (in mm) of shunt
  - d. Atrial shunt:
    - i. L to R: predominantly left to right
    - ii. Bidirectional
    - iii. R to L: predominantly right to left
    - iv. No shunt
  - e. Tricuspid regurgitation: Peak velocity in m/sec
  - f. Systemic BP
  - g. RV size: normal or dilated (this is subjective and should be determined at the discretion of your cardiologist)
  - h. RV function: normal or impaired

- i. If impaired systolic and/or diastolic dysfunction (note that the echocardiographer may only state that it is impaired so leave these unchecked if it cannot be determined)
  - i. LV size: below normal, normal, or dilated (this is subjective and should be determined at the discretion of your cardiologist)
  - j. LV function: normal or impaired (this is subjective and should be determined at the discretion of your cardiologist)
  - k. Plasma BNP level or plasma pro\_BNP level (check which one measured) in pg.ml
  - l. Modified McGoon index (for first ECHO only):
    - i. Diameter of aorta in mm
    - ii. Diameter of left pulmonary artery in mm
    - iii. Diameter of right pulmonary artery in mm
26. Treatment of pulmonary hypertension: check all medications used during the neonatal hospitalization to treat the pulmonary hypertension. Record date medication started and date medication stopped (if multiple courses are required, provide name of medication and dates using "other" entries or provide details in comments section at end of neonatal form. Leave "date ended" blank if infant is discharged home (or transferred to another center) on that medication.
27. Ventilation: record date and time of initial intubation
28. Ventilation: record date of final Extubation or check box if infant was never extubated- (this will include infants who expire while still intubated as well as infants who are transferred to another center while still intubated or infants who have complications that require a tracheostomy and continued ventilation at home or in a long-term care facility)
29. Enter values for O<sub>2</sub> and CO<sub>2</sub>:
- a. Highest pre-ductal PaO<sub>2</sub> in mm Hg and/or O<sub>2</sub> sat (check box if not available)
  - b. Highest post-ductal PaO<sub>2</sub> in mm Hg and/or O<sub>2</sub> sat (check box if not available)
  - c. Highest PaCO<sub>2</sub> in mm Hg (check box if not available)
  - d. Lowest PaCO<sub>2</sub> in mm Hg (check box if not available)
30. Side of Diaphragmatic Hernia: Check Left, Right, Bilateral, or Central
31. Repair done: yes or no
32. If **repair** was done:
- a. Enter date and time operative repair of CDH was begun
  - b. Location where repair performed: OR/operating theatre or NICU/intensive care unit
  - c. **Using the attached sheet of diagrams of CDH defects, have the operating surgeon select the diagram that best approximates the size of the defect encountered during surgery: A, B, C, or D (or draw defect using "D" if defect description not shown)- this field is critical (important for staging patients)- If you cannot determine the defect (and cannot contact the surgeon for his/her determination), excerpt the portion of the op note detailing the description of the diaphragmatic defect and paste into the comments section at the end of the form- Kevin and I will then try to determine the defect description**
  - d. Select type of repair: primary closure (closing defect requires sutures alone) or patch (closing defect requires use of sutures and a patch)
  - e. If a patch was used to close the defect, select type: PTFE (GoreTex), Alloderm, Dacron, mesh plug, muscle flap, Surgisis, or other (provide details in blank space)
  - f. Was a hernia sac present? Yes or No
  - g. Check if, at surgery, liver was found initially to be in the chest or abdomen
  - h. Check the approach used to repair the diaphragmatic defect: subcostal, thoracic, both (subcostal and thoracic), thoracoscopic, laparoscopic, or other (provide details in blank space)
  - i. Was there hepato-pulmonary fusion? yes or no
  - j. Was there a pulmonary sequestration? Yes or no

33. ECMO data:
  - a. Record date and time infant was first placed on ECMO
  - b. Record date and time infant was finally taken off ECMO
  - c. Select ECMO mode: VA, VA (+V), VV (DL), VV to VA
  - d. Last ABG prior to initiating ECMO:
    - i. PaO<sub>2</sub> (in mm Hg), check if value is pre-ductal or post-ductal
    - ii. O<sub>2</sub> sat (in %), check if value is pre-ductal or post-ductal
    - iii. PaCO<sub>2</sub> (in mm Hg)
  - e. Was a second run was required? If so, check Yes and enter start date and time, end date and time, and ECMO mode
34. Pneumothorax (prior to repair): yes or no, if Yes:
  - a. Date diagnosed
  - b. Side: left, right, bilateral
  - c. Intervention (check all that apply):
    - i. None (observation only)
    - ii. Thoracentesis
    - iii. Chest tube
    - iv. ECMO
    - v. Other (provide details)
35. Check all other surgeries performed during the neonatal hospitalization and enter the dates for each procedure. If the surgical procedure is not listed (or if multiple procedures were performed), please provide details of the procedure(s) and dates under "other surgery" or in the comments section at the end of the data collection sheet.
36. Outcome if infant expires: enter date and time of death.
37. Outcome if infant survives:
  - a. Enter date when infant is discharged from ICU (transferred from intensive care unit to regular neonatal unit)
  - b. Enter date at which infant is discharged home or is transferred and provide disposition:
    - i. Discharged home
    - ii. Transferred to another hospital
    - iii. Transferred to long-term care (within same institution)
  - c. Document pulmonary status at 30 days of age
  - d. Document pulmonary status at time of discharge or transfer
  - e. Document results of other pre-discharge evaluations:
    - i. Eye exam: normal, abnormal, or not done
    - ii. Cranial exam (head ultrasound, head CT, or cranial MRI): normal, abnormal, or not done
    - iii. Hearing evaluation (BAER or other): normal, abnormal, or not done
  - f. Weight at time of discharge (in kilograms)
  - g. Length at time of discharge (in cm)
  - h. Head circumference at time of discharge (in cm)
  - i. Document feeding at time of discharge:  
select method by which infant is receiving more than 50 % of calories: PO, NG (naso-gastric tube), or GT (gastrostomy tube)
  - j. Note date at which infant was on full enteral (no iv) feeds
  - k. Was GER (gastro-esophageal reflux) diagnosed? Yes or No
  - l. Check all discharge medications: a list of these can usually be found in the discharge note in the chart, on the discharge form given to parents, or in the dictated discharge summary in the chart.

38. Additional comments: include any relevant or clarifying information about this infant. Past comments have included: details of the pregnancy, summaries of findings at port-mortem, explanations of complications of ECMO or surgical repair, or other aspects that made this infant's course unique.

**CDH Prenatal Forms User Manual: Ultrasound and/or MRI**

**To be completed only for patients where CDH is diagnosed pre-natally.  
This form is optional.**

EDC: Estimated date of conception (start of gestation): used to calculate gestational age for ultrasound and MRI procedures.

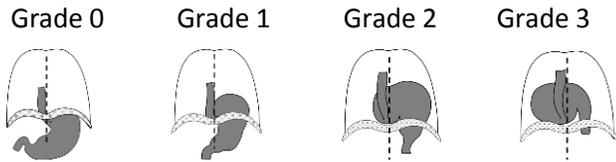
## **Prenatal Ultrasound:**

The **first** ultrasound should be done ideally between 20-24 weeks gestation (and as close to 24 weeks as possible).

The **second** ultrasound (done after 30 weeks gestation, ideally last ultrasound before delivery) can be recorded if done.

1. Date of ultrasound
2. Gestational age at time of exam in weeks
3. Side of hernia: Left, Right, Central, Bilateral
4. Sign of hydrops (check all that apply): none, skin edema, pleural effusion, pericardial effusion, ascites
5. Liver herniation: yes or no, if yes estimate:  $< 1/3$  thoracic cavity height or  $\geq 1/3$  thoracic cavity height
6. **LHR**: range 0.5 – 2.5, and check method used:
  - a. Method A:  
Lung AP diameter at MCL x perpendicular diameter at midpoint of AP diameter method  $((\text{Length 1} \times \text{Length 2})/\text{Head circumference})$
  - b. Method B:  
Lung longest diameter x widest perpendicular diameter method  $((\text{Length 1} \times \text{Length 2})/\text{Head circumference})$
  - c. Method C:  
Lung tracing method (Lung area/Head circumference)  
note: all measurements are on the contralateral lung  
note: all lengths and circumferences are in mm; area in mm<sup>2</sup>
7. Observed/Expected LHR (O/E LHR): range 0 – 150 % (record in percent %)  
LHR expected may be obtained from a published chart (*Peralta et al, Ultrasound Obstet Gynecol 2005; 26: 718-724*) or by using [www.perinatology.com/calculators/LHR.htm](http://www.perinatology.com/calculators/LHR.htm)
8. Lung/Thorax Ratio (L/T ratio): range 0 – 0.5  
Lung area / Thorax area  
For reference see *Usui et al, Pediatr Surg Int 2007; 23:971-976*

9. Grading of Stomach Herniation – Kitano Method:



Stomach herniation was categorized as:

Grade 0 - abdominal

Grade 1 - ipsilateral thoracic

Grade 2 - less than half of the stomach herniated into the contralateral chest

Grade 3 - more than half of the stomach herniated into the contralateral chest

10. Stomach Herniation - Cordier Method:

Grade 1 - stomach not visualized

Grade 2 - stomach visualized anteriorly next to the apex of the heart, with no structures in between the stomach and the sternum

Grade 3 - stomach showing abdominal structures anteriorly

Grade 4 - stomach showing abdominal structures anteriorly and stomach has its larger part posterior to the level of the atrial-ventricular heart valves.

11. Modified Mcgoon index:

- a. Diameter of aorta in mm
- b. Diameter of left pulmonary artery in mm
- c. Diameter of right pulmonary artery in mm

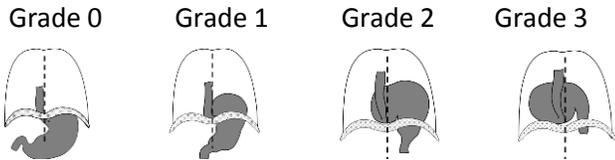
12. Was tracheal occlusion done? Yes or no

- a. If yes, at what gestation age (in weeks) was occlusion done?
- b. If yes, at what gestation age (in weeks) was occlusion removed?

13. Were any other malformations noted? yes or no, if yes, provide details

**Prenatal MRI:**

1. Date done
2. Gestational age at time of exam in weeks
3. Side of hernia: Left, Right, Central, Bilateral
4. Lung Volumes: left lung (in ml), right lung (in ml), total lung volume (left + right in ml)
5. Thoracic Volume (in ml)
6. Mediastinal Volume (in ml)
7. Percent Predicted Lung Volume (PPLV) (as %) =  $\text{Total Lung Volume} \times 100 / (\text{Thoracic Volume} - \text{Mediastinal Volume})$
8. O/E lung volume (as %)=  $\text{Observed (total lung volume)} \times 100 / \text{Expected lung volume (for gestational age)}$
9. Liver: estimated percent of liver in chest with 0 = all liver in abdomen and 100 = all (100 %) liver in chest
10. Were any other malformations noted? yes or no, if yes, provide details
11. Grading of Stomach Herniation - Kitano Method:



Stomach herniation was categorized as:

Grade 0 - abdominal

Grade 1 - ipsilateral thoracic

Grade 2 - less than half of the stomach herniated into the contralateral chest

Grade 3 - more than half of the stomach herniated into the contralateral chest

### **Completing the forms:**

1. The web site is now up-to-date and has the most current version of all the forms:  
<https://med.uth.edu/pediatricsurgery/research/research-centers-and-programs/cdhsg/>
2. To complete the electronic form:
  - a. Open the form CDH\_Data\_Form\_V4 in Word:
  - b. Click Save As ..., give the file a name (such as Year Birth-Center #-Patient # for Year), and save it as a word document (on your computer). Here I am saving as "Test 3":
  - c. Enter the information, using check boxes, number fields, time fields military time) or free text fields (for dates as well as other free text entries) where available.
  - d. After you finish entering the information, save the document again.
  - e. You may password-protect the document by selecting Tools – Options – Security, enter a password (you'll be asked to enter it again), then save the document one last time. The default password for each center will be an 8 digit password cdhsg plus center number (center 9 will use password cdhsg009, center cdhsg43 will use password 043, etc.). You may also use any password you would like (just be sure to let me know so I can open the files). There is no way to recover a password-protected file if you forget the password, so make sure you make a note of the password.
  - f. Email the document to [pamlally@gmail.com](mailto:pamlally@gmail.com)
3. You may also print the form out, enter the data, and mail the form to Kevin Lally at the address on the web site. Since we do not keep copies of the forms after the data is entered in the database, keep the original and mail us the copy (or keep a copy and mail us the original).