**CONGENITAL DIAPHRAGMATIC HERNIA FORM**

**(To be used for patients born on or after 1/1/2015)**

Center #:  Patient #:

Date of Birth:  Time of Birth:

 **[ ]**  Inborn

[ ]  Outborn: Date of Admission:  Time of Admission:

Sex: [ ]  M [ ]  F

Race: [ ]  Asian [ ]  Black [ ]  Hispanic [ ]  Native American [ ]  White [ ]  Other:

EGA (at birth):  weeks

Birthweight:  kg Length:  cm Head circumference:  cm

APGARs (1/5/10): //SNAP II Score (if done):

CPR (Cardio-Pulmonary-Resuscitation) in Delivery Room: [ ]  Yes [ ]  No

Method of Delivery: [ ]  Vaginal (Spontaneous) [ ]  Vaginal (Induced)

 [ ]  C-section (Elective) [ ]  C-section (Urgent/Non-elective)

Prenatal diagnosis of CDH: [ ]  Yes [ ]  No

 If **Yes**, diagnosis made at  weeks gestation

[Please provide Ultrasound and/or MRI information on pages 7-8 if data available]

If **No**, diagnosis made at Date:  Time:

Prenatal steroids: [ ]  Yes [ ]  No [ ]  Unknown- If yes, # doses:

Surfactant (after delivery): [ ]  Yes [ ]  No [ ]  Unknown- If yes, # doses:

Associated Non-Cardiac Anomalies (Check all that apply and please provide DX if known):

Karyotype sent: [ ]  Yes [ ]  No, if Yes, result: [ ]  Normal [ ]  Abnormal [ ]  Pending/Unknown

[ ]  Chromosomal – If Yes, please describe:

[ ]  Other Anomalies – If Yes, please describe:

**Associated Structural Cardiac Anomalies (Check all that apply):**

[ ]  ASD

[ ]  VSD

[ ]  AVSD (AV Canal)

[ ]  Pulmonic Valvular Stenosis/Atresia

[ ]  Pulmonary Artery Stenosis/Atresia

[ ]  TOF (Tetralogy of Fallot)

[ ]  Coarctation of Aorta

[ ]  TOGV (Transposition of Great Vessels or Transposition of Great Arteries)

### [ ]  Truncus Arteriosus

[ ]  Complex biventricular anatomy (i.e. heterotaxy syndrome)

[ ]  Anomalous Pulmonary Venous Return

[ ]  Single Ventricle Variant (hypoplastic left heart syndrome)

[ ]  Other- please describe:

(You may explain or elaborate on cardiac diagnosis and /or treatment in the Comments section at the end of the form)

Pulmonary Hypertension (PHTN):

First ECHO done on Date:

PHTN: [ ]  None [ ]  < 2/3 systemic [ ]  between 2/3 and systemic [ ]  > systemic

PDA: [ ]  L to R [ ]  Bidirectional [ ]  R to L [ ]  No shunt (closed)

 Diameter of ductus:       mm

Atrial shunt: [ ]  L to R [ ]  Bidirectional [ ]  R to L [ ]  No shunt (closed)

Tricuspid regurgitation peak velocity:       m/sec Systemic BP       /

RV size: [ ]  Normal [ ]  Dilated

RV function: [ ]  Normal [ ]  Impaired (If impaired, [ ]  Systolic dysfunction [ ]  Diastolic dysfunction

LV size: [ ]  Below normal [ ]  Normal [ ]  Dilated

LV function: [ ]  Normal [ ]  Impaired

Plasma level       (pg/ml) of [ ]  BNP or [ ]  pro\_BNP

To calculate modified McGoon Index:

 Diameter of Aorta:       mm

 Diameter of Left Pulmonary Artery:       mm

 Diameter of Right Pulmonary Artery:       mm

Second (closest to pre-op) ECHO done on Date:

PHTN: [ ]  None [ ]  < 2/3 systemic [ ]  between 2/3 and systemic [ ]  > systemic

PDA: [ ]  L to R [ ]  Bidirectional [ ]  R to L [ ]  No shunt (closed)

 Diameter of ductus:       mm

Atrial shunt: [ ]  L to R [ ]  Bidirectional [ ]  R to L [ ]  No shunt (closed)

Tricuspid regurgitation peak velocity:       m/sec Systemic BP       /

RV size: [ ]  Normal [ ]  Dilated

RV function: [ ]  Normal [ ]  Impaired (If impaired, [ ]  Systolic dysfunction [ ]  Diastolic dysfunction

LV size: [ ]  Below normal [ ]  Normal [ ]  Dilated

LV function: [ ]  Normal [ ]  Impaired

Plasma level       (pg/ml) of [ ]  BNP or [ ]  pro\_BNP

Last (closest to end of hospital course) ECHO done on Date:

PHTN: [ ]  None [ ]  < 2/3 systemic [ ]  between 2/3 and systemic [ ]  > systemic

PDA: [ ]  L to R [ ]  Bidirectional [ ]  R to L [ ]  No shunt (closed)

 Diameter of ductus:       mm

Atrial shunt: [ ]  L to R [ ]  Bidirectional [ ]  R to L [ ]  No shunt (closed)

Tricuspid regurgitation peak velocity:       m/sec Systemic BP       /

RV size: [ ]  Normal [ ]  Dilated

RV function: [ ]  Normal [ ]  Impaired (If impaired, [ ]  Systolic dysfunction [ ]  Diastolic dysfunction

LV size: [ ]  Below normal [ ]  Normal [ ]  Dilated

LV function: [ ]  Normal [ ]  Impaired

Plasma level       (pg/ml) of [ ]  BNP or [ ]  pro\_BNP

Treatment of Pulmonary Hypertension (PHTN):

|  |  |  |
| --- | --- | --- |
| Check if Used (use “Other” for additional courses of iNO as well as unlisted medications) | Date Started | Date Ended |
|   [ ]  | Inhaled Nitric Oxide – Maximum dose:  ppm |  |  |
|  [ ]  | Sildenafil [ ]  Oral [ ]  iv |  |  |
|  [ ]  | Endothelial Receptor Blockade |  |  |
|  [ ]  | Prostacyclin |  |  |
|  [ ]  | Alprostadil (PGE1) |  |  |
|  [ ]  | Milrinone |  |  |
|  [ ]  | Other (specify):  |  |  |
|  [ ]  | Other (specify):  |  |  |
|  [ ]  | Other (specify):  |  |  |
|  [ ]  | Other (specify):  |  |  |
|  [ ]  | Other (specify):  |  |  |

**Ventilation:**

Intubated at: Date:  Time:

Extubated at: Date:  **[ ]**  Never extubated

Values in the first 24 hours of life (pre-ECMO):

|  |  |
| --- | --- |
| Highest **pre**-ductal PaO2:   mm Hg (or kPascal[ ] ) O2 sat: % | Highest **post**-ductal PaO2:  mm Hg (or kPascal[ ] ) O2 sat: % |
| Highest PaCO2:  mm Hg (or kPascal[ ] ) | Lowest PaCO2:  mm Hg (or kPascal[ ] ) |

**[ ]**  **Pneumothorax (PRIOR to repair):** [ ]  Yes [ ]  No

 If Yes, Date of diagnosis:

 Side of pneumothorax: [ ]  Left [ ]  Right [ ]  Bilateral

 Intervention (check all that apply):

 [ ]  None (observation only)

[ ]  Thoracentesis

[ ]  Chest tube

[ ]  ECMO

[ ]  Other:

Date of resolution:

**Side of Diaphragmatic Hernia:** [ ]  Left [ ]  Right [ ]  Bilateral [ ]  Central

**Repair:** Doneon Date:  Time: [ ]  Not repaired

Location where repair done: [ ]  OR/Operating theatre [ ]  NICU/Intensive care unit

Diaphragm Defect: [ ]  A [ ]  B [ ]  C [ ]  D

    

(Have surgeon identify which diagram (A, B, C, D) most closely approximates defect noted intra-operatively. Orientation: diagram is drawn with the diaphragm (defect) on the patient’s left and you are looking up from the abdomen towards the chest)

Type of Diaphragm Repair: [ ]  Primary [ ]  Patch

 If patch: [ ]  PTFE [ ]  Alloderm [ ]  Dacron [ ]  Mesh plug

 [ ]  Muscle flap [ ]  Surgisis [ ]  Other:

Hernia Sac: [ ]  Yes [ ]  No

Liver: [ ]  Chest [ ]  Abdomen

Approach: [ ]  Subcostal [ ]  Thoracic [ ]  Thoracoscopic [ ]  Laparoscopic

 [ ]  Both subcostal and Thoracic [ ]  Other:

Hepato-pulmonary fusion: [ ]  Yes [ ]  No

Pulmonary sequestration: [ ]  Yes [ ]  No

**ECMO Data:**

**[ ]**  Placed on ECMO: started at Date:  Time:

 ended at Date:  Time:

ECMO Mode: [ ]  VA [ ]  VA (+V) [ ]  VV (DL) [ ]  VV to VA

Last ABG (blood gas) before going on ECMO:

PaO2:  mm Hg (or kPascal) **[ ]** Preductal **[ ]** Postductal

O2 Sat:  % **[ ]** Preductal **[ ]** Postductal

PaCO2:  mm Hg (or kPascal)

**[ ]**  Second ECMO run: started at Date:  Time:

 ended at Date:  Time:

ECMO Mode: [ ]  VA [ ]  VA (+V) [ ]  VV (DL) [ ]  VV to VA

**Other Surgical Procedures** (Check all that apply and provide dates):

|  |  |  |
| --- | --- | --- |
| **[ ]**  | Repair of recurrent CDH | Date:  |
| **[ ]**  | Gastrostomy tube (no fundoplication) | Date:  |
| **[ ]**  | Fundoplication, G-tube [ ]  Yes [ ]  No | Date:  |
| **[ ]**  | Lysis of adhesions / surgery for SBO | Date:  |
| **[ ]**  | Closure of ventral hernia | Date:  |
| **[ ]**  | Cardiac catheterization | Date:   |
| **[ ]**  | Cardiac surgery (details: ) | Date:  |
| **[ ]**  | Other surgery (details: ) | Date:  |

**Outcome:**

**[ ]**  **Death**: Date of death:  Time of death:

**[ ]**  **Survived** to discharge home or transfer

 [ ]  Transferred out of NICU/Intensive Care Unit on Date:

Discharged home or transferred on Date: **-** disposition:

**[ ]** Discharged home

**[ ]** Transferred to another hospital

**[ ]** Transferred to in-hospital service for long-term care

Pulmonary Status at **30 Days of Age**:

[ ]  Extubated and on room air

[ ]  Extubated and on nasal cannula

[ ]  Nasal CPAP

[ ]  Mechanical ventilation

[ ]  ECMO

Pulmonary status at Time of **discharge/transfer**:

[ ]  Extubated and on room air

[ ]  Extubated and on nasal cannula

[ ]  Nasal CPAP

[ ]  Mechanical ventilation

Eye exam: [ ]  Normal [ ]  Abnormal [ ]  Not done

Head U/S: [ ]  Normal [ ]  Abnormal [ ]  Not done

Head CT: [ ]  Normal [ ]  Abnormal [ ]  Not done

Cranial MRI: [ ]  Normal [ ]  Abnormal [ ]  Not done

Hearing eval: [ ]  Normal [ ]  Abnormal [ ]  Not done

At Time of (or closest to) discharge:

Weight:  kg Length:  cm Head circumference:  cm

Feeding at Time of discharge/transfer:

 [ ]  PO (> 50 % feeds po)

 [ ]  NG (≥ 50 % feeds by gavage)

 [ ]  GT (≥ 50 % feeds by G-tube)

Date on full enteral feeds:

GER (Gastro-esophageal reflux) diagnosed: [ ]  Yes [ ]  No

**Discharge medications** (Check all that apply):

|  |  |
| --- | --- |
| Respiratory:[ ] Diuretics[ ] Inhaled bronchodilators[ ] Inhaled steroids[ ] iNO[ ] Prostacyclin[ ] Sildenafil[ ] Theophylline[ ] Antibiotics[ ] Seizure medications[ ] Sedatives/analgesics | Gastrointestinal: [ ] Prokinetic agents [ ] Antacids(ranitidine, proton pump inhibitors, etc.) [ ] Erythromycin (used to increase motility) [ ] HyperalimentationCardiac: [ ] Digoxin [ ] Captopril [ ] Aspirin |

(Any medications not listed here, please list in comments section below)

Additional Comments about this Patient:

**ULTRASOUND AND MRI DATA COLLECTION: ONLY FOR PRENATALLY DIAGNOSED CDH**

EDC (Estimated Date of Conception) for fetus:

Maternal: Age:  (years) G P

**FIRST PRENATAL ULTRASOUND:**

Date:

Gestational age at time of exam: weeks

Side of Hernia: [ ]  Left [ ]  Right [ ]  Bilateral [ ]  Central

Sign of Hydrops: [ ]  None [ ]  Skin edema [ ]  Pleural effusion [ ]  Pericardial effusion [ ]  Ascites

Liver Herniation:

[ ]  No [ ]  Yes- If yes, [ ]  <1/3 thoracic cavity height [ ]  ≥1/3 thoracic cavity height

% herniation if known: %

LHR:  (range 0.5 – 2.5)

Method used: [ ]  Method A [ ]  Method B [ ]  Method C [ ]  Unknown/not stated

Observed/Expected LHR:  (range 0 – 150 %)

Lung/Thorax (L/T) ratio:  (range 0 – 0.5)

Stomach Herniation (Kitano Method- see manual for explanation):
[ ]  Grade 0 [ ]  Grade 1 [ ]  Grade 2 [ ]  Grade 3

Stomach Herniation (Cordier Method- see manual for explanation):
[ ] Grade 1 [ ]  Grade 2 [ ]  Grade 3 [ ]  Grade 4

To calculate Modified McGoon index:

Diameter Aorta: mm

Diameter Left Pulmonary Artery: mm

Diameter Right Pulmonary Artery: mm

Was tracheal occlusion done? [ ]  No [ ]  Yes

 If yes, at what gestational age (weeks) was occlusion done:

If yes, at what gestational age (weeks) was occlusion removed:

Other malformations? [ ]  No [ ]  Yes - If yes, provide details:

**SECOND PRENATAL ULTRASOUND:**

Date:

Gestational age at time of exam: weeks

Side of Hernia: [ ]  Left [ ]  Right [ ]  Bilateral [ ]  Central

Sign of Hydrops: [ ]  None [ ]  Skin edema [ ]  Pleural effusion [ ]  Pericardial effusion [ ]  Ascites

Liver Herniation:

[ ]  No [ ]  Yes- If yes, [ ]  <1/3 thoracic cavity height [ ]  ≥1/3 thoracic cavity height

% herniation if known: %

LHR:  (range 0.5 – 2.5)

Method used: [ ]  Method A [ ]  Method B [ ]  Method C [ ]  Unknown/not stated

Observed/Expected LHR:  (range 0 – 150 %)

Lung/Thorax (L/T) ratio:  (range 0 – 0.5)

Stomach Herniation (Kitano Method- see manual for explanation):
[ ]  Grade 0 [ ]  Grade 1 [ ]  Grade 2 [ ]  Grade 3

Stomach Herniation (Cordier Method- see manual for explanation):
[ ] Grade 1 [ ]  Grade 2 [ ]  Grade 3 [ ]  Grade 4

To calculate Modified McGoon index:

Diameter Aorta: mm

Diameter Left Pulmonary Artery: mm

Diameter Right Pulmonary Artery: mm

Other malformations? [ ]  No [ ]  Yes - If yes, provide details:

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**PRENATAL MRI:**

Date:

Gestational age at time of exam: weeks

Side of Hernia: [ ]  Left    [ ]  Right    [ ]  Bilateral [ ]  Central

Lung volumes:  Left ml   Right ml Total (left + right) ml

TV: Thoracic volume  (ml)

MV: Mediastinal volume  (ml)

Percent Predicted Lung volume (PPLV) %

PPLV = Total lung volume \* 100 / (Thoracic volume – Mediastinal volume)

O/E total lung volume:

Liver: estimated percent of liver in chest:  % (0 = all liver in abdomen / 100 = all liver in chest)

Grading of location of the fetal stomach (Usui Method- see manual for explanation):

Stomach Herniation:   [ ]  Grade 0      [ ]  Grade 1      [ ]  Grade 2      [ ]  Grade 3

Other malformations? [ ]  No    [ ]  Yes - If yes, provide deta