**CONGENITAL DIAPHRAGMATIC HERNIA FORM**

**(To be used for patients born on or after 1/1/2021)**

Center #:  Patient #:

Date of Birth:  Time of Birth:

 **[ ]**  Inborn

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

Sex: [ ]  M [ ]  F

Ethnicity: [ ]  Hispanic/Latino [ ]  Not Hispanic/Latino [ ]  Unknown/Not Reported

Race: [ ]  Asian [ ]  Black/African American [ ]  Hawaiian/Pacific Islander [ ]  Native American/Alaskan Native [ ]  White [ ]  Unknown/Not Reported

EGA (at birth):  weeks Birthweight:  kg APGARs (1/5): /

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

Prenatal steroids: [ ]  Yes [ ]  No [ ]  Unknown

Surfactant (after delivery): [ ]  Yes [ ]  No [ ]  Unknown

Genetic studies (Check all that apply and please provide DX if known):

Chromosomal analysis (Karyotype): [ ]  Sent [ ]  Not Sent

Result: [ ]  Normal [ ]  Abnormal [ ]  Pending [ ]  Unknown

Chromosomal microarray analysis (CMA): [ ]  Sent [ ]  Not Sent

Result: [ ]  Normal [ ]  Abnormal [ ]  Pending [ ]  Unknown

Sequencing test type: [ ]  Not sent

 [ ]  Single gene/panel; Result: [ ]  Normal [ ]  Abnormal [ ]  VUS [ ]  Pending [ ]  Unknown

 [ ]  Whole Exome (WES); Result: [ ]  Normal [ ]  Abnormal [ ]  VUS [ ]  Pending [ ]  Unknown

 [ ]  Whole Genome (WGS); Result: [ ]  Normal [ ]  Abnormal [ ]  VUS [ ]  Pending [ ]  Unknown

Diagnosis made/Comment: please describe:

[ ]  Other Anomalies-If Yes, please describe:

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

[ ]  ASD [ ]  VSD

[ ]  AVSD (AV Canal)

[ ]  Pulmonic/Pulmonary Valvular/Artery Stenosis/Atresia

[ ]  TOF (Tetralogy of Fallot)

[ ]  Coarctation of Aorta [ ]  Hypoplastic aortic arch

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

### [ ]  Truncus Arteriosus

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

[ ]  Total Anomalous Pulmonary Venous Return (TAPVR)

[ ]  Single Ventricle Variant (hypoplastic left heart syndrome)

[ ]  Other- please describe:

Pulmonary Hypertension/Cardiac Dysfunction (CDH-PH/CD):

First ECHO done on Date:       Time:

PH: [ ]  None [ ]  < 2/3 systemic [ ]  between 2/3 and systemic [ ]  > systemic [ ]  Present but cannot quantify

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

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

Tricuspid regurgitation peak velocity:       m/sec Systemic BP       /

Septal position: [ ]  Normal [ ]  Flattened [ ]  Further left deviation

RV size: [ ]  Normal [ ]  Dilated

RV function: [ ]  Normal [ ]  Impaired

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

LV function: [ ]  Normal [ ]  Impaired

Plasma level       (pg/ml) of pro-BNP; Date:

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

PH: [ ]  None [ ]  < 2/3 systemic [ ]  between 2/3 and systemic [ ]  > systemic [ ]  Present but cannot quantify

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

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

Tricuspid regurgitation peak velocity:       m/sec Systemic BP       /

Septal position: [ ]  Normal [ ]  Flattened [ ]  Further left deviation

RV size: [ ]  Normal [ ]  Dilated

RV function: [ ]  Normal [ ]  Impaired

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

LV function: [ ]  Normal [ ]  Impaired

Plasma level       (pg/ml) of pro-BNP; Date:

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

PH: [ ]  None [ ]  < 2/3 systemic [ ]  between 2/3 and systemic [ ]  > systemic [ ]  Present but cannot quantify

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

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

Tricuspid regurgitation peak velocity:       m/sec Systemic BP       /

Septal position: [ ]  Normal [ ]  Flattened [ ]  Further left deviation

RV size: [ ]  Normal [ ]  Dilated

RV function: [ ]  Normal [ ]  Impaired

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

LV function: [ ]  Normal [ ]  Impaired

Plasma level       (pg/ml) of pro-BNP; Date:

Treatment of Pulmonary Hypertension (CDH-PH):

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

**Ventilation:**

Intubated at: Date:  Time:

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

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

|  |  |
| --- | --- |
| 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[ ] ) |

**ECLS Data:**

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

 ended at Date:  Time:

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

Last ABG (blood gas) before going on ECLS:

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

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

PaCO2:  mm Hg (or kPascal)

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

 ended at Date:  Time:

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

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

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

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 [ ]  Primary repair with Patch overlay

If patch: [ ]  PTFE [ ]  PTFE/combination patch; combination material:

[ ]  Muscle flap [ ]  Other:

Hernia Sac: [ ]  Yes [ ]  No

Liver: [ ]  Chest [ ]  Abdomen

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

 [ ]  Both subcostal and thoracic [ ]  Other:

Estimated Blood Loss (EBL) at Operation:

**Complications/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:  |
| **[ ]**  | Bleed requiring reop for hemorrhage control (site: ) | Date:  |
| **[ ]**  | Cardiac catheterization | Date:   |
| **[ ]**  | Cardiac surgery (details: ) | Date:  |
| **[ ]**  | Tracheostomy | Date:   |
| **[ ]**  | Other surgery (details: ) | Date:  |

**Outcome:**

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

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

Discharged home or transferred on Date:

**[ ]** 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

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

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

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

At time of (or closest to) discharge:

Weight:  kg

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**

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

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

Was fetoscopic endoluminal tracheal occlusion (FETO) performed? [ ]  No [ ]  Yes (If yes, fill in table below)

|  |  |  |
| --- | --- | --- |
|  | Balloon IN | Balloon OUT |
| Date |  |  |
| EGA |  |  |
| O/E LHR |  |  |
| LHR |  |  |
| O/E TFLV |  |  |
| TFLV |  |  |
| Liver herniation  | [ ]  No [ ]  Yes- If yes, [ ]  <1/3 thoracic cavity height[ ]  ≥1/3 thoracic cavity height | [ ]  No [ ]  Yes- If yes, [ ]  <1/3 thoracic cavity height[ ]  ≥1/3 thoracic cavity height |

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

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

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 details: