British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)

Congenital Diaphragmatic Hernia Data Collection Form

Data Collection Form - CASE

Case Definition:
Any live-born infant with a congenital diaphragmatic hernia, defined as a developmental defect of the diaphragm present at birth allowing herniation of abdominal contents into the chest. Infants with defects occurring in any position (e.g. postero-lateral, central) should be included.

Please return the completed form to:
BAPS-CASS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 289701
Phone: 01865 289714

Case reported in: ______________
Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.

2. Please record the ID number from the front of this form against the infant’s name on the Clinician’s Section of the blue card retained in the BAPS folder.

3. Fill in the form using the information available in the infant’s case notes.

4. Tick the boxes as appropriate. If you require any additional space to answer a question please use the space provided in section 7.

5. Please complete all dates in the format DD/MM/YY, and all times using the 24hr clock e.g. 18:37

6. If you do not know the answers to some questions, please indicate this in section 7.

7. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 7 to describe the problem.

Definitions

1. UK Census Coding for ethnic group

   WHITE
   01. British
   02. Irish
   03. Any other white background

   MIXED
   04. White and black Caribbean
   05. White and black African
   06. White and Asian
   07. Any other mixed background

   ASIAN OR ASIAN BRITISH
   08. Indian
   09. Pakistani
   10. Bangladeshi
   11. Any other Asian background

   BLACK OR BLACK BRITISH
   12. Caribbean
   13. African
   14. Any other black background

   CHINESE OR OTHER ETHNIC GROUP
   15. Chinese
   16. Any other ethnic group
### Section 1: Antenatal data

1.1 **Was CDH suspected antenatally?**
- Yes [ ]
- No [ ]
  
  **If Yes, at what gestational age?** [ ] weeks

1.2 **Which feature suggested the diagnosis? (please tick all that apply)**
- Stomach/bowel in chest [ ]
- Liver herniation [ ]
- Other [ ]
  
  **If Other, please specify**

1.3 **Was polyhydramnios present antenatally?**
- Yes [ ]
- No [ ]

1.4 **Was the Lung Head Ratio (LHR) measured?**
- Yes [ ]
- No [ ]
  
  **If Yes,**
  
  - What was the lowest LHR? [ ]
  - What date was this measured? / / D M Y YMD

1.5 **Was fetal therapy undertaken?**
- Yes [ ]
- No [ ]
  
  **If Yes,**
  
  - Was FETO balloon tracheal occlusion undertaken? Yes [ ]
    
    **If Yes, please state**
    
    - Date of occlusion / / D M Y YMD
    - Date and time of balloon retrieval / / D M Y YMD: h m mh
  
  - Were antenatal corticosteroids administered? Yes [ ]
    
    **If Yes, please state**
    
    - Date of first course / / D M Y YMD
    - Number of courses given

1.6 **What was the mother’s year of birth?** [ ]

1.7 **Please give the first alphabetical part of mother’s postcode (e.g. OX for Oxfordshire, EH for Edinburgh, L for Liverpool)** [ ]

1.8 **Was this a multiple pregnancy?**
- Yes [ ]
- No [ ]
  
  **If Yes,**
  
  - How many fetuses?
  - Did any of the other fetuses have CDH? Yes [ ]

1.9 **Was there a family history of CDH?**
- Yes [ ]
- No [ ]
  
  **If Yes, please state which relative(s):**

1.10 **Was the surgical team involved in the antenatal planning of care?**
- Yes [ ]
- No [ ]

1.11 **Was a member of the surgical team involved in the antenatal counselling of the parents?**
- Yes [ ]
- No [ ]

### Section 2: Birth data

2.1 **What was the mode of delivery?**
- Vaginal delivery [ ]
- Pre-labour caesarean section [ ]
- Caesarean section after onset of labour [ ]

2.2 **Ethnic Group**

*For guidance please see inside front cover*
2.3 What was the gestational age at birth? *(completed weeks)*

2.4 What is the sex of the infant? Male [ ] Female [ ] Indeterminate [ ]

2.5 What was the birth weight?

2.6 What was the head circumference?

2.7 What was the 5min Apgar score?

2.8 Was surfactant given at birth? Yes [ ] No [ ]

2.9 Was the infant transferred from another hospital after delivery? Yes [ ] No [ ]

   If Yes, please specify:
   Hospital infant was born in:

   Date of transfer

2.10 Were there any other anomalies confirmed or suspected? Yes [ ] No [ ]

   If Yes, please complete table below:

<table>
<thead>
<tr>
<th>Anomaly</th>
<th>Suspected antenatally <em>(Tick if yes)</em></th>
<th>Diagnosed postnatally <em>(Tick if yes)</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Section 3: Pre-Operative Investigations and Management

3.1 Was a chest X-Ray performed? Yes [ ] No [ ]

3.2 Which side was the hernia defect? Left [ ] Right [ ] Bilateral [ ]

3.3 Was an echocardiogram performed pre-operatively? Yes [ ] No [ ]

3.4 Was any ventilatory support used prior to surgery? Yes [ ] No [ ]

   If Yes, please indicate strategies used prior to surgery and the order of use:

   | Conventional mode ventilation [ ] |
   | High frequency oscillation [ ] |
   | ECMO [ ] |
   | Liquid [ ] |
   | Nasal CPAP [ ] |

3.5 Were inotropes used? Yes [ ] No [ ]

   If Yes, please list agents used:

3.6 Were pulmonary vasodilators used? Yes [ ] No [ ]

   If Yes, please indicate agents used *(tick all that apply)*

   Nitric oxide [ ]
   Sildenafil [ ]
   Other [ ]

   If Other, please specify ________________________________
### Section 4: Operation details

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Was an operation performed?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>If No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please indicate why not</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Then go to section 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If Yes, please continue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.2 What was the date of operation?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4.3 What was the type of hernia?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Posterolateral</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Central</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Anteromedial</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Agenesis</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>4.4 Was ECMO used peri-operatively?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>If Yes, for how many days was it used?</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>4.5 Was any other peri-operative ventilation technique used?</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>If Yes, was it</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Conventional mode ventilation</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>High frequency oscillation</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>For how many days was the infant ventilated post-operatively?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4.6 What surgical techniques were used? (tick all that apply)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Primary diaphragm repair</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>If Yes, please specify suture material</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patch repair</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>If Yes, please specify patch material</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Abdominal wall patch (abdominoplasty)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>If Yes, please specify patch material</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Chest drain deployed</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Minimally invasive surgery</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Fundoplication</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>If Yes, please specify</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4.7 Was malrotation treated during the same surgical procedure?</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
### Section 5: Morbidity during primary admission

Please indicate if any of the following were present.

**5.1 Chylothorax**
- If Yes, how was this managed?
  - TPN
  - Octreotide
  - Other
- If Other, please specify

**5.2 Recurrent hernia**
- If Yes, please specify
  - Method of repair
  - Date of repair

**5.3 Neurological sequelae (CNS dysfunction)**
- If Yes, please specify problem

**5.4 Pneumothorax**
- If Yes, was this
  - Pre-operative
  - Post-operative
  - Both

**5.5 Other morbidity**
- If Yes, please specify

### Section 6: Outcomes

#### A: Hospital Discharge

**6a.1 Has the infant been transferred to another hospital?**
- If Yes, please give
  - Name of hospital
  - Date of transfer
  - Responsible clinician

**6a.2 Has the infant been discharged home?**
- If Yes, please give
  - Date of discharge
  - Was the baby discharged home on oxygen?

**6a.3 Was a neonatal hearing screen undertaken before discharge/transfer?**
- If Yes, what was the result?
  - No impairment
  - Other
- If Other, please specify

**6a.4 Did this infant die?**
- If Yes,
  - What was the date of death?
  - What was the principle cause of death as stated on the Death Certificate?
Section 7

Please use this space to enter any other information you feel may be important

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Section 8:

Name of person completing the form

Designation

Today’s date

You may find it useful in the case of queries to keep a copy of this form.

Was a post mortem examination performed?  Yes ☐ No ☐

If Yes,

Was this a coroner’s PM?  Yes ☐ No ☐

What type of hernia was confirmed?  Posterolateral ☐ Central ☐ Anteromedial ☐ Agenesis ☐

Was pulmonary hypoplasia evident? Yes ☐ No ☐

Were any other congenital anomalies identified?  Yes ☐ No ☐

If Yes, please specify ________________________________

B: Parental information

6b.1 Were the parents given any of the following support information?  Yes ☐ No ☐

Contact details for any parent based CDH support group?  Yes ☐ No ☐

In-house information leaflets?  Yes ☐ No ☐

Resuscitation training before primary discharge?  Yes ☐ No ☐