ID Number:

Date of operation:

Date of Transfer to Your Hospital:

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

Congenital Diaphragmatic Hernia

Data Collection Form - CASE OUTCOMES ONE YEAR

Please return the completed form to:

BAPS-CASS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 617775
Phone: 01865 289714

Case reported in: _____

National Perinatal Epidemiology Unit

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.

Section 1: Survival data

1.1 Did this infant survive? Yes ☐ No ☐

If No, please specify date of death D D / M M / Y Y

What was the primary cause of death as stated on the death certificate? *(Please state if not known.)* _____

Was a post mortem examination performed? Yes ☐ No ☐

1.2 Was the infant transferred to another hospital before discharge? Yes ☐ No ☐

If Yes, please give name of hospital _____

name of responsible consultant _____

and date of initial transfer D D / M M / Y Y

1.3 Was the infant discharged home after initial surgery? Yes ☐ No ☐

If Yes, please give date of first discharge home D D / M M / Y Y

Section 2: Morbidity during the 1st year following birth

2.1 Did a chylothorax develop at any stage? Yes ☐ No ☐

If Yes, how was this managed? *(please tick all that apply)*

TPN ☐

Octreotide ☐

Other ☐

If Other, please specify _____

2.2 Was a recurrent hernia present? Yes ☐ No ☐

If Yes, please specify

Method of repair _____

Date of repair D D / M M / Y Y

2.3 Were there any neurological sequelae? Yes ☐ No ☐

If Yes, please specify problem _____

2.4 Is the infant now fully orally fed? Yes ☐ No ☐

If No, please indicate how the child is currently being fed:

- NG tube feeding ☐
- PEG gastrostomy ☐
- TPN as an inpatient ☐
- TPN at home ☐

2.5 Was prophylactic medical therapy given for gastro-oesophageal reflux? Yes ☐ No ☐

If Yes, please specify drugs used _____

2.6 Has gastro-oesophageal reflux been diagnosed? Yes ☐ No ☐

If Yes, was medical therapy given? Yes ☐ No ☐

If Yes, please specify drugs used _____

Was fundoplication performed? Yes ☐ No ☐

If Yes, was this Open ☐ Laparoscopic ☐

Date of procedure D D / M M / Y Y

What type of fundoplication was performed?

- Nissen ☐
- Thal ☐
- Toupet ☐
- Watson ☐
- Other ☐

If Other, please specify type _____

Was a feeding gastrostomy placed? Yes ☐ No ☐

2.7 Was any other late morbidity diagnosed? Yes ☐ No ☐

If Yes, *please tick all that were diagnosed*

- Adhesive bowel obstruction ☐
- Oxygen dependency ☐
- Orthopaedic ☐
  - **If Yes,** was there a pectus chest wall deformity? Yes ☐ No ☐
- Other ☐
  - **If Yes,** please specify _____

2.8 Is the infant currently on any medication? Yes ☐ No ☐

If Yes, please tick all that were prescribed

- Diuretics ☐
- Bronchodilators ☐
- Steroids ☐
- Inotropes ☐
- Vasodilators ☐
- Other ☐
  - **If Other,** please specify _____

2.9 Have the family/infant been referred or are they going to be referred to a Medical Genetics Service? Yes ☐ No ☐

2.10 Have arrangements been made for further follow-up? Yes ☐ No ☐

If Yes, was this:

OPD clinic appointment Yes ☐ No ☐

Multidisciplinary clinic appt (neonatologist, surgeon in attendance) Yes ☐ No ☐

Section 3:

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

Section 4:

4.1 Name of person completing the form _____

4.2 Designation _____

4.3 Today's date D D / M M / Y Y

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