



BPSU Surveillance of Pierre Robin Sequence in the UK and ROI

(Short study name: Pierre Robin Sequence)

Commences in January 2016

Pierre Robin Sequence (PRS) is a condition present from birth which causes babies to have a small jaw, cleft palate, and large tongue. Together, these features can cause affected babies to have problems with their breathing and feeding in the new-born period and early childhood. In some cases feeding difficulties can be overcome by using special feeding bottles, and mild breathing problems can be treated by nursing the baby on their front to move the jaw and tongue forward. In more severe cases they may need support from an artificial airway or feeding tube for a period of time until their jaw grows. In the most severe of cases an operation may be needed to help the child to breathe safely.

We currently know little about the number of children affected by PRS or the best way to manage their breathing and feeding difficulties. The aim of this study is to identify how many babies with PRS are born in the UK and Republic of Ireland (ROI) each year, and to gather information about how medical teams are currently treating any breathing and feeding difficulties that they encounter. We hope that this study will help us to better understand how common PRS is amongst children in the UK and ROI, how best to manage their breathing and feeding difficulties, and how their health progresses over time.

Duration: Surveillance will be undertaken for 13 months, commencing from January 2016 with a 12 month follow-up.

Case definition: Please report any live-born infant, born in the UK or ROI with the following clinical features:

- Cleft palate

AND

- Micrognathia/ retrognathia or glossoptosis

AND

- Evidence of resulting compromise, with at least one of the following features:

- i) Signs of upper airway obstruction
- ii) Feeding difficulties
- iii) Faltering growth (loss of >10% weight in the first week of life or fall across two centile lines on a standardised growth chart)

Website: www.rcpch.ac.uk/bpsu/PRS

Funding: This study is being funded by the BPSU through the Sir Peter Tizard Bursary

Ethical approval: This study has been approved by NRES Committee – South East Scotland REC 2 (REC reference: 15/SS/0049; IRAS project ID: 171982) and has been granted Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0141)

Further information: If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

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