

**Project Number:** CC022

**Title:** Do infants born with cleft palate and Robin Sequence (RS) exhibit fewer communication behaviours compared to those with isolated cleft palate (ICP)?

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**Scientific Outline:**

There is a large body of work describing the effect of a cleft palate on speech and language development<sup>1,2,3</sup>, but little research has been carried out into the additional effects of a diagnosis of Pierre Robin Sequence (PRS).

From a clinical point of view, it would be useful to know how early we can detect risks for communication difficulties in these children, so that early intervention can be implemented. This study proposes to investigate the early communication behaviours of infants with non-syndromic RS and cleft palate compared to those with non-syndromic isolated cleft palate.

**Research questions**

1. Do parents of babies with PRS and cleft palate report fewer communication behaviours than babies with isolated cleft palate?
2. Are there any categorical differences in communication behaviours across the two groups, for example expressive behaviours versus receptive behaviours?

This proposal will look to perform a descriptive study comparing answers from the parent questionnaire given at 13 months of age as part of the Cleft Collective Speech and Language Study (CC-SL) with regard to communication behaviours across two groups. The Speech and Language Questionnaire requires parents to indicate 'yes' if their child exhibits a particular behaviour and 'not yet' if they have not yet reached that point of development.

The sample will include participants in the CC-SL born with PRS and cleft palate and with isolated cleft palate (ICP) with completed questionnaires. Babies with additional syndromic diagnoses will be excluded.

Inferential statistics will be used where appropriate to determine any significant group differences across the above categories using a Kruskal-Wallis test. Through regression analysis, confounding variables will be accounted for – for example, sex, age, hearing, socioeconomic status.

The results from this initial descriptive study will be the first to compare infant communication outcomes in children with non-syndromic PRS +CP and those with non-syndromic ICP. If early differences are seen further research would be advised. Analysis of babble patterns and consonant development in this population would be possible through use of the LENA data collected as part of the CC-SL, using the Timestamper software developed for the Timing of Primary Surgery (TOPS)

study<sup>4</sup>. There is a lack of robust longitudinal data in this population. Building on this study, through the Cleft Collective, it would be possible to complete a follow-up study at 3 years using the same questionnaire and data from speech and language assessments carried out by speech and language therapists (SLTs) at 3 years of age. Similar parent questionnaires will be available at 5, 8 and 10 years. This would enable us to begin to investigate early risk factors for all speech, language and communication difficulties in this population.

## References

<sup>1</sup> Sell, D, Harding, A. and Grunwell, P. (1999) GOS.SP.ASS.'98: An Assessment for Speech Disorders Associated with Cleft Palate and/or Velopharyngeal Dysfunction (Revised). *International Journal of Language & Communication Disorders*, 34 (1), pp. 17–33.

<sup>2</sup> Henningsson, G., Kuehn, D.P., Sell, D., Sweeney, T., Trost-Cardamone, J.E. and Whitehill, T.L. (2008) Universal Parameters for Reporting Speech Outcomes in Individuals with Cleft Palate. *The Cleft Palate-Craniofacial Journal*, 45 (1), pp. 1–17.

<sup>3</sup> Hardin-Jones, M. and Chapman, K.L. (2011) Cognitive and Language Issues Associated with Cleft Lip and Palate. *Seminars in Speech & Language*, 32, pp. 127–40.

<sup>4</sup> Hardwicke, JT, Ricahrds, H, Cafferky, L, Underwood, I, ter Horst, B, Slator, R (2016) Outcomes of cleft palate repair in patients with Pierre Robin Sequence: A matched case-control study. *Plastic Reconstructive Surgery* Vol. 137 (3), pp. 927-933.