The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

AUTUMN NEWSLETTER 2025

One of the largest cleft lip and palate research programmes in the world

Investigating the causes of cleft, the best treatments for cleft and the long-term impact of cleft on the family

15 year questionnaire

We have been sending out our 15 year questionnaire for over 6 months and we have had over 200 responses. These are from parents of 15 year olds and from the young people themselves.

If you have a child who will soon be turning 15 then look out for yours either by email or post.

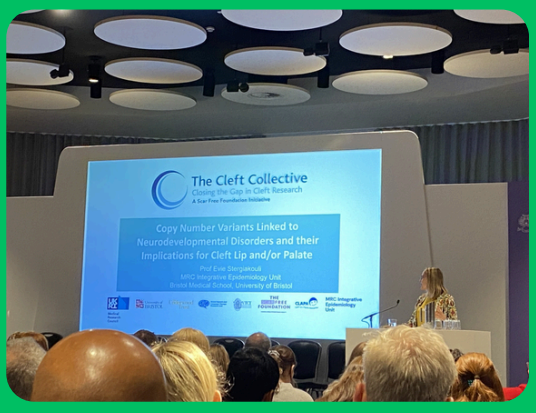
You will receive a £10 voucher for each questionnaire returned.

Cleft@18-23 study

It is now over a year since the Cleft@18-23 study started. The aim is to investigate outcomes at the end of routine care for young adults born with a cleft lip and/or palate. One of the things we are doing is inviting all 18-23 year olds born with a cleft to attend one of our research clinics held all around the UK. We pay travel costs and give a £50 voucher as a thank you. At the clinic, we ask participants to complete a questionnaire, have a short speech and hearing assessment, have their photo taken and scan the inside of their mouth. It takes around 2-3 hours. If you know someone who might be interested, scan the QR code for more information or go to: www.bristol.ac.uk/cleft18-23-get-involved

Craniofacial Society of Great Britain and Ireland conference 2025, in Newcastle

Members of the Cleft Collective team attended this conference in May to share findings from our latest research, including genetic and speech and language research. There were also presentations from other researchers who have used Cleft Collective data to carry out their own research.



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How cleft-related speech errors affect children's communication

Cassandra Aligheiri carried out a study of 157 three-year-olds from the Cleft Collective, which found that children with certain types of speech errors (those made nearer the front of the mouth and those where air can leak into the nose during speech) were less likely to be understood by most people than children with other types of speech errors (those made further back in the mouth). Interestingly, teachers and carers were able to understand the children well regardless of the error type.
These findings **highlight the need for targeted, individualised speech therapy** focused on the types of errors that most impact real-world communication.
Read more here: https://pubmed.ncbi.nlm.nih.gov/40408135/

Latest research findings

Copy number variants and their impact on development and behaviour in cleft lip/palate

Alex Rammos examined genetic information from children in the Cleft Collective study to look for specific rare genetic changes called copy number variants or CNVs. We compared children born with cleft lip and/or palate (CL/P) to children in the general population.
Findings showed that children born with CL/P who have these genetic changes were more likely to experience developmental delays and behavioural difficulties by age 5.
These findings suggest that genetic testing could help identify which children born with CL/P might benefit from extra developmental support early on.
Read more here:
https://tinyurl.com/4rrdnrbu

Longitudinal psychological well-being in caregivers of young children with cleft lip and/or palate

A study using questionnaire data from the Cleft Collective investigated long term psychological well-being in caregivers of young children born with CL/P, to inform screening practices and early intervention.
Findings showed that **quality of life and psychological well-being in caregivers is generally positive at 5 years.** A minority experienced poorer outcomes suggesting that routine assessment by a multidisciplinary team would be recommended. If support is provided early, parents and other caregivers may be able to adjust more quickly to having a baby born with a cleft. You can read more here:
https://academic.oup.com/jpepsy/article/50/9/831/8126536

This research is only possible because you completed our questionnaires and donated biological samples - Thank you!