



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

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Funding News!!

We are excited to announce that we have been awarded £1,000,000 by The Underwood Trust which will enable us to keep the study running for another five years! This is fantastic news as it means we can continue the work we are doing in understanding the causes, best treatments and outcomes for children born with cleft.

The
**Underwood
Trust**

www.theunderwoodtrust.org.uk/

10,000th Participant!

Congratulations to the **Broomfield hospital research nurse team (Mid and South Essex NHS Foundation Trust)** who have recruited our **10,000th** participant!! Here's what they had to say:

"Recruiting the 10,000th Patient for The Cleft Collective is a fantastic achievement for the study and also great news for our Research Team who work closely with our Cleft team at Broomfield Hospital. We have been recruiting together since 2014 and we are so proud to have reached this milestone. Thank you to all the Cleft Families who have given up their time to be involved."



Paul Morris
Principal
Investigator at
Broomfield and
Cleft surgeon



Martina, Karen and Natalie
Research nurse team



Robyn & Elsie

Elsie was recruited at a Five-Year audit clinic at Broomfield hospital. This is what her mum Robyn had to say: *"When asked, if I would donate DNA for The Cleft Collective, for research into the causes of clefts, I was happy to oblige. I am grateful to the NHS and the wonderful doctors and nurses for all they have done for my daughter. Donating saliva for research, will not change my daughter's journey, but it may help her get answers to why she has a cleft. The research may mean fewer children are born with a cleft. Although, being born with a cleft is not the end of the world, no parent would choose it for their child and therefore I feel this research is important. I hope that as many families as possible come forward to take part in the study, to see if something can be learned. We are fortunate that funding has been granted to try and find answers, and I feel as a parent, helping with research is a way of giving something back to the cleft community."*

Research Nurse Workshop

In March 2022 we finally managed to get our dedicated study recruiters together to have a virtual catch up. It was great to see 15 out of our 16 recruitment sites share how they were adapting to recruiting participants with covid restrictions in place. It was also the perfect opportunity for the Bristol study team to give an update on our latest research. This is useful as the information can then be fed back to families who are thinking of being part of the study. Thank you to all who attended and keep up the brilliant recruitment!

Have any questions for us? Want to check your status in the study or recently moved?

Email us: cleft-collective@bristol.ac.uk

Call us: 0117 3310025

Text us: 07799072093

Publications

Using data from the Cleft Collective two research papers have been published so far in 2022. The first paper looked at parent and caregivers' views on the effectiveness of speech and language therapy provided online during COVID-19. There were challenges in telemedicine but 92.4% of parents said it was somewhat or very effective.

The second paper described the current surgical practices used around the UK to repair a cleft lip and/or palate. This paper included average age of children at repair and the techniques used.

Further info can be found on our website under 'publications'. More publications in 2022 to follow....

Associate PI Scheme

Sophie Butterworth is a junior cleft fellow based at Newcastle's Royal Victoria Infirmary. She has just successfully completed the National Institute for Health and Care Research (NIHR) Associate Principal Investigator (PI) Scheme. The scheme is a six month in-work training opportunity, providing practical experience for healthcare professionals starting their research career and Sophie chose the Cleft Collective as the study to support her with her training. Well done Sophie! We look forward to working with you on more research projects.



Policy Workshop

We recently held a workshop in Bristol to discuss how research findings from the Cleft Collective can be used to make a positive impact on cleft care. One way to do this is by informing cleft care policies.

The Cleft Collective team were joined by cleft clinicians from around the UK including five surgeons, one ear, nose and throat consultant, two psychologists, four speech and language therapists and an orthodontist. We had lots of detailed discussions on findings to include in future policy briefings, infographics, and animations.



Cleft Congress 2022

The 14th International Congress of Cleft Lip, Palate and related Craniofacial Anomalies was held in Edinburgh between Monday 11th July – Friday 14th July.

Cleft Collective was there showcasing all our latest research! A total of 17 papers connected with the Cleft Collective were accepted for the Congress, comprising ten oral presentations and seven posters.

Plus, we held a workshop to share more about the Cleft Collective dataset and how researchers/academics/clinicians can access it for their own research. It was so great to be able to spread the word about the Cleft Collective and we look forward to lots of new collaborations with our international colleagues!

Welcome to Reshma!

Reshma has joined our team as project coordinator to cover Rhiannon's maternity leave. If you give the office a call, chances are Reshma will be the person that picks up the phone!

