



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 thrilled to announce that we have received further funding for the study! This means that we can now continue to recruit until March 2023. Our thanks go to **The Underwood Trust** and **VTCT Foundation** who have each awarded us **£100,000!**

You can find out more about these amazing charities here:



[www.theunderwoodtrust.org.uk/](http://www.theunderwoodtrust.org.uk/)  
[www.vtctfoundation.org.uk/](http://www.vtctfoundation.org.uk/)



**Recruitment update**

We have recruited **9555** participants from **3414** families into the study so far. This includes **586** participants who were recruited whilst still pregnant; this means that we can collect cord blood. Thank you so much to all of you that have consented to be part of The Cleft Collective, you are making a real difference to cleft research!

**Meet our recruiters in Bristol!**

Toni Farmery and Elysia Gower are Clinical Trial Coordinators and carry out the recruitment for us at Bristol Royal Infirmary/Children's hospital. This is their experience of the last 18 months.....

*'In March 2020, all non-urgent studies were paused to prioritise the COVID-19 pandemic. All study activity, including cleft repair surgeries, ceased for seven months.*

*During this time, we were committed to providing non-clinical support to COVID research studies. However, the pause also allowed us to spend our downtime catching up with tasks that we didn't have time to tackle before, for example, creating a task list for use as a comprehensive 'how-to guide' for any new members of Cleft Collective research staff to use.*

*It is a huge relief that cleft surgery has now started again and recruitment to the study is steadily increasing. Despite the challenges we have faced over the last 18 months, our team have managed to find a happy medium between recruiting to COVID and other surgical research studies. We feel that The Cleft Collective team have done a great job at adapting the study to overcome the limitations brought about by the pandemic.'*



**Craniofacial Society of Great Britain and Ireland Conference 2021**

After the face-to-face conference was delayed due to COVID, the Welsh Cleft Team managed to put on a brilliant virtual conference instead! We were so proud that we had five oral presentations and five posters accepted. This meant that we could update cleft clinicians, researchers and other people in the cleft world with the work that we have been doing on our recruitment, data collection and research using the data. This included reports on behavioural outcomes for children born with cleft and the use of antibiotics during surgery.



**Genetics data**

Back in 2018, the Scar Free Foundation awarded us funding to 'genotype' our biological samples. This means that we can use genetic data to investigate the biological and environmental causes of cleft. The genotyping has now been completed on the samples we hold so far and one of our researchers, Garan Jones, is using this data to look at whether mother's genes contribute to the development of cleft in their children.



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

Email us: [cleft-collective@bristol.ac.uk](mailto:cleft-collective@bristol.ac.uk) Call us: 0117 3310025  
Text us: 07799072093

# RESEARCH NEWS

Update from **Alex Davies** on his cleft research role

This role is generously sponsored by Craniofacial Australia, the charitable foundation whose aim is to promote the best outcomes for those born with facial difference by educating healthcare professionals and supporting research.



This year I have been using Cleft Collective data to explore the effect of antibiotics on healing after cleft palate repair. A fistula (a hole in the palate following repair) can result in food and drink passing into the nose, as well as affecting speech. This may need further operations to correct. It is thought that infection may cause a fistula. Cleft Collective data suggests that antibiotics given after the operation may not help prevent a fistula. We are hoping to undertake a further trial to investigate this more.

I have also been investigating children born with Pierre Robin sequence and cleft palate. The data shows certain syndromes occur regularly and should be routinely screened for as their presence means that these children may need extra help with their breathing and feeding.

I am grateful to all the children and their families who have allowed their data to be used by the Cleft Collective. This data is helping to improve the care that children born with a cleft receive.

Update from **Matt Fell** on his cleft research role

The cause of cleft is important yet complex as there are lots of environmental and genetic factors believed to be involved. My work with the Cleft Collective has been to investigate the role of cigarette smoking to see whether it could be one of many risk factors for cleft. I used three approaches to address one question. First, I carried out a review of already published non Cleft Collective studies and found a moderate association reported between smoking and cleft.



Second, I used publicly available data in the UK to look at annual trends in smoking and cleft births to see if there was a link; there was some evidence to suggest a reduction in the number of children born with a cleft following the 2007 national smoking ban in England, Wales and Northern Ireland but not in Scotland.

My final method will use genetic information from mothers enrolled in the Cleft Collective who donated saliva to further investigate the role of smoking and other factors in cleft. I look forward to bringing you the results of this study in the near future.

Smoking could be **one of many** factors which may be involved in the development of a cleft. We aim to look at a variety of different factors to help us investigate this.

## Speech and Language Therapy during COVID-19

Using the responses from the COVID-19 questionnaire Lucy Southby has been looking at parent views and experiences of speech and language therapy during the early part of the pandemic. More delays were reported by parents of older children and the rate of delays varied across the country.



Some children still received speech and language therapy through an alternative method to face-to-face appointments, such as online appointments. Some families reported difficulties accessing speech and language therapy online and some families felt their children struggled with concentration during their appointment. Most families reported that the alternative method of speech and language therapy was at least "somewhat effective". A common response from parents was that online speech and language therapy was "better than nothing". The full findings of this work have been written up into two research papers which will be available soon. More information regarding our COVID-19 questionnaire results can be found on our website under the 'News' section: <http://www.bristol.ac.uk/cleft-collective/news/2020/cvd19infographic.html>