



The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

The world's largest cleft lip and palate research programme



Newsletter from the Bristol research team

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

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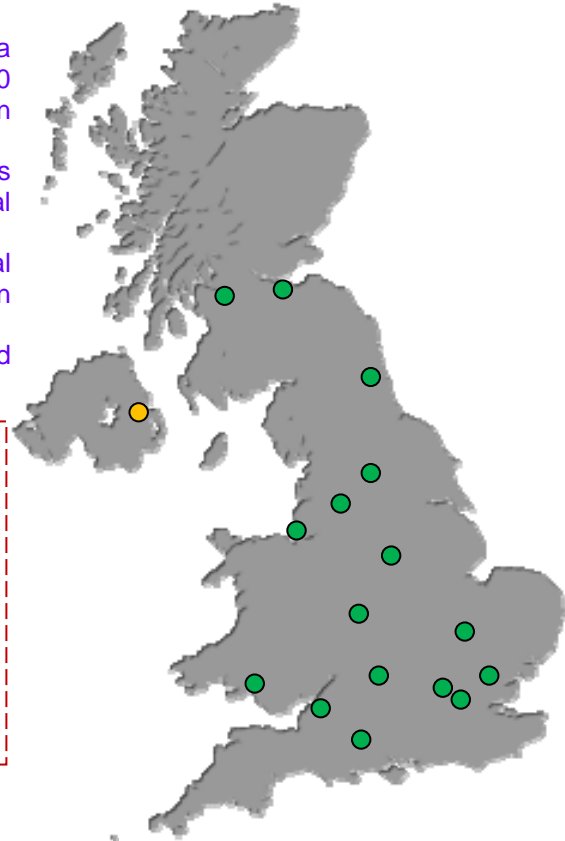
Adolescents wanted for online study

5000 participants in 5 years!

The Cleft Collective is 5 years old and has passed a significant milestone with the recruitment of over 5400 participants. This includes mothers, fathers, children born with cleft, and siblings from nearly 2000 families. Sixteen cleft teams are now recruiting families across the UK [in green], and we are working with the final team (Belfast) [in yellow].

We now have an exciting resource with the potential to achieve significant advances in understanding in this field.

We would like to thank the families, cleft teams and research nurses for their fantastic support.



Antenatal Recruitment

Since launching the antenatal part of the study in September 2016 where we recruit pregnant mums whose unborn babies have received a diagnosis of cleft, The Cleft Collective team have succeeded in gaining ethical approval from 58 maternity units. This means that mums giving birth at these units will be able to donate their cord blood for cleft research.

Thank you so much to the 30+ mums who have already consented to be part of this aspect of the study. So far, we have collected 19 cord bloods which is absolutely fantastic!

SUCCESS STORY

Following the recruitment of the first family into The Cleft Collective antenatal cohort in Salisbury, the study was recently featured in an NIHR (National Institute for Health Research) article supporting research at Salisbury Hospital:

<https://www.nihr.ac.uk/news/salisbury-hospital-offers-more-patients-than-ever-before-the-chance-to-participate-in-research/6660>



Mum, Grandma and baby Jimmy

Recent changes to our team

Welcome to Manmita Rai (right). Manmita has joined the team as our new Data Preparation Assistant and Research Secretary.

As well as helping with the day to day running of the project, Manmita will be cleaning the data and preparing it for our researchers.



Questionnaires

The Cleft Collective are now sending out 18 month, 3 year and 8 year questionnaires to parents, as well as a questionnaire for 8-year-old children. If we have sent you a questionnaire it would be great if you could fill it in and send it back to us in the prepaid envelope. **Remember, for every questionnaire that you return to us you will receive a £10 gift voucher as a thank you!**

As this is a long-term study, it is crucial that our participants continue to return their questionnaires to us. Although the questionnaires can be time-consuming to complete, without them we will be unable to answer our three key questions: 1) *What caused my child's cleft?* 2) *What are the best treatments for child?* 3) *Will my child be OK in the future?*

Thank you to all participants for their continued contribution to The Cleft Collective.

Welcome, also, to Bruna Costa (left) who is joining the team as a Research Associate. Bruna's background is in Health Psychology, and she has a particular interest in the psychological outcomes associated with different health conditions and how to best support individuals and their families. Bruna is extremely excited to be joining The Cleft Collective; a research programme which she believes will greatly improve clinical practice and contribute to a better future for those affected. Bruna will be working alongside Nicola Stock.



Summer student inspired by Cleft Collective research

Christina Tran, a fourth year Dentistry student at the University of Bristol was recently awarded a prestigious INSPIRE summer studentship, and she chose to spend her placement working with The Cleft Collective research team. Under the supervision of Gemma Sharp, Christina has been looking at the association between maternal stressful life events and risk of cleft. The experience has given Christina a glimpse into the fascinating research underway in The Cleft Collective. She hopes to do more research throughout her career in dentistry. In her project, Christina found that although some previous studies have shown that mothers who experience stressful life events around the time of conception have a higher chance of giving birth to a baby with a cleft, more evidence is needed before we can draw stronger conclusions. Stressful life events are one of the risk factors that we have been collecting data on and plan to study in The Cleft Collective.



Biological Samples
All the biological samples kindly donated by our participants are received and logged into the labs using a unique barcode number so they remain anonymous.

The different samples are processed by a small team of lab technicians; DNA is extracted from saliva and blood is spun which causes it to separate into different layers of plasma and white blood cells. The plasma can be used for future biochemical analysis and the white cells for DNA. All samples are kept in a secure location at -80°C for future research. We have recently processed some samples for use in the first Cleft Collective project looking at which genes are turned on and off in cleft.

Adolescents (16-18 years old) both with and without cleft wanted for online study.

Matthew Ridley is a PhD Researcher at the Centre for Appearance Research (University of the West of England) and a member of the psychology research team here at The Cleft Collective. Matthew is investigating resilience and how best to promote positive long-term outcomes in individuals with cleft. He is about to go live with his final PhD study - an online survey questionnaire.

If you are aged between 16 and 18 years old, with or without a cleft, and would like to take part/would like more information, please contact Matthew – Matthew.Ridley@uwe.ac.uk

New cleft research finding

Laurence Howe a PhD student working on cleft genetics (supervised by **Sarah Lewis**) has discovered that genetic variation increasing the chance of having a cleft, also predicts philtrum width (the width of the vertical groove in the middle area of the upper lip) in the general population.

On average, those with a higher genetic risk for cleft have a narrower philtrum. This suggests that whether an individual has a cleft or not is controlled by a normal biological process occurring during early development and that cleft genes may cause cleft lip by adversely affecting the development of the philtrum.

Update from The Cleft Collective Speech and Language Study

The Cleft Collective Speech and Language Study is now recruiting from 12 sites and has 465 participants – over one third of the target!

Over 130 recordings have been collected from 13-month olds in the study and 90 children have completed their 24-month SLT assessments at their local cleft centre. Our oldest children are now approaching their 3-year clinical assessment and so far we have received 6 36-month SLT forms.



This Autumn, we will be joined by **Hannah Lane**, SLT (Speech and Language therapist) with Doncaster and Bassetlaw NHS Trust. Hannah was successful in her application for a research internship as part of the Health Education England research internship and will be working alongside the Cleft Collective team and the Bristol Speech & Language Therapy Research Unit until next Spring.

Gemma Sharp gains FHEA status

In recognition of her experience and training in teaching, **Gemma Sharp**, who is a lecturer in molecular epidemiology and part of The Cleft Collective, was recently accepted as a Fellow of the Higher Education Academy.

Gemma teaches research methods and genetics to medicine and dentistry students. She often uses examples from cleft research to increase awareness of cleft amongst the next generation of dentists and doctors.



Calling all participants!

Thank you for your participation in The Cleft Collective study!

Have you received a Starter Pack or questionnaire from us?

Your checklist:

- 1) Complete and return consent forms to your cleft team
- 2) Complete and return questionnaires to The Cleft Collective – we will enter you into our monthly prize draw!
- 3) Take saliva samples using the kits provided and return them to the labs at the University of Bristol

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

Please get in touch with us using the contact details provided overleaf.