



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

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### Antenatal recruitment has begun!

The Cleft Collective now has permission to recruit families into the study while mum is still pregnant, after the family has received an antenatal diagnosis of cleft. This means that we can collect cord blood as soon as the baby is born. Cord blood is a rich source of both the mum's and the baby's DNA, and will give us unique insight into the genetic and environmental causes of cleft.

We already have our first two maternity units set up and ready to go; Heartlands Hospital and Warwick Hospital, which both feed into the Birmingham cleft team, and have recruited our first family! We are currently working with lots of other hospitals and hope to set up more maternity units in the coming weeks.

**3,929 individuals**  
(mums, dads,  
children, siblings)

**1,396 families**



### Latest figures

The days may be getting shorter but The Cleft Collective Cohort Studies are showing no signs of slowing down!

Fourteen cleft teams are now recruiting families, with two more cleft teams on track to begin recruiting in the coming months.



Our latest figures also show that we are more than a third of the way to reaching our recruitment target of 3,000 families!

Thank you to everyone supporting The Cleft Collective research programme.

### A voucher to say thank you

As a thank you to families for completing questionnaires, we are now able to offer a £10 voucher for every questionnaire we receive from a parent, and a £5 voucher for every child questionnaire we receive.

We have now begun to send out several **new sets of questionnaires**, including questionnaires for parents whose children have recently turned 3-years-old, and parents whose children have recently turned 8-years-old. For the first time, we will also be asking 8-year-old children to complete their own questionnaire.



### New member of the team

Welcome to Fabio Zucchelli,  
Research Associate.

Fabio will be supporting the Psychology team to carry out qualitative interviews with parents enrolled in the Birth Cohort Study, as well as health professionals involved in their care.

This study is funded by a Vice Chancellor Early Career Researcher Award from UWE.



### Calling all participants!

Thank you for your ongoing participation in The Cleft Collective Cohort Studies!

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
- 3) Take saliva samples using the kits provided and return to the labs at the University of Bristol

**Do you have any questions for us, want to check your status in the study or recently moved?**

Please get in touch with us.

### Promoting The Cleft Collective at Harvard

In August, one of our geneticists, Gemma Sharp, attended the Society for Craniofacial Genetics annual meeting at Harvard Medical School in Boston.



She presented on the work underway in The Cleft Collective and exciting plans for future research on the genetics of cleft. She received excellent feedback, and is looking forward to working with other research groups from around the world soon!



## cleft trainee collaborative

A new initiative which we are keen to support is The Cleft Trainee Collaborative, which was recently formed as part of the Craniofacial Society of Great Britain and Ireland. In other areas of health care, trainee medical professionals have assisted in collecting information to make sure that large studies such as The Cleft Collective are as complete as possible. Cleft is an area which is well suited to such a research collaborative, and the group have proposed a number of potential projects. Initially, they aim to collect information on the specific type of cleft of each child enrolled in the Cohort Studies, which will be very valuable to The Cleft Collective.

The Cleft Trainee Collaborative is open to all members of multidisciplinary cleft teams who are interested in cleft research.

If you are interested then please contact the trainee collaborative at: [clefttraineecollaborative@gmail.com](mailto:clefttraineecollaborative@gmail.com) or follow them on twitter: @cleft\_collab.

### **Are you a qualified health professional with experience of working with families affected by cleft lip and palate?**

Previous research has demonstrated that the information and care families receive during and after the diagnosis is crucial in helping them to cope with the challenges ahead. Health Professionals play a key part in this, yet their views have not been heard before.

We would like to invite you to participate in an individual, open-ended interview over the telephone, about your experiences of working with families affected by cleft lip and palate, even if your experience is minimal.

This study is open to qualified cleft specialist Psychologists, Nurses, and Speech & Language Therapists, as well as non-specialist professionals, including Sonographers, Midwives and Health Visitors.

For more information or to express your interest in taking part, please contact Nicola: [Nicola2.Stock@uwe.ac.uk](mailto:Nicola2.Stock@uwe.ac.uk).



## **Meet Donna – one of our Research Nurses!**

*"I consider myself very fortunate to have been able to become involved in The Cleft Collective study and work with the cleft team, based at the Royal Manchester Children's Hospital.*

*The care given to the patients at the hospital is superb. The team approach is patient orientated, and very child-friendly. Dr Bellardie is the PI of the study at RMCH, and we as research colleagues value the positive input that he has on The Cleft Collective Study.*

*I have had a varied nursing career, and have been involved in research for many years, although it has only been my sole focus for the last 5 years. I have done all my nursing training in South Africa, and have lived in the UK for the last 16 years. I do at times, compare the availability of services, and have been quite in awe of the treatment given to the patients.*

*Attracting potential participants to the cohort study works best when the researchers are seen as part of the overall team."*

### **The Cleft Collective Speech and Language Study (CC-SL)**

The CC-SL study is going from strength to strength with ten sites now recruiting and over 250 participants recruited so far!



Yvonne Wren presented the study to the International Association of Logopedics & Phoniatrics in Dublin in August, and received interest from other researchers who would like to apply to use information gathered by The Cleft Collective to help understand how we care for and support families of children born with cleft palate.

Sam Harding has now joined the CC-SL team. She will be working with the cleft teams and coordinating a monthly update about the latest recruitment figures and activities.

Finally, the first group of children recruited to the study have now reached two years of age, and the forms from their routine speech and language therapy assessments are being returned to the research team.

### **NEWS in brief...**

- Thank you to the CLAPA Bristol Branch for supporting The Cleft Collective research programme with PPI activity.
- Thank you to the David and Claudia Harding Foundation for their donation of £5,000 to the Cleft Lip and Palate Association, following an application from The Cleft Collective to Winton Capital.