



The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

Newsletter from the Bristol research team

The world's largest
cleft lip and palate
research programme



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Summer 2018

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



The Cleft Collective recently held a bake sale and raised £198.95 for CLAPA.

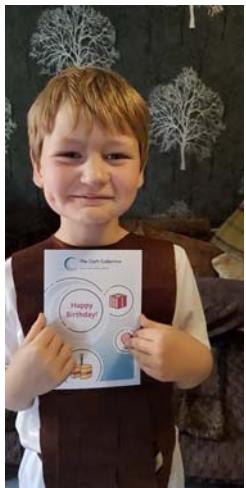
If you want to get involved in fundraising for CLAPA visit:
www.clapa.com

Birthday Cards!

We are now sending out birthday cards to our study children enrolled in The Cleft Collective!

Make sure your child receives theirs by keeping your contact details up to date.

You can update your details by emailing:
cleft-collective@bristol.ac.uk



EXCITING FUNDING NEWS!!

We are very pleased to announce that we'll soon be using your saliva samples to generate genetic data, thanks to a generous grant from the Scar Free Foundation. Genetic data will allow us to study the genetic causes of cleft, but it can also tell us important information about non-genetic (environmental) causes. This is one of the reasons we set The Cleft Collective up, so generating genetic data is a real landmark. We're very thankful to the Scar Free Foundation and we look forward to using the data to carry out some exciting and important research... Watch this space!

Recruitment update

The Cleft Collective has now recruited over **6900** participants from **2450** families. This includes mothers, fathers, children born with cleft, and siblings from families recruited antenatally, postnatally and at 5 years old.

The antenatal recruitment has increased over the last 6 months with **87** maternity units now approved to collect cord blood, and **78** cord bloods collected so far. This is a huge achievement and we are very grateful to all of the families, cleft teams and research nurses who are so supportive of the study.

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The Cleft Collective abroad!



Dr Gemma Sharp recently flew the flag for The Cleft Collective at the Epidemiological Birth Cohort Studies Conference in Oulu, Finland. The conference attracts representatives from cohort studies across Europe to discuss the best methods for collecting and analysing data. Gemma presented a poster explaining how The Cleft Collective was set up, what we hope to find, and what we've found so far. The conference was really useful for introducing us to other European birth cohorts that could potentially provide data on "control" children without a cleft who were born around the same time as the children in The Cleft Collective.



Dr Sarah Lewis (our genetics theme lead) attended the 6th Pan African Cleft Lip and Palate Scientific Congress which was held in Nairobi, Kenya on 25-27th March. This was attended by hundreds of people from throughout Africa, and with representatives from around the world. There were many interesting talks showing new surgical techniques, a more holistic approach to treatment which is now being adopted worldwide, and some nice examples of countries collaborating with each other and sharing best practice on community education and involvement.

Sarah gave two talks; one was a keynote talk on using genes to identify risk factors and understand biological pathways to cleft. The other was a short talk about The Cleft Collective cohort, how participants are recruited and what data is collected.

Keynote speech at Craniofacial Conference for Great Britain and Ireland

Yvonne Wren, The Cleft Collective Speech and Language study lead, delivered a keynote speech at this years' Craniofacial conference in Birmingham. She reported on her work with another large cohort study, the Avon Longitudinal Study of Parents and Children (ALSPAC), and her findings regarding why some children have persistent speech disorder. While this work was with non-cleft children, Yvonne is using the same approach with Cleft Collective data to investigate why some children born with cleft palate have persistent speech disorder and others do not.



Have your say!

We've been working with CLAPA to set up a Public Involvement group who can advise The Cleft Collective team going forward. We're looking for parents, young people, and adults affected by cleft to review the way the study is run, to help us develop our questionnaires, and to guide our future research agenda.

If you would like more information about how to join the group and what being a member involves, please contact

Anna.Martindale@clapa.com.



New Research Secretary

Welcome to Ruth Wade (right). Ruth has joined the team as Research Secretary to help the operations team with the day to day running of the study. Ruth will be scanning in all the consent forms and questionnaires that come in, as well as dealing with your queries on the phone.



General Data Protection Regulation (GDPR) and The Cleft Collective

The Cleft Collective is committed to protecting and safeguarding the personal data of all its participants. Information on how we store and process the data we obtain is detailed within our patient information sheet which can be found at www.bristol.ac.uk/dental/cleft-collective/families/methods/.

If you wish to withdraw from the study or no longer want to hear from us please let us know via cleft-collective@bristol.ac.uk

Update from The Cleft Collective Speech and Language Study

In June, we received approval from Leeds and have just recruited our first participants from this site! We are now in discussions with Glasgow and hope to start recruiting from there very soon. We now have 613 participants, 195 recordings at 13 months and 193 copies of SLT assessment forms at ages 18, 24 and 36 months.



Hannah Lane, Speech and Language Therapist with Doncaster and Bassetlaw NHS Trust, has been working with us on an internship funded by Health Education England. She has been exploring early speech and language therapy intervention for children born with cleft palate to find out what is provided in the UK. She has also looked at what has been published about this already.

New funding for The Cleft Collective Speech and Language Study

The Speech and Language Study has been successful in applying for funding to investigate how speech and language therapy is provided to children born with cleft palate across the UK. The information from this work will enable us to develop a questionnaire to collect information on speech and language therapy received by children in The Cleft Collective Speech and Language Study.

Congratulations to cleft surgeon David Sainsbury and the Cleft Multidisciplinary Collaborative for getting their first paper published! We are proud to have supported this research.



The paper is called 'Establishing a Network to Support Cleft Lip and Palate Research in the United Kingdom' and can be accessed here:
<http://journals.sagepub.com/doi/10.1177/1055665618790174>

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 in the FREEPOST envelopes
2. Complete and return questionnaires to The Cleft Collective – **you will get a £10 voucher for each questionnaire completed!**
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.