The Cleft Collective
Closing the Gap in Cleft Research
A Scar Free Foundation Initiative

One of the largest
cleft lip and palate
research programmes

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Newsletter from the Bristol research team

Autumn 2019

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

Funding news!

We are thrilled to announce that The MRC (Medical Research Council) have **awarded** a project grant of **£625,000** to Drs Sarah Lewis, Evie Stergiakouli and Gemma Sharp to use genetic data collected in the Cleft Collective to identify genetic and environmental causes of cleft. They will do this in collaboration with colleagues from Bonn University in Germany.

Recruitment update

The Cleft Collective has now recruited over **8383** participants from **2988** families. This includes mothers, fathers, children born with cleft, and siblings from families recruited antenatally, postnatally and at 5 years old.

Changed your email recently?

Contact us with your new email address to let us know.
We use email to send newsletters and study updates – don't miss out!

In this Issue:

Cleft Collective Speech and Language Study

Here is a photo of one of our participants in the Cleft Collective Speech and Language study wearing the vest which contains the LENA recording device. The device records over one day and then the recording is analysed automatically. We can see from this analysis the times when the child has babbled the most and we listen just to those sections, usually no more than six 5-minute segments, to measure the type of babbling and speech sounds the child uses. In the future, we will be able to use this information to see whether children's babbling at age 1 can predict who needs early speech and language therapy intervention.

Participant feedback

We received the following feedback from one of our participants on the back of their completed questionnaire:
"Thank you for your continued support and research. The world is a better place with people and organisations like this around"

It's always lovely for the team to get feedback like this and to know that we have such brilliant support!

Prefer to complete our follow up questionnaires online??

We will soon be offering you the chance to do this.
Watch this space!
Don't worry, the paper option will still be available if you prefer that!

Using your data for research

Have you ever wondered what the information you give us is used for?

You can find out who has ethical approval to use the data and what they want to research using the following link:
www.bristol.ac.uk/cleft-collective/families/progress/projects/

Here are some of our recent data requests:

- Holly Peryer is one of Birmingham's Speech and Language therapists. She has requested to use the data collected in the Cleft Collective Speech and Language study to identify if babies born with different cleft types (lip, palate, lip and palate) vary in how they communicate.
- Sammy Berman is studying for her MSc in Public Health. As part of her studies, Sammy requested to use the Cleft Collective questionnaire data to evaluate the wellbeing of children with cleft lip and/or palate at age 5 years.

CLAPA and Cleft Collective Consultation Group

As part of our effort to involve people affected by cleft throughout the development of the study, we have worked with CLAPA to put together a consultation group. This group is made up of a small group of people from the cleft community who are personally affected by cleft lip and palate, either as parents and carers, or as people born with a cleft themselves. A few times a year, the group will meet to discuss different aspects of the Cleft Collective's research. This is mostly done through video calling with one face-to-face meeting each year.

The people in this group use their personal experiences to help develop materials, as well as guide the research strategy for the future. This includes providing feedback and a fresh perspective on everything from participant recruitment to the development of research questions.

They're a vital part of the Cleft Collective and we are extremely grateful for their input as volunteers!

To find out more or to join this group, email: anna.martindale@clapa.com

In March this year, we welcomed the group to Bristol for a day of presentations and discussions around the next exciting phase of the study. To read more about the day, please go to: https://www.clapa.com/news-item/a-day-at-the-cleft-collective/

The day involved a trip to our labs……

Fragile biological samples are preserved in these tanks by cooling them to very low temperatures using liquid nitrogen

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 us – **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. Contact details are overleaf!

Have you seen our new animation which explains the study? Head to our YouTube channel to watch – it's only 3 minutes long!

https://www.youtube.com/watch?v=ShoCmF1P7Tc

Genetics update!

Sarah Lewis who leads our genetics team has been out spreading the word about The Cleft Collective!

In June this year, Sarah went to the University of Pittsburgh to attend and give a talk at a conference on facial genetics, it was attended by leading genetics experts researching cleft from around the world. See photo below.

She also attended the European Cleft Palate Craniofacial conference in Utrecht and gave a talk on "how genetic data can help us to understand the causes and consequences of being born with an orofacial cleft".