



# The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

One of the largest  
cleft lip and palate  
research programmes



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

## 100 cord bloods collected!

Thank you to all the **amazing mums** that have donated cord blood. One of the questions we can investigate using cord blood is: *are babies exposed to any toxins whilst they are in the womb?*



## Recruitment update

The Cleft Collective has now recruited over **7700** participants from **2735** families. This includes mothers, fathers, children born with cleft, and siblings from families recruited antenatally, postnatally and at 5 years old.

Welcome to the **Belfast cleft team** who are now part of the study. This means we now have **all** of the cleft sites recruiting participants for us!

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# Good news!

## EPOCH

The Medical Research Council recently awarded Gemma Sharp (who is part of The Cleft Collective team) a prestigious **£660,000 New Investigator Research Grant** to lead a research project that will use Cleft Collective data.

The Exploring Prenatal influences on Childhood Health (EPoCH) project investigates how parents' lifestyles in the important prenatal period might affect the health of their children, including their chance of being born with a cleft.

You can follow the progress of EPoCH at <https://epoch.blogs.bristol.ac.uk/>



All of the biological samples you send back to us are processed and stored in the Bristol Bioresource Laboratories (BBL) which has been named **UK Biobank of the year 2018** by the UKCRC Tissue Directory and Coordination Centre.



Dr Yvonne Wren leads the Speech and Language sub study. She was co-author of a paper which recently won an **Editor's award** in the Journal of Speech, Language and Hearing research.

The paper looked at digital intervention for children with speech sound disorder



It was great to see the BBC including a baby born with cleft in the series 'Call the Midwife', raising much needed awareness.



## 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:

<http://www.bristol.ac.uk/dental/cleft-collective/professionals/access/>

Here are some of our recent data requests:

- Using **data collected from the surgeon** following a baby's cleft palate repair and **data collected at age 5**, we will look at which surgical techniques help with better speech and growth outcomes.
- Using **data collected from your biological samples** we will be able to explore and identify factors which may increase the chance of a cleft.
- Using **data collected at age 3**, we will identify if there are any differences in how well a child's speech is understood by the people around them based on what type of cleft they have.

## Staff Changes

Congratulations to our project coordinator **Rhiannon** on the birth of her baby, Arabella Rose.



**Ruth Wade** is stepping up to Rhiannon's role whilst she is on maternity leave.



We welcome **Amy Ardon** to the role of research secretary.

Drs Laurence Howe, Gemma Sharp and Sarah Lewis who are part of The Cleft Collective team, investigated whether moderate amounts of alcohol consumed by mothers during pregnancy influenced how a baby's face developed. They found **no strong evidence that facial features were affected by moderate levels of alcohol intake**. In the future, we will be able to use the same method to find out if drinking alcohol during pregnancy contributes to the development of a cleft.

More information can be found here:

<https://www.ncbi.nlm.nih.gov/pubmed/30772781>

## \*New\* Speech and Language research

Speech and Language therapists Caroline Williams, Miriam Seifert and Holly Peryer have joined the Bristol Speech and Language Therapy Research Unit team on secondments from their clinical roles to work on research using Cleft Collective data.

Caroline is carrying out focus groups to understand the range of speech and language therapy interventions provided for children born with cleft palate in the first five years.



Miriam is investigating reports from parents of children's intelligibility at age 3.

Holly will further her research on speech outcomes following different approaches to lip repair in children with bilateral cleft lip.



Lucy Southby (Speech and Language Therapist based at Addenbrookes), has nearly finished recruiting to her PhD study which is looking at how children born with cleft palate process speech which they hear. This work will help us understand more about whether we might need to make changes to the kinds of speech and language therapy assessment/intervention we provide for some children born with clefts.

## Have your say!

Is there anything you'd like to see in our newsletters?

If there is, let us know!

Our contact details can be found overleaf.

## 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.