The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

The world's largest cleft lip and palate research programme

Telephone: +44 (0)117 331 0025
Web: www.cleftcollective.org.uk
Email: cleft-collective@bristol.ac.uk
Facebook: www.facebook.com/cleftcollective
Twitter: @CleftCollective

Newsletter from the Bristol research team

Summer 2016

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

In this Issue:

Project milestones

New genetic studies

Awards and achievements

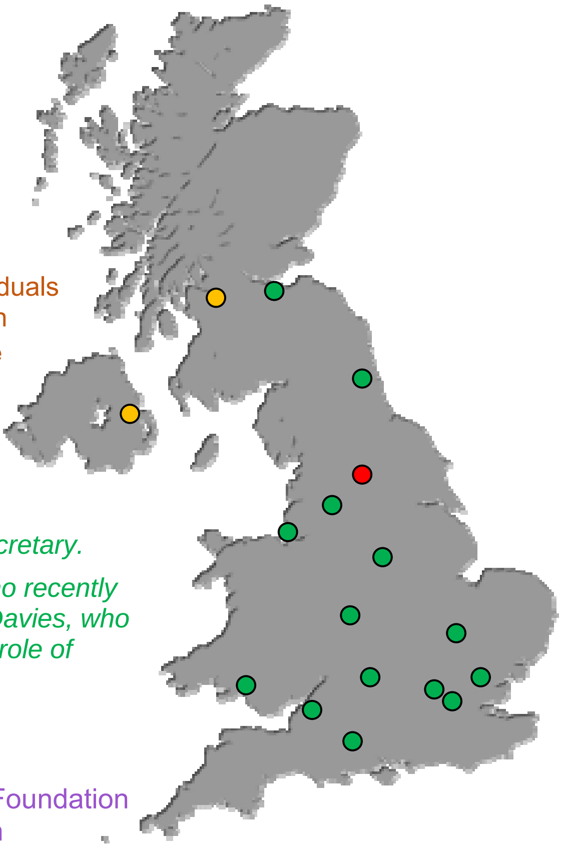
Adults born with cleft lip/palate wanted for interview study

Latest figures

Summer is here and The Cleft Collective Cohort Studies have had another busy six months. Fourteen cleft teams are now recruiting families [in green], and two more cleft teams [in yellow] are on track to begin recruiting in the coming months.

We have now recruited just over 3,590 individuals (including mothers, fathers, children born with a cleft, and unaffected siblings) from almost 1280 families. This means we are over a third of the way to reaching our target of 3,000 families!

Thank you to everyone supporting The Cleft Collective research programme.



Recent changes to our team

Welcome to Beth Smith (pictured), our new Research Secretary.

Welcome back to our Project Manager Kerry Humphries, who recently returned to her role after having her daughter, Poppy. Amy Davies, who provided maternity cover, has stayed with us in the new role of Research Coordinator.

Project Milestones

The Cleft Collective is an initiative of the UK-based charity, The Scar Free Foundation (previously called The Healing Foundation). The Scar Free Foundation recently announced their support in extending The Cleft Collective Cohort Studies for an **additional 18 months**. This is fantastic news and means that under the current funding, the Cohort Studies can continue to recruit families and collect data until September 2018. Thank you to The Scar Free Foundation for this opportunity.

The Cleft Collective is about to send out **the next set of questionnaires**. This represents the next phase of data collection, and will include questionnaires for parents in the Birth Cohort whose children have now turned 3-years-old, and parents in the 5-Year-Old Cohort whose children have now turned 8-years-old. For the first time, we will also be asking 8-year-old children to complete their own questionnaire. 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.

NEWS in brief...

- Our paper on how The Cleft Collective was set up has been published: http://bit.ly/1YRNAqD.
- A fond farewell to Rosanna Preston and a warm welcome to David Stokes, new CEO of CLAPA: http://bit.ly/28LU8Y8.
- Send your photos to cleft-collective@bristol.ac.uk and we'll use them to promote cleft awareness!
- The Burns Research Showcase took place in July: http://bit.ly/28KvVPP.
- Welcome to new CFSGBI President Peter Hodgkinson.
- Well done to everyone who contributed to Cleft Awareness Week 2016!
- Changing Faces have launched their new website: http://bit.ly/28KS3dS.

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 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.

"Beyond the Horizon"

The Cleft Collective disseminated the latest updates and research findings at the annual conference of the Craniofacial Society of Great Britain and Ireland in April. Congratulations to Dr Karine Latter and her team in Nottingham for a highly successful and enjoyable event.

The Cleft Collective was also represented at the annual conference of the British Psychology Society (BPS) in April, in a symposium focusing on 'Faces'.

Update from The Cleft Collective Speech and Language Study

The Cleft Collective Speech and Language study is going from strength to strength. Ten sites are now recruiting and we have 180 participants. For more information, please contact Dr Yvonne Wren at: yvonne.wren@speech-therapy.org.uk.

Could genes be related to educational achievement in cleft lip/palate?

We are performing a genetic study to investigate whether genetic risks for cleft are linked to educational outcomes later in life. Our results can help identify those at increased risk of poor achievement at an early stage, and increase appropriate support when it is needed most.

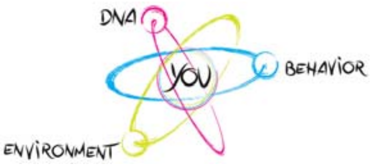
Adults wanted for 'Life Story' interview

Matthew Ridley is currently studying for his PhD in Psychology, which focuses on the long-term outcomes for people affected by cleft lip/palate. He is currently recruiting adults who were born with a cleft to participate in a one-to-one 'life story' interview over the telephone about their experiences.

For more information, or to express an interest in taking part in this study, please contact Matthew: Matthew.Ridley@uwe.ac.uk.

How does the environment affect the development of cleft lip/palate during pregnancy?

We are about to begin an exciting new "epigenetic" study. This involves analysing the blood, and the lip or palate tissue from 150 children, to see if we can find genes that are turned on or off in different types of cleft. This will provide an interesting insight into the causes of cleft.



Awards and Achievements

The Cleft Collective's **Dr Nicola Stock** has been presented with the Berkowitz Long-Term Outcomes Study Award for the 2015 paper *"'It doesn't just stop at 18". Psychological adjustment and support needs of adults born with cleft lip and/or palate'.* The award was announced at the annual meeting of the American Cleft Palate-Craniofacial Association in Atlanta on behalf of the Cleft Palate Foundation. This award demonstrates the growing recognition of the importance of psychology within the field of cleft lip/palate, and of the value of qualitative studies. Nicola is also the first UK recipient of the award.

A heartfelt thank you to the Adult Voices Council of the Cleft Lip and Palate Association for their continued support of this work (see http://bit.ly/28Lo87y), and to everyone who participated in the study. To read more about the study: http://bit.ly/1U3JDwL.

Pictured: Nicola with Adult Voices Co-Chairs Tony Ruel and Andrew Dixson-Smith after presenting the findings of the study at the Appearance Matters 6 conference in 2014.

Dr Nicola Stock is also a recent recipient of the UWE Vice Chancellor's Early Career Research Award for 2016/2017. This award will enable her to carry out an interviews with parents who are enrolled in The Cleft Collective Cohort Studies, and with various Health Professionals who are involved in their care. The study will allow for qualitative data to be gathered alongside the quantitative data which is already being collected. More details will be released soon.

Lucy Southby, Highly Specialist Speech and Language Therapist from the Spires Cleft Centre (Oxford site) has been awarded a HEE/NIHR Clinical Doctoral Fellowship with the University of Bristol. Her study aims to describe the speech processing skills of children born with a cleft palate in relation to their speech articulation skills, and will include information from some of the children from The Cleft Collective 5-Year-Old Cohort. This research will help us to understand what types of speech and language therapy might help children born with cleft palate.

One of our Chief Investigators, **Professor Nichola Rumsey** was recently awarded an OBE for her services to people affected by an altered appearance. Nicky is pictured with her family, after accepting her OBE from HRH Prince William, Duke of Cambridge.

Appearance Matters: The Podcast

Rated 5* and featured in a recent BPS article (http://bit.ly/28KxTyo), the podcast is available now on iTunes and Soundcloud.

Subscribe now to hear all our episodes, including an episode dedicated to the charity that makes our work possible. Find out about their recent change of name to the Scar Free Foundation, and all about their new research strategy.

Other topics include a look at the importance of psychological support from the perspectives of adults born with CL/P.