

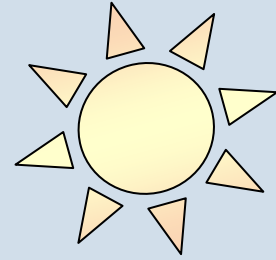


The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative

The largest cleft lip and palate research programme in the world



Newsletter from the Bristol Research Team

Email: cleft-collective@bristol.ac.uk

Web: www.bristol.ac.uk/cleft-collective

Twitter: [@CleftCollective](https://twitter.com/CleftCollective)

Summer 2013

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

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Great progress with our feasibility study

We are currently running a small study at the South West Cleft Unit in Bristol, to test the collection and storage of biological samples. The study began in April and five families have already donated saliva, blood and discarded tissue (taken at the time of the baby's cleft operation). Thank you to these amazing families and to the Cleft Team for doing such a fantastic job.

Cleft Awareness Week & CLAPA

We had lots of fun during this year's Cleft Awareness Week and are really enjoying our on-going work with CLAPA! First we visited CLAPA's Children and Young People's Council members (pictured), to discuss the challenges and benefits of growing up with a cleft. We then attended the Celebration Event to meet with families, and to host a Workshop for adults with cleft. Later, we spent an afternoon with CLAPA's Adult Voices, thinking about ways to improve services for adults with cleft. Finally, we participated in the Sonographer's Day, hosted by CLAPA and the British Medical Ultrasound Society, where it was great to see so many parents, sonographers and midwives discussing the challenges of antenatal diagnosis of cleft. Thank you to CLAPA for their continued collaboration and to all parents, young people, adults and health professionals who help to make our visits so useful and enjoyable.

Cohort Studies approved in England & Wales!

The Cleft Collective Cohort Studies, which will collect biological samples and longitudinal data from families affected by cleft, have now received NHS Ethical Approval to proceed in England and Wales. The Cohort Studies have also been adopted into the National Institute for Health Research Portfolio. This means that Cleft Teams will be eligible for financial assistance, to support them in collecting the data from families. This is a big step towards getting the Cohort Studies up and running!

The Cleft Collective on tour!



Since our last newsletter in January, members of

the Bristol team have been driving around the UK visiting the Cleft Teams and their research departments. We have also had enquiries from a number of maternity units around the UK, who are interested in participating at the antenatal stage. Thank you to the Teams who have already welcomed us. We look forward to making more visits soon!



Cleft Care UK research almost complete!

Did you and your child take part in the recent Cleft Care UK research? Have you returned your lifestyle and patient satisfaction questionnaires? The Cleft Care UK project has managed to recruit well over its target, but only 56% of the questionnaires have been received. To increase the effectiveness of this unique research study, please return your existing questionnaires ASAP, or contact Martin Persson for further information:

martin.persson@uwe.ac.uk

Where dreams come true...

The 12th International Congress on Cleft Lip/Palate and Related Craniofacial Conditions at the Walt Disney World resort in Orlando attracted more than 1400 professionals from 65 countries. The UK was well represented by The Cleft Collective teams and NHS Cleft Teams from around the UK. Congratulations to Edinburgh who won the vote to host the 14th International Congress in 2021. This is great news for the UK and will be an opportunity to demonstrate the fantastic services and research activities happening across Britain.

NEWS in brief...

- Congratulations to our lovely Project Manager Kerry, who got married in May!
- We had great feedback from the Craniofacial Society of Great Britain and Ireland's Annual Conference in Birmingham!
- Thank you to all the wonderful adults who recently took part in research interviews with The Cleft Collective's Nicola Stock. Updates coming soon! Thanks also to the Cleft Clinical Studies Group who reviewed the study.
- The Cleft Collective is on Facebook! Please show your support and 'like' our page: www.facebook.com/cleftcollective.
- We're still looking for photos to use in our promotional materials and presentations! Email Nicola2.Stock@uwe.ac.uk.

