



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

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

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Recruitment of families begins!

The Cleft Collective Cohort Studies, which will collect biological samples and questionnaire data from families affected by cleft, have now begun recruiting in England and Wales. The Birmingham Cleft Team has already recruited three families after just two weeks, and the Cleft Team in Swansea aren't far behind. Guy's + St. Thomas' Cleft Team in London are currently setting up, and more teams will be ready to start in the New Year. Families who previously took part in the Cleft Care UK study have also participated. DNA from 100+ individuals has already been collected. The feasibility study has also been completed successfully by the South West Cleft Unit, producing high quality results. A huge thank you to all families, CLRNs, cleft teams and their R&D departments for their hard work and support in 2013.

The Cleft Collective gets Royal seal of approval!

HRH The Countess of Wessex visited the Cleft Collective Cohort Studies at the University of Bristol in October. HRH met members of the research team and was given a tour of the laboratories. The Countess also met with new-born Barnaby Cox (pictured), Oliver Rigg, who was born with a cleft and is now 14, and members of the South West Cleft Unit based at Frenchay Hospital. The Countess is Patron of the UK charity The Healing Foundation, who funds The Cleft Collective research programme. More photographs are available online at: www.facebook.com/cleftcollective.



HRH The Countess of Wessex with Barnaby and his parents Rebecca Turner and Sam Cox. Photograph by Martin Chainey.

CLAPA Conference in Glasgow

We enjoyed another successful CLAPA conference this year, with talks from The Cleft Collective's Nicola Stock, Stephanie Tierney and Jonathan Sandy. Videos of all the conference talks are available online now: <http://vimeo.com/clapa/videos>

Study calls for better support for fathers of children with cleft

Research by The Cleft Collective's Nicola Stock suggests that fathers may require better information and support to help them deal with the challenges of having a child born with a cleft. Although fathers play a key role in their child's development and family well-being, they can often be forgotten. The study offers a number of recommendations for research and treatment in this area.

Thank you to CLAPA for all their support. A summary of the research can be found online at

www.bristol.ac.uk/cleft-collective and www.info.uwe.ac.uk/news.

The full article is now available from The Cleft Palate-Craniofacial Journal (in press).

Measuring speech in one-year-olds – A pilot study

Dr Yvonne Wren is looking for families who can help her test the collection of speech samples in The Cleft Collective studies. Families will be given a recording device for their baby to wear in customised clothing for one day. The device will record all the speech used by the baby and the sounds heard in their environment. Dr Wren is interested to know what this experience is like for families and any problems that they encounter. If you would like to know more about this pilot study, please contact Yvonne at: Yvonne.wren@speech-therapy.org.uk

Starter Packs

Have you received one of our Starter Packs in the post but not returned it yet? Please contact us with any enquiries.



NEWS in brief...

- Congratulations to Eleanor + Keith for completing the Rickshaw Challenge 2013 for BBC's Children in Need! Watch on YouTube.
- Thank you to The Healing Foundation for inviting us to present at their recent AGM.
- All the very best to Sue Carroll, who has left the Cleft Lip and Palate Association after 12 years.
- Does appearance matter? Visit www.euronews.com for an online discussion about the pressures people face.
- If you'd like to keep up to date with our research and receive information about opportunities to take part, email us at cleft-collective@bristol.ac.uk. We're also still looking for photos to use in our promotional materials and presentations!

Wishing all our followers a very Happy Christmas and all the best for the New Year!

