



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

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Happy New Year!

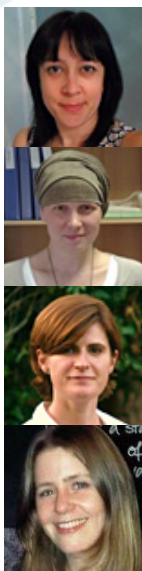
2012 was a great year for The Cleft Collective. We officially launched in March and have since met with cleft teams, families, the Cleft Lip and Palate Association (CLAPA) and various experts, to make sure our protocols for carrying out the research are as effective as possible. Thanks to everyone who gave us their support. In this newsletter we outline some of the highlights of 2012, with a glance at what 2013 may bring...

CLAPA conference 2012

The Cleft Lip and Palate Association (CLAPA) hosted another fantastic conference in September 2012. The Cleft Collective was represented by Nicola Stock, who led a presentation on user involvement in research, Martin Persson who ran a workshop for adults with cleft, and Kerry Humphries, who helped to run The Cleft Collective stand throughout the day.



Nicola and Martin at the 2012 CLAPA Conference in Bristol



Welcome new staff

New team members (top to bottom): Kerry Humphries (Project Manager), Beate St Pourcain (Lecturer in Epidemiology), Yvonne Wren (Research Speech and Language Therapist) and Maggie Bailey (Project Administrator).

Feasibility study approved and adopted!

We have been given approval to test the collection and analysis of biological samples at the time of the child's surgery, and will receive associated support costs. This feasibility study will go ahead in March 2013 in collaboration with the South West Cleft Team.

PPI + *dirty design*

Thanks to the help of our parent representatives and the design skills of Dirty Design, we now have a number of fantastic documents, including information leaflets for parents and this newsletter!

The Cleft Collective Scientific Workshop

In September 2012, we held a one-day workshop for members of every cleft team in the UK and a variety of other experts to obtain feedback on our current protocols. Following the feedback we received, we decided to change our strategy to include a cohort of five-year-olds in addition to our birth cohort. We spent a few months re-drafting the protocols and are now preparing to submit our final ethics application in February 2013. Thank you to everyone who attended.

Your photo here?

Do you have any photographs you'd like to share? We are still collecting photographs for our Cleft Image Bank, which aims to capture what life is really like when someone is born with a cleft. Many families and adults have already sent us their photos, and seen them appear in leaflets, newsletters, on the web and on TV! For more information please email Nicola at: Nicola2.Stock@uwe.ac.uk.

CLEFT CARE UK

We have now completed two years of recruitment, attended 78 clinics and have 257 participants so far. We have currently received 2364 data items and are contacting cleft teams about the remaining 18%. We would like to thank all of you for how fantastically helpful and supportive you have been for Cleft Care UK.

Adults wanted for research!

A new study is looking at the experiences of adults who have grown up in the UK with a cleft. This includes parents who were born with a cleft themselves. The study involves a one-hour telephone interview.

Contact Nicola2.Stock@uwe.ac.uk for more info.

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