



The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative

The world's largest
cleft lip and palate
research programme



Newsletter from the Bristol Research Team

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Summer 2014

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

In this Issue:

- Support for adults with cleft
- Craniofacial conference 2014
- 3D Imaging workshop
- Speech and Language study begins
- Fantastic fundraising

Measuring speech in one-year-olds with cleft palate

Congratulations to The Cleft Collective's Dr Yvonne Wren who was recently granted ethical approval to carry out her Speech and Language study across the UK. Dr Wren is now looking for families who can help her test the collection of speech samples in The Cleft Collective Cohort 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



Research progress

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. Cleft teams are recruiting in Birmingham, Swansea, Guy's and St Thomas', Bristol and Manchester. Trained and almost ready to start are cleft teams in Oxford, Nottingham and Great Ormond Street. To find out when your local cleft team is likely to begin recruitment for The Cohort Studies, please get in touch with us or speak to your cleft team directly. Over 300 individuals (including mums, dads, children and siblings) have been recruited from over 100 families so far. Thank you to all families, local research networks, cleft teams and NHS Trusts for their support.



Sarah Hill with her parents Suzanne and Robert Morgan after completing the Paris Marathon in 4:38:21.

Fantastic fundraising!

Sarah Hill, a Dental Hygienist who graduated from the University of Bristol in 2012 recently ran a marathon in Paris to raise money for The Cleft Collective Cohort Studies. During her training Sarah spent some time at the South West Cleft Unit in Bristol. She said "I found this particular rotation extremely interesting and that is why I'd like to give something back and help to raise money for this research project which I believe is vital for the future". Sarah completed the marathon in an amazing time of 4:38:21. Congratulations to Sarah on her achievement and a huge thank you for her donation to our research.

Calling all participants!

Thank you for your participation in The Cleft Collective Cohort Studies!

Have you received a Starter Pack from us?

Your checklist:

- 1) Complete and return consent forms to your cleft team
- 2) Complete and return questionnaires to The Cleft Collective
- 3) Take saliva samples using the kits provided and return to the labs at the University of Bristol



Got any questions?

Please get in touch with us using the contact details provided above!

Study calls for better support for adults born with cleft lip/palate

Research by The Cleft Collective's Nicola Stock suggests that although most individuals adjust well to having a cleft, many may require additional information, further treatment and psychological support well into their adult years. Nicola said "many thousands of adults across the UK and the world are living with a cleft lip/palate, and yet many are unaware of the support that is available to them. Routine cleft care normally concludes around the age of 18 years, and as a result, relatively little is known about the longer-term outcomes." The study, which involved interviews with 52 adults born with a cleft, also identified the importance of understanding the risk of recurrence in future generations.

Thank you to all of the participants involved in this study, and to CLAPA for their support. Visit www.clapa.com/adults for information, support and events.

A summary of the research can be found online at: <http://www.bristol.ac.uk/dental/cleft-collective/news/2014/31.html>.

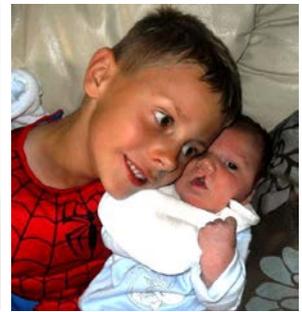
Full articles will be available from *The Cleft Palate-Craniofacial Journal* (in press).



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Cleft lip/palate: What is the impact on siblings?

As part of our ongoing work with CLAPA, we are carrying out a study about siblings of children with cleft lip and/or palate.

If you are a **brother or sister** of someone with a cleft OR a **parent** of a child with a cleft and a child without a cleft, we would like to hear from you!

We would like to interview siblings about what it is like to grow up with a brother or sister with a cleft, about any positive effects or difficulties they experienced, and about how CLAPA may be able to improve the support they offer to families. We would also like to ask their parents about what they feel the impact on their child's siblings has been.

Siblings aged 13 years or over and their parents are invited to tell their story.

For more information, please get in touch with Nicola by emailing: Nicola2.Stock@uwe.ac.uk.

Cleft New Zealand

We were delighted to be joined by Dr John Thompson, an epidemiologist from the University of Auckland, in March. Dr Thompson has a background in paediatric research and is keen to run a similar study to The Cleft Collective in New Zealand. We hope to continue this collaboration and support the New Zealand research team as much as possible.

Thank you also to the charity Cleft New Zealand who invited The Cleft Collective's Nicola Stock to speak over Skype during a Summer



Camp for young people with cleft. New Zealand's Cleft Awareness Day takes place on Saturday 4th October 2014. For more information visit: www.faceit.org.nz.

Craniofacial Conference, Oxford 2014

The Cleft Collective had a strong presence at the Craniofacial Conference again this year, with presentations from Kerry Humphries (Project Manager), Jonathan Sandy (Principle Investigator and Professor of Orthodontics) and Nicola Stock (Research Psychologist). We also attended the Patient and Public Involvement (PPI) workshop hosted by CLAPA, as well as the Psychology, Nursing and Surgical Special Interest Groups. Thank you to the conference organisers and attendees for an enjoyable and informative few days.

3D Imaging Workshop

In June, members of The Cleft Collective team will meet with health professionals working in cleft teams around the UK. The meeting will take place in London and attendees will discuss the possibility of collecting 3D facial images from families who are enrolled in The Cleft Collective Cohort Studies.

Collecting 3D images would help us to see if there is a relationship between the faces of the child, the parents and the siblings, and will hopefully tell us more about how cleft occurs in families. 3D imaging has many advantages over traditional 2D photographs. This aspect of The Cohort Studies will only take place in hospitals where the 3D technology is already available.

We will share our progress on this soon!

Sneak peek!

Look out for our **new website** which is coming soon!

You can also follow us on Facebook: www.facebook.com/cleftcollective and Twitter: @CleftCollective

Welcome to the team!

A warm welcome to Rhiannon Bennett (Research Secretary) who joined The Cleft Collective team in March.

Rhiannon is no stranger to cohort studies, having worked for ALSPAC (Avon Longitudinal Study for Parents and Children) for the past four years.

We are also grateful to Helen Price (Academic Administrator) who supports the team when needed with research-based administration.



Rhiannon Bennett
Research Secretary



Helen Price
Academic Administrator



NEWS in brief...

- You can still contribute to our Cleft Image Bank by sending your photos to: Nicola2.Stock@uwe.ac.uk.
- Sign up to receive updates from us by contacting: cleft-collective@bristol.ac.uk.
- ALSPAC have published their 1000th paper! They have been collecting data since 1991 – we hope we can be as successful!
- The Healing Foundation Burns Collective was launched in June 2013 – watch out for updates: <http://bit.ly/1IP7Rbk>.
- Want to know more about the Centre for Appearance Research? Watch our video: <http://bit.ly/1oFB5gP>.
- Thank you to VTCT for their lovely article on HRH Countess of Wessex's visit to The Cleft Collective in Bristol: <http://bit.ly/1jqvHsr>.
- The Cleft Collective appears in The Telegraph newspaper! (9th June 2014)

We wish all of our followers a fantastic summer!