



# The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative

The world's largest  
cleft lip and palate  
research programme



Winter 2014

Newsletter from the Bristol Research Team

Telephone: +44 (0)117 342 4412  
Web: [www.cleftcollective.org.uk](http://www.cleftcollective.org.uk)  
Email: [cleft-collective@bristol.ac.uk](mailto:cleft-collective@bristol.ac.uk)  
Facebook: [www.facebook.com/cleftcollective](https://www.facebook.com/cleftcollective)  
Twitter: @CleftCollective

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

## In this Issue:

The SW Cleft Team move

Meet a Research Nurse

CLAPA conference 2014

Speech and Language study  
begins

We're on the web!

## Research milestones

It's been a fantastic year for The Cleft Collective Cohort Studies!

Cleft teams in Birmingham, Swansea, Guy's and St. Thomas', Bristol, Manchester, Great Ormond Street, Oxford, Nottingham, Edinburgh and Salisbury are now recruiting families. Cleft teams in Chelmsford and Liverpool are also due to start recruiting in the New Year.

So far, we have recruited over 1,000 individuals (including mothers, fathers, children with cleft and siblings) from almost 350 families.

This represents a huge achievement and the research team is extremely grateful to everyone who has been involved to date.

## 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



## The South West Cleft Team has moved!

We're delighted to be joined by the South West cleft team at the Dental Hospital in Bristol, where The Cleft Collective research team is based.

Visit the new webpage: <http://bit.ly/1q0O5SK>



## Have any questions for us, want to check your status in the study or recently moved home?

Please get in touch using the contact details provided above!

## Meet Aman!

Aman is a Clinical Research Nurse responsible for recruiting families into The Cleft Collective Cohort Studies at Guy's and St. Thomas' Hospital in London.



*"My interest in research came from working in a Paediatric Trauma Accident and Emergency department over the past 6 years, where I took the opportunity to support numerous research studies facilitated in the department. I developed a love of Research Nursing and started working as a Clinical Research Nurse in February 2014. I have now been given the opportunity to help coordinate and recruit families to The Cleft Collective Cohort Studies. Working on the largest cleft research programme worldwide, in a department that is really engaging, is very motivating. It is a great experience and a joy to promote a project that will make a huge difference to patients and families.*

*I have enjoyed every aspect of this study from the initial set up stages to being accepted into the team and recruiting patients. The element of the job that is particularly exciting is teaching families about their participation. Being aware that not everyone wants to be part of a research study, I have developed a better awareness of how families feel about research in general. When a family decides not to go ahead with the study, I see it as a learning curve to help us improve as a department and ensure the families are as engaged and informed as they can be."*



# The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative



## Lorena loves Christmas – and so do we!

We would like to wish all our followers a very Happy Christmas and say a huge THANK YOU for everything you've contributed to our research this year.

Within a generation we hope to know more about what causes cleft, the best treatments for cleft and how best to support individuals with cleft and their families. This is only possible with your help. Here's to another fantastic year in 2015!

### Have any photos you'd like to share?

Please contact [Nicola2.Stock@uwe.ac.uk](mailto:Nicola2.Stock@uwe.ac.uk) or send them to us via our Facebook page: [www.facebook.com/cleftcollective](http://www.facebook.com/cleftcollective)

### We're on the web!

We're very pleased to announce the launch of our new website: [www.cleftcollective.org.uk/bristol](http://www.cleftcollective.org.uk/bristol). We hope you find all the information you need on the website, but we would also welcome feedback. You can also get in touch with us any time using the contact details provided at the top of this newsletter.



### Spreading the word at conferences

2014 saw the 6<sup>th</sup> 'Appearance Matters' biannual conference of the Centre for Appearance Research, based at UWE. The Cleft Collective had a strong presence at the two-day event, and was privileged to be joined by members of CLAPA, including Adult Voices Co-Chairs Andrew and Tony who presented alongside The Cleft Collective's Nicola Stock on the importance of support for adults with cleft. A video of the conference is available here: <http://go.uwe.ac.uk/AM6film>.

We were also delighted to participate in this year's CLAPA Conference in October, which adopted the theme of the Patient Voice. The Cleft Collective's Jonathan Sandy discussed past achievements and future ambitions in cleft research, while Nicola Stock described how participation in patient-centred research can support the empowerment of the cleft community.



Left to right: PhD researcher Amanda Bates, CLAPA CEO Rosanna Preston, The Cleft Collective's Nicola Stock and CLAPA Adult Voices Co-Chairs Tony Ruel and Andrew Dixon-Smith at the Appearance Matters 6 conference in Bristol, July 2014.

The conference also marked **CLAPA's 35<sup>th</sup> birthday** – a huge achievement and happy celebration!

### The Cleft Collective Speech and Language Study has begun!

Following a successful pilot, families who are involved in The Cleft Collective Birth Cohort in Birmingham are now being invited to participate in the speech and language study. This new project will follow children's speech and language development in the first three years and begins with asking parents to record their child's speech using a special recording device called LENA.

Here is a picture of our first participant, Archie, wearing the special vest which contains the recording device. You can find out more about the study and watch a short film about the LENA recording device at [www.cleftcollective.org.uk](http://www.cleftcollective.org.uk).



### NEWS in brief...

- New guidance launched to improve 'unacceptable' detection rate of cleft palate: <http://bit.ly/12roV4w>.
- "It doesn't all just stop at 18". New research on adults with cleft published: <http://dx.doi.org/10.1597/14-178>.
- Congratulations to CLAPA Volunteer Award runner-up Harry Feather, who contributed his expertise to The Cleft Collective.
- New HealthTalk.org website on cleft launched: <http://bit.ly/1vTck4Q>. Please send feedback to [A.J.Searle@bristol.ac.uk](mailto:A.J.Searle@bristol.ac.uk).
- Congratulations to Changing Faces' James Partridge for winning the Body Confidence Award! Watch here: <http://bit.ly/1FXE618>.
- We're hiring! The Cleft Collective Cohort Studies are looking for an infrastructure manager to join our team: <http://bit.ly/1vVdIVM>.
- Thank you to everyone who participated in our siblings study. Findings will be made available soon!
- A warm welcome to The Healing Foundation to Sir Bruce Keogh and Alex Mahon – exciting times ahead!
- CLAPA's research pages are now up and running. Take a look here: <http://www.clapa.com/medical/research>.
- Sign up to receive updates from us by contacting: [cleft-collective@bristol.ac.uk](mailto:cleft-collective@bristol.ac.uk).