



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

### In this Issue:

- The Cleft Collective new offices
- Experiences of siblings
- Meet a Clinical Research Nurse
- Latest research findings
- Long-term outcomes of cleft
- New team members

## Research milestones

It's been another fantastic few months for The Cleft Collective Cohort Studies! Cleft teams in Birmingham, Swansea, Guy's and St. Thomas', Bristol, Manchester, Great Ormond Street, Oxford, Nottingham, Edinburgh, Salisbury, Chelmsford and Liverpool are now recruiting families. Cleft teams in Cambridge and Glasgow are also on track to begin recruiting in the coming months.

So far, we have recruited over 2,000 individuals (including mothers, fathers, children with cleft and siblings) from almost 740 families. This means that in the last six months, **our recruitment rate has doubled!**

Birmingham, Swansea, Guy's and St Thomas, Bristol, Great Ormond Street and Salisbury are also recruiting to The Cleft Collective Speech and Language Study.

Once again, the research team is proud of this collaborative achievement and is extremely grateful to everyone who has been involved to date.

## Calling all participants!

A huge 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 (**you will be entered into our prize draw!**)
- 3) Take saliva samples using the kits provided and return to the labs at the University of Bristol



**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.

## The Cleft Collective has moved!

*We're delighted to have moved to a new location! Our new offices are based at Oakfield House, alongside the hugely successful 'Children of the 90's' cohort study (<http://www.bristol.ac.uk/alspac>).*

### Our new postal address:

*The Cleft Collective  
Oakfield House  
Oakfield Grove  
University of Bristol  
BS8 2BN  
United Kingdom*

*Please note that our phone number has also changed (see above).*

## Meet Jane!

Jane Lovatt is a Clinical Research Nurse responsible for recruiting families into The Cleft Collective Cohort Studies at Birmingham Children's Hospital.



*"My interest in research began at University 10 years ago and I've been hooked ever since! I became a Research Nurse in 2010 where I worked on a single Neonatal study. I then joined the NIHR Clinical Research Network (then Medicines for Children) in 2011 where I took on numerous trials. They were mainly CTIMP studies so when I had the opportunity to work on The Cleft Collective Cohort Studies I was really excited. I started off on my own coordinating, screening and recruiting families to the Postnatal Cohort and the 5-Year-Old Cohort. It was so interesting attending clinic with the Specialist Cleft Nurses, meeting new mums and dads and learning about the different types of cleft that can occur. At first I was apprehensive talking to families who had just had their first baby diagnosed with a cleft, but once I got talking I realised how interested and how enthusiastic families are about research, even if the research will not benefit them directly. Everyone wants to help, and they know that research matters and everyone should be given the opportunity to take part. For any new Research Nurses I would say the most important thing is to remember is that everyone should be given the opportunity to participate in research and never back away from approaching a family, even in what may appear to be difficult circumstances, you just never know, they may say yes."*



# The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative

## Our team is growing!

A warm welcome to new team members **Mike Croning** (Infrastructure Developer), **Sarah Lewis** (Senior Lecturer in Genetic Epidemiology), and **Evie Stergiakouli** and **Gemma Sharp** (Lecturers in Genetic Epidemiology).

Welcome also to **Amy Davies** who has taken on the Project Manager role while Kerry Humphries is on maternity leave, after the birth of her beautiful baby girl Poppy.

We also welcomed new PhD student **Matt Ridley** to the team this month. Matt's PhD will focus on the long-term outcomes for individuals born with cleft, one of the top James Lind Alliance research priorities (<http://www.lindalliance.org/top-tens.asp>), over the next 3 years.

## Conferences and workshops

As usual, we've been busy attending conferences and hosting workshops to spread the word about The Cleft Collective and share best practice. Thank you to everyone who attended the first **Cleft Collective Research Nurse Workshop** in March. Your experiences and ideas were hugely valuable and much appreciated.

Thanks to the team at Guy's and St Thomas' Hospital for a fantastic and informative few days at the annual conference of the **Craniofacial Society for Great Britain and Ireland** in April. Congratulations to former Presidents Kate Le Marechal and Jacqueline Smallridge, and to Karine Latter, President of the Society for 2015/2016. The Cleft Collective team authored two oral and two poster presentations this year.

Members of the team also attended the **10<sup>th</sup> European Craniofacial Congress** in Göteborg, Sweden in June, delivering two symposia, plus two other talks during the conference.

## Good luck Beate and Maggie!

Congratulations to Beate St Pourcain on her new appointment in Nijmegen and our thanks for her role in The Cleft Collective programme.

A sad farewell and good luck to Project Coordinator **Maggie Bailey**. Maggie has made a huge contribution to the project since it began and will be hugely missed. Congratulations to **Rhiannon Bennett** who will be stepping up to this role.

## Latest research findings

### **"No one ever told me it was a possibility": The heritability of cleft lip/palate**

*A new study by The CC's Nicola Stock and Nichola Rumsey has found that few young adults with cleft are aware that cleft can be a heritable condition. The study has called for more accurate information and opportunities to access genetic counselling for young adults with cleft, and emphasised the need for high quality research into the causes of cleft. To read more, visit:*  
<http://www.clapa.com/news/article/2137>.



### **What is the impact of cleft lip/palate on unaffected siblings?**

*Sibling relationships are among the most unique social connections. Previous research has suggested that unaffected siblings of children with long-term health conditions may be at risk of psychological difficulties. This study which was carried out in collaboration with the Cleft Lip and Palate Association found siblings of children with cleft to have information and support needs which are not often met, alongside a number of positive outcomes. A more inclusive approach to care is recommended. To read more, visit:*  
<http://www.clapa.com/news/article/2139>.

### **Early communication behaviours in children born with and without cleft palate**

*In order to assess early communication behaviours, nineteen children born with and without cleft palate were audio-recorded for one day at 13 months of age. The study found children with cleft palate to have lower rates of vocalisations, fewer conversational turns and to be slightly behind their peers without cleft in terms of early development. However, the small size of the sample and the wide variation between children did not allow for firm conclusions to be drawn. The Cleft Collective Speech and Language Study has now begun recruiting families. The study aims to shed further light on children's communication development and to offer recommendations for improvements in cleft care. To find out more or to express an interest in taking part, please visit:*  
[www.cleftcollective.org.uk/bristol/speech](http://www.cleftcollective.org.uk/bristol/speech).

### **NEWS in brief...**

- Wishing Speech and Language Therapist Liz Albery a very happy retirement from cleft care.
- Thank you to Cleft New Zealand for inviting Nicola Stock to speak at the Youth Camp and Annual General Meeting.
- Dates for your diary include the **Appearance Matters 7 conference**, hosted by the Centre for Appearance Research (28-30<sup>th</sup> June 2016, The Royal College of Surgeons, London) and the annual **CLAPA conference 2015** (21<sup>st</sup> Nov, Holiday Inn Camden-Lock).
- Does being beautiful get you further in life? Nicola Stock features in The Independent: <http://ind.pn/1F69nlp>.
- Have any photos you'd like to send us? Please contact [Nicola2.Stock@uwe.ac.uk](mailto:Nicola2.Stock@uwe.ac.uk) for more information.
- Sign up to receive updates from us by contacting: [cleft-collective@bristol.ac.uk](mailto:cleft-collective@bristol.ac.uk).