



The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

One of the largest cleft lip and palate research programmes



Spring 2020

Newsletter from the Bristol research team

Telephone: +44 (0)117 331 0025
Web: www.cleftcollective.org.uk
Email: cleft-collective@bristol.ac.uk
Facebook: 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:

Cleft Collective at Buckingham Palace

Covid-19 update

PIER prize

Genetics workshop

COVID-19

We hope that you are well during these strange and worrying times. The Cleft Collective has had to pause recruitment whilst the NHS focuses on Coronavirus, but we will be back up and running again once this is all over. We are still sending out online follow up questionnaires so keep an eye out on your email and check your junk mail!



The Cleft Collective team keeping in touch

New animation

Take a look at our new 3-minute animation about cleft genetics. It shows the research we are carrying out using the biological samples our participants have donated to the study. Scan the QR code with your smartphone to watch!



Here is Freddie keeping himself busy during lockdown by making a car out of cardboard! Nice one Freddie!



Recruitment update

The Cleft Collective has now recruited over **9032** participants from **3223** families. This includes mothers, fathers, children born with cleft, and siblings from families recruited antenatally, postnatally and at 5 years old.

PIER Prize

We are thrilled to announce that we and our friends at CLAPA have won the Royal College of Paediatric and Child Health/NIHR Paediatric Involvement and Engagement in Research (PIER) prize. The prize recognises significant contributions to excellent patient engagement for NIHR Clinical Research Network Portfolio studies. This would not be possible without our fantastic participants who are so supportive of what we do! Thank you to CLAPA for supporting us with this very important work. We hope we will be able to collect our award soon.



Cleft Collective at Buckingham Palace

On 4th December 2019, two of The Cleft Collective team, Professor Jonathan Sandy and Kerry Humphries were invited by our funders, The Scar Free Foundation to afternoon tea at Buckingham Palace! It was to celebrate their 20th anniversary and was hosted by Scar Free patron HRH The Countess of Wessex. We can report that the cakes were delicious! Congratulations to The Scar Free Foundation for reaching such a milestone and thank you for your ongoing support.



Photo courtesy of The Scar Free Foundation

THE SCAR FREE FOUNDATION

MAKING A WORLD WITHOUT SCARS A REALITY



Have any questions for us, want to check your status in the study or recently moved? Email us (cleft-collective@bristol.ac.uk) to let us know.

If you want to receive study updates and newsletters, make sure we have your latest email address!

A message from Abi

I was born 9 years ago with a cleft soft palate which was fixed when I was a baby. I don't remember it but sometimes I do worry I might sound different or hear differently from other people. But I don't think I am very different from my friends because everyone is different and that's ok.

Sometimes I feel sad I have to go to the hospital for checks and long appointments but that is ok and it is what I was born with and makes me me.

The Cleft Collective is important to me because they are trying to make things better for children like me and trying to find out about clefts. The work they are doing is helping doctors and nurses learn more and how to fix clefts better. Maybe they can find how to stop them. Also, it's helping people who look after children to help them not to worry about their cleft and make them feel better. I like being part of it.



Early careers workshop

In March we attended a meeting in London with the Early Career Researcher (ECR) group. The ECR group are cleft clinicians who are interested in undertaking their own research into cleft. We support the group by showing them what data we hold which could answer their research questions. Follow the link to find the research projects we have approved so far: <http://www.bristol.ac.uk/cleft-collective/families/progress/projects/>

Research with CRANE database

We have recently started a project with the Cleft Registry and Audit Network (CRANE). You may know that the CRANE database collects information about all children born with cleft lip and/or cleft palate in England, Wales and Northern Ireland. This database was set up by the Department of Health in 2000. Our project is to make sure that when we carry out our research, we all hold the most accurate record of the type of cleft your child has. To do this, we have received information from CRANE for our participants who have consented for us to do so.



Online questionnaires now live!!

We are now sending out our follow up questionnaires online! If your child has recently turned 18 months, 3 years, 5 years, 8 years or 10 years you should have received an email with a link to complete your questionnaire. Check your junk folder just in case!

Don't worry, you can still fill in a paper copy of the questionnaire if you would prefer.

If you complete a questionnaire for us, on paper or online, you will receive a £10 voucher to say thanks!

PPI workshop

On Saturday 14th March 2020, the Cleft Collective welcomed CLAPA's Cleft Collective Patient



Consultation Group to Bristol for a day of presentations and discussions around the next phase of the study. Amongst other things the group gave some valuable input into our next animation on genetics which you can view here:

<https://www.youtube.com/watch?v=sX4F3aLB5Po>

If you are interested in becoming part of the group, please get in touch with us or CLAPA. In addition to this annual face to face meeting, two remote meetings take place each year via video conferencing.

Genetics workshop

On the 7th November 2019 we held a cleft genetics workshop which was attended by world leaders in cleft genetics, from the UK, USA, Germany and Norway. The workshop was to bring experts together to discuss how we could all use Cleft Collective data to answer important questions regarding cleft genetics. It was a successful day with some great research ideas coming out of it.



Speech and Language study update

The study has successfully recruited over two-thirds of their target figure (that is over 800 participants!).

Thank you to all of the speech and language therapists who are sending us the 24- and 36-month assessment forms. You are brilliant!