



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

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**New Chief Investigator!**

In June 2020, Professor Jonathan Sandy retired as Chief Investigator and Dr Yvonne Wren took over the role. Yvonne has been involved with the study since the very beginning as she leads the Cleft Collective Speech and Language Study. She is well known to both the NHS cleft teams and the CLAPA Cleft Collective Patient Consultation Group. Jonathan will continue to be involved with the study.



**COVID-19 update**

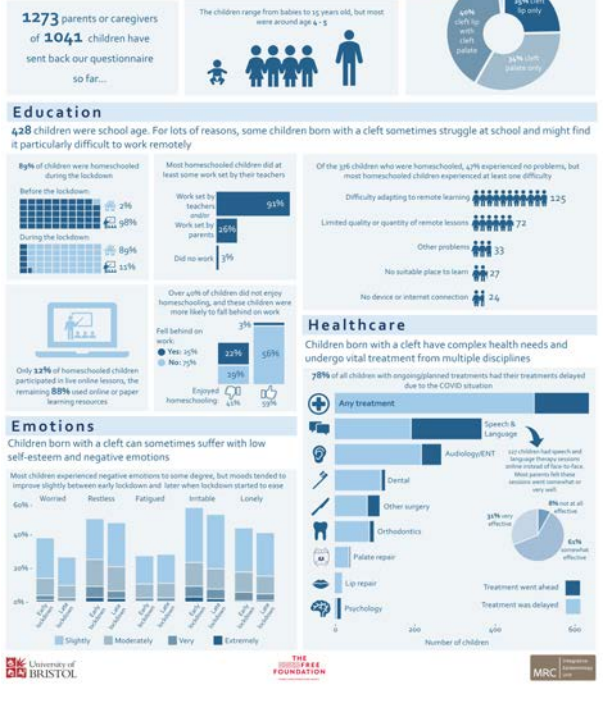
We are back up and running and welcoming new participants! A big thank you to the NHS cleft teams and research nurses who are doing a brilliant job of helping us to keep the study going through these difficult times. You are *AMAZING!*



**COVID-19 questionnaire**

Thank you to all our participants who completed the COVID-19 questionnaire. The questionnaire highlighted the impact of the pandemic on cleft treatment and education. We found that 78% of children with ongoing or planned treatments had their treatments delayed due to COVID-19. Speech and language therapy was offered online instead of face-to-face at some cleft centres. Where it was offered online 92% of parents felt these sessions were "very" or "somewhat" effective. During the first lockdown 89% of school aged children were home schooled. 53% of these children experienced at least one difficulty with home schooling. Most children experienced negative emotions to some degree, but moods tended to improve when the first lockdown started to ease.

**How were children born with a cleft affected by the COVID lockdown?**



Scan the QR code with your smartphone to see a bigger version, go to our website or click on:  
[Cleft Collective infographic](#)



The Bonn cleft study started in 2004 and has collected over 3000 DNA samples from more than 1000 cleft families in Germany. Around 400 children born with a cleft from these families have been included in a previous genetic study, but genetic material from the mothers and the rest of the children are being analysed in collaboration with the Cleft Collective to help identify genetic and environmental causes of cleft.



Dr Kerstin Ludwig & Dr Elisabeth Mangold (Bonn)

**Recruitment update**  
The Cleft Collective has now recruited over **9145** participants from **3263** families. This includes mothers, fathers, children born with cleft, and siblings from families recruited antenatally, postnatally and at 5 years old.

Have any questions for us? Want to check your status in the study or recently moved?

Email us:



[cleft-collective@bristol.ac.uk](mailto:cleft-collective@bristol.ac.uk)

# ★ INTRODUCING ★

## Rachel is a member of our Patient Consultation Group

As a medical librarian, I usually get involved with the research process only after findings have been published. I teach NHS staff search techniques for discovering relevant research papers in health care databases and carry out detailed searches on their behalf. Joining the Cleft Collective Consultation Group was an opportunity to influence research at the other end of the process, while studies and survey instruments are still being designed and data being collected. I am a parent of a teenager with a cleft lip and palate and have a cleft lip myself, so it's been incredibly interesting and rewarding to provide input to the work of the Cleft Collective. Being part of the consultation group means I can help researchers ask the questions that are important to families like mine. We can also help them ask these questions in a sensitive and ethical way that respects our real-life experiences.



## Matt Fell

I am a Plastic Surgery Registrar, training in the South West of England. I have been fascinated by cleft lip and palate since being a medical student and have steered my surgical training towards achieving my goal of becoming a cleft surgeon. Funding from the Vocational Training Charitable Trust (VTCT) has enabled me to take up an exciting opportunity to step away from surgical training and work with the Cleft Collective for one year, supervised by Professor Sarah Lewis. During this year, I will investigate the role of maternal smoking as a causal factor for clefts. This project will provide me with high quality research training and the findings will hopefully contribute to our growing knowledge about the role of environmental factors in the cause of cleft lip and palate.



## Garan Jones

From 2013 I worked for the NHS as a bioinformatician specialising in rare diseases. I left the NHS in 2017 to complete a PhD at the University of Exeter researching the underlying genetic causes of muscle weakness with age. I have recently started as a Senior Research Associate with the Cleft Collective working on a number of projects with genetic data. I am planning to collaborate with colleagues from the University of Bonn (Germany) to investigate whether the mother's genes can affect development of cleft in their babies whilst still in the womb. I will also be investigating the genetics of children who were born with a cleft.



## Lucy Southby

I have just completed my PhD research, funded by an HEE/NIHR Clinical Doctoral Research Fellowship, investigating speech input processing skills in children born with cleft palate and their relationship with speech articulation at age 5 years. Having worked closely with The Cleft Collective team over the course of my PhD, I am now working as a Senior Research Associate at the Bristol Speech and Language Therapy Research Unit, in North Bristol NHS Trust. In this role I am collaborating with the Cleft Collective team by conducting research using Cleft Collective data. I am also able to bring my perspective as a speech and language therapist to the wider Cleft Collective team through my continued clinical work in one of the regional cleft teams.



## Alex Davies

I am pleased to have been appointed to the joint fellowship between the South West Cleft Service and the Cleft Collective to undertake specialist training in cleft lip and palate surgery. The post is generously sponsored by Craniofacial Australia, the charitable foundation whose aim is to promote the best outcomes for those born with facial difference by educating healthcare professionals and supporting research. I am delighted to have the opportunity, alongside my surgical training, to work with the Cleft Collective whose ambitious and important work is perfectly placed to make a real difference to the care of children born with cleft lip and/or palate.

