



One of the largest cleft lip and palate research programmes



# The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

The Underwood Trust

## WINTER NEWSLETTER 2025

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



### PPI meeting, Nov 2024

In November 2024, the Cleft Collective and CLAPA Patient Consultation Group (PCG) met in person at the Wills Memorial Building in Bristol. We had a great day talking about new and upcoming research using data from the Cleft Collective. Areas of research discussed included genetic analyses, differences between left and right sided cleft lips, dental decay and speech and language therapy at age 5. The PCG meet three times a year (twice online and once in person) and help inform research using Cleft Collective data. If you are interested in becoming a member of the PCG please get in touch at: [cleft-collective@bristol.ac.uk](mailto:cleft-collective@bristol.ac.uk)



### New Cleft Film

Watch our new 4 minute Cleft Film 'Leading the way in cleft research for better lives and futures', detailing the cleft research taking place at the University of Bristol:

<https://www.youtube.com/watch?v=imyJx8x-oGQ>

### 15 year questionnaire



Our 15 year questionnaire is ready to go! If you have a child in the study who is 15 years old you will soon receive your latest questionnaire, and if you have consented to your child completing questionnaires then they will receive one too. This can be completed online or on paper and you will receive a £10 voucher for each questionnaire returned.



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Cleft@18-23  
SHAPING FUTURES TOGETHER

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NIHR

In our last newsletter, we reported that we had secured funding from the National Institute of Health Research (NIHR) to investigate variation in outcomes for young adults who were born with a cleft lip and/or palate. The Cleft@18-23 study has now started and the team are in the process of setting up research clinics with each of the regional cleft services. If you or someone you know is aged 18-23, was born with a cleft and are interested in getting involved see: [Cleft@18-23 study](#) | [Bristol Dental School](#) | [University of Bristol](#) or contact [cleft-1823@bristol.ac.uk](mailto:cleft-1823@bristol.ac.uk) for more information.



## ENT Congress in Sao Paulo, Sept 2024

Professor Yvonne Wren, was invited to Brazil to speak at the annual ENT (Ear, Nose and Throat) congress in Sao Paulo. As well as being able to meet many speech and language therapists at the conference, it also provided an opportunity for connecting with members of cleft clinical teams in Brazil and raising awareness of the Cleft Collective as a data resource for cleft research.



## Welcome to Alex Rammos!

My name is Alexandros Rammos and I am a senior research associate with expertise in genetic research. I will be working with Professor Evie Stergiakouli to understand how often children born with cleft lip and/or palate (CL/P) face learning, mental health, or developmental challenges, and how these compare to other groups of children without cleft. I also aim to explore genetic factors that may contribute to these challenges. My previous research has focused on understanding genetic influences on learning and development in children and young people, as well as how certain developmental and mental health conditions can vary across individuals.

If you want to read about how the study was set up and what data we have available for researchers to use, click the link below and read our new protocol paper:

<https://pubmed.ncbi.nlm.nih.gov/38969383/>

## PPIE Showcase, June 2024

In June 2024, Rhiannon Bennett represented The Cleft Collective at the University of Bristol Public & Patient Involvement & Engagement (PPIE) Showcase to share best practice in public engagement. Rhiannon presented on our work with the CLAPA Cleft Collective Patient Consultation Group (PCG) who we meet with a few times a year. This event highlighted the importance of working with those with lived experience when conducting research.



Our Chief investigator, Professor Yvonne Wren has been named in the Association for Child and Adolescent Mental Health long list for their awards [Celebrating the Future of CAMH: ACAMH Awards 2024 Long list - ACAMH](#). Nominees are all individuals with a sustained contribution to translating research into practice over a number of years.



## New research findings



Sarah Lewis, genetics lead within the Cleft Collective, was involved in a study that used CRANE (The Cleft Registry and Audit Network) data. The data were linked to a dataset of hospital visits across the UK to investigate whether children born with a right-sided cleft were more likely to have additional birth anomalies when compared to children born with a left-sided cleft. The study found that the prevalence of additional congenital anomalies was similar between children born with a left- or right-sided cleft among those children born with a cleft lip only, but among children born with a cleft lip and palate, children born with a right-sided cleft were more likely to have additional anomalies compared to children born with a left-sided cleft. To read the paper click: <https://doi.org/10.1177/10556656241261918>

**HAVE ANY QUESTIONS FOR US? WANT TO CHECK YOUR STATUS IN THE STUDY OR RECENTLY MOVED?**



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