

## Contact us

The Cleft Collective  
School of Oral and Dental Sciences  
University of Bristol  
Lower Maudlin Street  
Bristol  
BS1 2LY  
United Kingdom

**Tel:** +44 (0)117 342 4412

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

**Website:** [bristol.ac.uk/cleft-collective](http://bristol.ac.uk/cleft-collective)

**Twitter:** @CleftCollective

**Facebook:** [facebook.com/CleftCollective](https://facebook.com/CleftCollective)



# The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative

A UK-wide research programme investigating the causes of cleft, the best treatments for cleft and the long-term wellbeing of those affected.



THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements



*“Why our baby? Could we have prevented the cleft? Without our help there may never be an answer to the question of ‘why?’. That is the reason I value the opportunity to participate in the research. I can’t change the fact that my baby has a cleft but I can help to provide answers for future generations.”*

Rachel McDermott,

Mum to 2-year-old Emily, who was born with a unilateral cleft lip and gum

# The Cleft Collective

## Who are we?

The Cleft Collective is the largest cleft lip and palate research programme in the world. We are funded by the UK charity The Healing Foundation, and supported entirely by voluntary contributions.

Key partners within The Cleft Collective include the University of Bristol, the University of Manchester, Central Manchester University Hospitals NHS Foundation Trust and the University of the West of England.

## What do we hope to achieve?

A cleft of the lip and/or palate is very common, affecting around 1,000 babies per year in the UK. After their baby has received a diagnosis of cleft, parents often ask three main questions:

- What caused my baby's cleft?
- What are the best treatments for my baby?
- Will my baby be OK as he/she grows up?

We hope to answer these three questions by setting up a Birth Cohort Study and a 5-year-old Cohort Study of children born with cleft lip and/or palate.

We will ask families to join our study either after they receive a diagnosis or at their 5-year audit clinic. Families will then be asked to provide biological samples (such as saliva) and to complete questionnaires at appropriate time points.

We aim to recruit over 3,000 families into the study from April 2013 onwards, with the help of every NHS Cleft Team in the UK. We then hope to follow each family as their baby grows up.

Taking part in the study is completely voluntary and will not impact on your child's cleft treatment. This is because all of the research will take place alongside your child's normal treatment, or can be done from your home. Any data we receive from you will be kept and analysed anonymously. You may also be offered the opportunity to take part in related cleft research if you would like to.

*"Our daughter's cleft palate was diagnosed after birth and our first reaction was 'what is it and how did she get it?'. Every cleft is unique and individual to the family, and research such as this is paramount in helping to provide long-term answers into the care and treatment of clefts. To be part of this research is giving a voice to our children as well as ourselves - the outcomes will be invaluable to the future of cleft care."*

Ana and John Hobbs,

Mum and Dad to 2-year-old Abi, who was born with a cleft of the soft palate

We believe that this research will tell us more about the environmental and genetic causes of cleft; will help us to make decisions about the best treatments for cleft; and will develop our understanding about how we can help children to adapt positively to having a cleft as they grow up.

If you are interested in taking part in this research or would like more information, please inform your cleft team as soon as possible, or contact The Cleft Collective directly using the contact details provided on the back of this leaflet.

Thank you very much for taking the time to read this information.



Harry with brother Robert. Harry was born with a unilateral cleft lip and palate.



Thomas was born with a bilateral cleft lip and palate.

Aidan was born with a bilateral cleft lip and palate. Aidan's dad Clayne was also born with a cleft.



Florence was born with a bilateral cleft lip and palate