For the UK
cleft community

Cleft Lip and Palate Action

About us

Registered with FUNDRAISING REGULATOR

Registered Charity England & Wales (1108160) and Scotland (SC041034)

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What is a cleft?

- In **early pregnancy**, parts of the face form separately and then join in the middle
- For **one in 700 babies**, this doesn't happen as it should
- A **cleft lip** is one or two gaps in the upper lip
- A **cleft palate** is a gap in the roof of the mouth
- A baby can have a cleft lip, cleft palate, or both together
- It's usually caused by a complicated mix of genetic and environmental factors

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What is the impact?

- **Feeding:** Most babies need to use special bottles and teats from CLAPA to feed
- **Hearing:** Many children with a cleft palate have recurring hearing issues
- **Speaking:** A cleft palate affects how certain sounds are made
- **Teeth:** A cleft can affect the shape and position of teeth and make dental care more difficult
- **Appearance:** Visible scars can affect confidence and self-esteem

Cleft myth 1:

Cleft is 'fixed' with surgery as a baby

Fact: the cleft treatment pathway is 20+ years

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Every cleft is unique, just like every child, so the exact treatment needed will vary. Treatment can include:

Operations: babies born with a cleft will need at least one operation to repair their cleft and may need more as they grow up to help with things like teeth, speech, breathing.

Speech therapy: around 50% of children born with a cleft palate need extra help to make certain sounds clearly

Help with hearing: many children born with a cleft palate need grommets or hearing aids

Dental and orthodontic work: braces, surgical treatment, and other interventions are often needed

Psychological support: support from cleft-specialist Clinical Psychologists

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Cleft myth 2:

Cleft doesn't happen in the UK, does it?

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Fact: cleft occurs in one in 700 births

On average, three babies are born with a Cleft in the UK each day

What is CLAPA?

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- **Cleft Lip and Palate Action** (CLAPA) are the national charity supporting, connecting, celebrating and championing the UK cleft community.
- CLAPA is there from the moment of diagnosis and throughout a lifetime with cleft, so nobody has to go through their cleft journey alone.
- We receive **no NHS or government funding** and we rely on donations to continue our vital work.

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CLAPA's Services

- Specialist feeding bottles
- One-to-one support
- Online support groups and events
- Supporting research
- Children and young people's service
- Adult services
- Information service
- Raising awareness and campaigning

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Kevin, Sanjana & Arin's Story

Shock & fear at diagnosis: At the 20-week scan, Kevin and Sanjana were told their first baby, Arin, would be born with a cleft lip and likely a cleft palate. They were overwhelmed by anxiety and uncertainty but reassured when introduced to the cleft team and CLAPA's support.

Stressful pregnancy: Complications—including umbilical cord concerns and the need for amniocentesis—made the pregnancy an emotional "roller coaster." They feared for Arin's health and felt their joy turn to constant worry.

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Kevin, Sanjana & Arin's Story

Arin's early arrival: Arin was born early via emergency c-section in July 2022. Despite the chaos and fear leading up to his birth, his safe arrival brought relief and renewed confidence.

CLAPA's vital support: The CLAPA Welcome Pack, specialist bottles, Facebook community, and connection with other parents helped ease feeding worries and gave them reassurance, encouragement, and a sense of belonging.

Moving forward: Arin has now had his initial surgeries, is thriving at pre-school, and is a happy, energetic child. Kevin and Sanjana are grateful to the cleft team and CLAPA, and feel proud to be part of the community.

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How can you help?

- Spread the word on what you have found interesting today. Learn more about supporting people affected by cleft and our work at clapa.com
- Follow and share our social media – we are **‘@CLAPAcommunity’** on Instagram, Facebook, LinkedIn and TikTok.
- Being born with a cleft might make you different – but everyone is different! So please join us to **celebrate** these differences.

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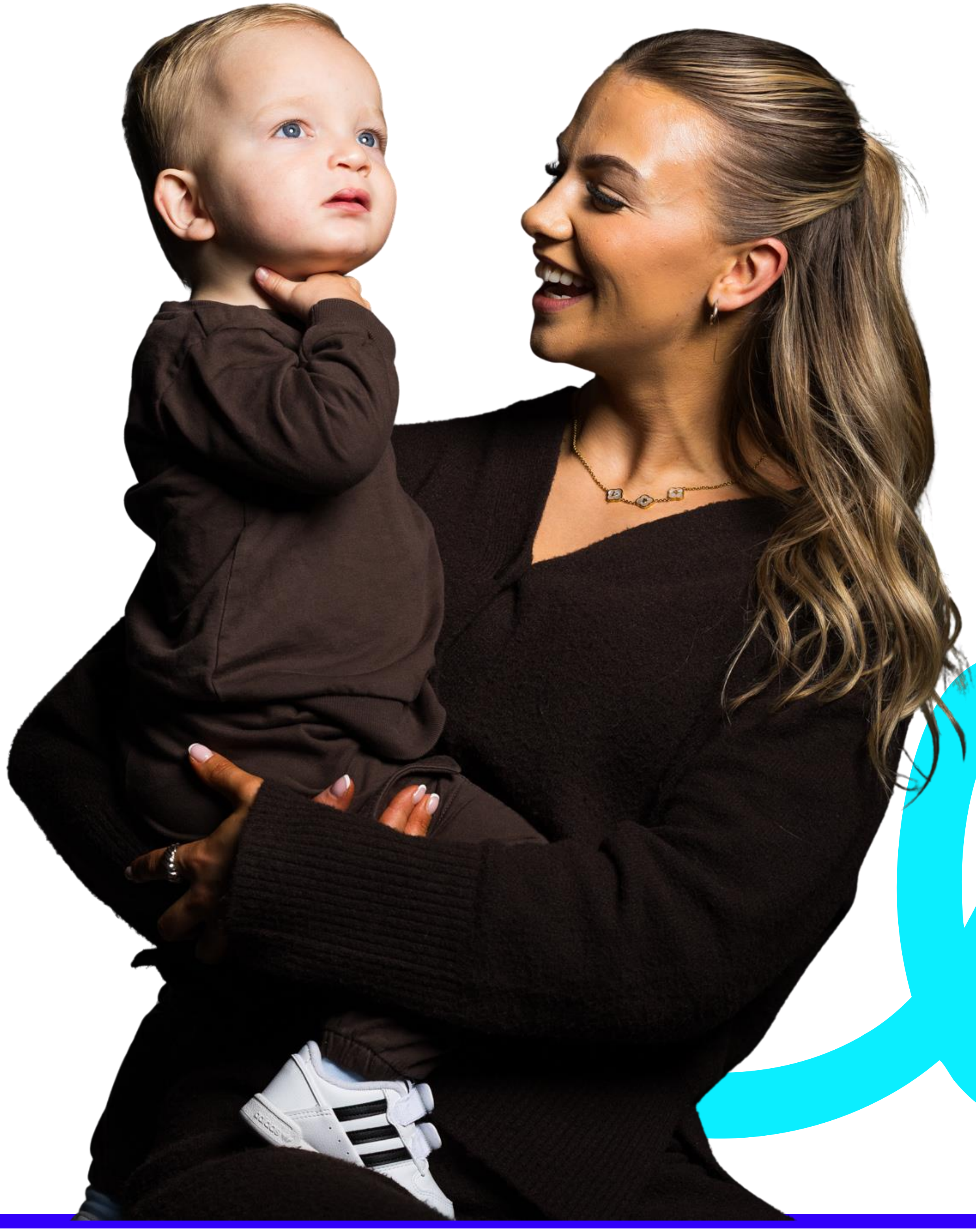
The difference you've made

CLAPA has **no government or NHS funding**. We rely entirely on generous donations and fundraising from people like you to continue our work.

Your donations help to keep our services **free and accessible** to everyone who needs them.

In the past few years, you've helped us **reach and support** more people than ever!



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Thank you!

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