

Notes for Editors

ABOUT CLAPA

The Cleft Lip and Palate Association (CLAPA) is a national charity working to **improve the lives of people born with a cleft and their families in the United Kingdom.**

One in 700 babies are born with a cleft lip and/or palate, a lifelong condition which impacts everyone differently. CLAPA is a 20,000-strong community of parents, patients, healthcare professionals and more, all dedicated to raising awareness and working together to overcome any barriers caused by cleft lip and palate.

Our vision is of a society where everyone affected by cleft feels supported, connected and empowered to take control wherever they are on their cleft journey. CLAPA works towards this vision by providing knowledge, practical support, a community and a voice to people affected by cleft.

OUR WORK:

- Online and local **support groups** help people affected by cleft to feel positive, connected, and in control.
- **Local and national events** bring people together so no one has to go through their journey alone.
- CLAPA provides **specialist feeding equipment** for babies born with a cleft in the UK, and supplies nearly 500 new families with free 'Welcome Packs' each year.
- Trained **parent and patient volunteers** provide **one-on-one support** at all points of the cleft journey.
- Our **information service** is comprehensive, accessible and community-led.
- Trained volunteers **educate schools, local communities and healthcare professionals** about cleft lip and palate.
- We actively promote opportunities to get involved with **research about cleft lip and palate**, and collaborate with researchers to make their work accessible to our community.
- CLAPA is well-respected as the **voice of people affected by cleft in the UK**, and our staff and volunteers sit on a number of boards and committees looking to improve care.

ABOUT CLEFT LIP AND PALATE

Cleft means 'split' or 'separation'. During pregnancy separate areas of the face develop individually and then join together (fuse) at around 2-3 months. If some parts do not join properly the result is a cleft, the type and severity of which can vary from child to child. The tissue is still there; it has just not fused, and often is pulled back as the foetus grows. This is what allows surgeons to repair the cleft without taking tissue from elsewhere.

A '**cleft lip**' is a notch or gap in the upper lip – a 'unilateral' cleft lip means one gap, while a 'bilateral' cleft lip indicates two gaps which sometimes extend up into the nostrils. A '**cleft palate**' is a hole or split in the roof of the mouth. The condition affects approximately 1 in every 700 babies born around the world,.

Around 1,200 babies are born each year with a cleft in the UK, or 100 each month. Approximately 45 % will have a cleft palate only, 23 % will have a cleft lip only, 22 % will have a unilateral cleft lip and palate, and the remaining 10 % will have a bilateral cleft lip and palate.

How does it happen?

There is no single known cause of cleft lip and/or palate. Sometimes there is a clear genetic link where it is passed down through a family, other times it occurs as a one-off when a number of environmental and genetic factors work together in a way which **could not have been predicted or prevented.** It is very unlikely that a child's cleft developed because of something their mother did or didn't do.

In some cases, a cleft is caused by a **syndrome.** There are over 200 syndromes listing cleft as a symptom, and these have various causes and implications.

What problems can it cause?

Problems associated with cleft lip and/or palate include **feeding difficulties** (a cleft palate often means a vacuum cannot be formed with the mouth which prevents suckling from a breast or bottle), **hearing issues** (such as glue ear), **speech problems** (around 50% of children with a cleft palate need ongoing speech therapy to be understood by their peers), differences in **facial growth**, badly placed **teeth** and occasionally **psychological issues** to do with having a visible facial difference and/or different-sounding speech.

How is it treated?

A cleft lip is surgically repaired when a child is 3-6 months old. A cleft palate is repaired between 6-12 months. Every child's cleft is unique, as are their treatment needs, which will be handled by one of the multidisciplinary NHS Cleft Teams around the UK.

Treatment may include further surgeries to improve speech, hearing, teeth placement, and the appearance of the face and profile. Some of these are major surgical procedures requiring years of preparation and a lengthy recovery time. Hearing aids or grommets are commonly used to improve hearing in children with a cleft palate, and many children will also undergo speech therapy.

There is a treatment pathway in place from birth to adulthood, however further treatment where necessary is available to adults of any age, including access to psychological services.

TERMINOLOGY

The term '**harelip**' is outdated and offensive; it should not be used.

We use the term 'cleft lip and/or palate' (or just 'cleft') to indicate everyone who has a cleft lip, a cleft palate, or a cleft lip and palate together. 'Cleft palate' is often incorrectly used to mean 'cleft lip' or 'cleft lip and palate'. Please see these diagrams for more information: www.clapa.com/what-is-cleft-lip-palate/

We don't use '**deformity**' or '**disfigurement**' because of the negative connotations. Instead, use '**visible difference**'.

We don't use '**birth defect**', instead we use the more neutral '**condition**', or, if necessary, the medically appropriate term '**congenital abnormality**', which means something different you were born with.

At CLAPA we also prefer to use what is called '**people first language**' which puts the person before their condition, so we would use the term 'baby with a cleft' as oppose to 'cleft baby'. For more information, see our Language Guide on our Press & Media page: www.clapa.com/about-us/press-media/

CONTACT DETAILS

For general media enquiries, please contact Anna Martindale (Communications & Information Manager) on 020 7833 4883, or at anna.martindale@clapa.com