



2023 - 2024

Impact Report



Registered with
**FUNDRAISING
REGULATOR**

CLAPA 
Cleft Lip & Palate Association

ABOUT CLAPA

THE CLEFT LIP AND PALATE ASSOCIATION

Every day in the UK, three babies are born with a cleft. It can have an ongoing impact on feeding, speech, hearing, teeth placement and more. The treatment pathway is 20+ years, and many babies have their first surgery at just three months old.

CLAPA is the United Kingdom's cleft lip and palate support charity.

We help people born with a cleft, and their families, from diagnosis to adulthood with comprehensive and reassuring information, a welcoming community of people with shared experiences, and evidence-based services and resources. We make sure that no one affected by cleft in the UK has to go through their journey alone.

IN THIS REPORT



Bottles & Teats
Page 3



Camp CLAPA Weekends
Page 11



Online Events
Page 5



The Online Cleft Community
Page 13



One-to-one Support
Page 7



Supporting Cleft Research
Page 15



Support for Under 18s
Page 9



Fundraising
Page 17



Support for Adults
Page 10



Finances
Back Page



The CLAPA Staff Team in 2024

CLAPA IN 2023/24

Boosted by the incredible success of the #SaveCLAPA Appeal, this was a year of exciting new projects and leaps forward, not just in service delivery, but in all the vital behind-the-scenes work that makes CLAPA possible.

Highlights include the launch of the Cleft++ Mentoring Service, new events to support grandparents, dads and young people, and smashing the target of our first-ever Big Give campaign at Christmas. We are proud to end this year having supported thousands of people in need from all corners of the cleft community, and with many exciting plans to support thousands more in the years to come.

To everyone who has supported our work this year, from major funders to regular donors, cupcake sellers, marathon runners, and social media followers, we'd like to say a huge THANK YOU! In this report, you'll read about people finding their cleft community, feeling more positive and confident about their futures, and using their experiences to support others. All of this was only possible thanks to your support. Together, we're creating a kinder world for people affected by cleft lip and palate. As we look ahead to a future for CLAPA that feels brighter than ever, we hope you're as excited as we are to see what's next.

Claire Cunniffe
CLAPA Chief Executive

BOTTLES & TEATS

FEEDING BABIES BORN WITH A CLEFT

Many babies born with a cleft cannot breastfeed or use regular feeding equipment. CLAPA manufactures and supplies special bottles and teats to families and hospitals around the United Kingdom. These bottles and teats are used and recommended by NHS Clinical Nurse Specialists.

With CLAPA's free 'Welcome Packs' of special bottles and teats, babies can leave the hospital faster after birth so families can enjoy those precious early weeks bonding with their baby at home. Further items of feeding equipment are available on CLAPA's subsidised online shop, and extra free items are sent to vulnerable families when needed.



"Thank you so much for your help. Mum received these a few days ago and was very happy [...and] grateful. Baby has gone from taking 45 minutes to feed to 15 minutes!"



NHS Clinical Nurse Specialist who requested free-of-charge items for a vulnerable family



10,838

bottles and teats sent out



728

Welcome Packs sent to new families



141

free items for vulnerable families





At such an overwhelming and daunting time, it is so reassuring and helpful having CLAPA provide the Welcome Pack of bottles and teats which were needed to feed my baby right from day one.

Family who received a CLAPA Welcome Pack



Each Welcome Pack costs CLAPA around £50

Special thanks to The Croda Foundation and The Boshier-Hinton Foundation for funding this service.

ONLINE EVENTS

BRINGING THE CLEFT COMMUNITY TOGETHER

CLAPA's free online events allow people affected by cleft to share their experiences, receive practical advice, and find their 'cleft community'. We run a regular schedule of diverse and engaging events on different topics to welcome people at all stages of the cleft journey.

All of CLAPA's online events have a strong volunteer presence, with most being facilitated by volunteers with personal experience of cleft who can use this to steer the conversation and create meaningful connections with attendees.



53

online events like support groups



960

attendees to events



50%

came to more than one event



6

live Q&As led by experts



1,225

watchers during and after

NEW IN 2023/24

'Dads Discuss'
support groups for dads
and fatherly figures



"I've never really spoken to any other dads who have a child born with a cleft, so it was nice chatting to dads who have shared similar experiences as me."

5

Grandparents'
support groups



"The event was welcoming, informative, and protected. I feel better equipped to help my son, daughter in law and future grandchild. I am very grateful to the volunteers for all their practical tips."

'Chat & Chill' events
for young people



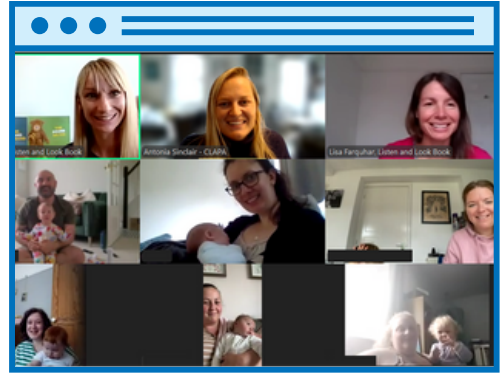
"Thank you, this was so timely and helpful. My daughter had been worrying about when she would get braces (she's had two bone grafts now) and was so upbeat after the call!"



The really practical, straight forward advice given by the SLTs will make a real difference to how I support my baby's speech development. It was an extremely useful & informative session, thank you.



- Parent who attended a 'Babble and Play' session

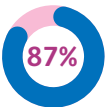


It's absolutely wonderful. It feels like our journey is part of a similar club of people and it gives me strength to do my absolute best for the baby and give them the most wonderful start in life - free from worrying.

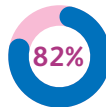


Parent in antenatal support group

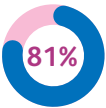
"AFTER THIS EVENT, I FEEL..."



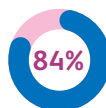
More connected with others in the cleft community



More positive about my connection to cleft



More confident about coping with cleft-related challenges



More knowledgeable about the topic of the event



Each support group event costs CLAPA around £600. Special thanks to Smile Train USA and the National Lottery Community Fund for supporting this work.

ONE-TO-ONE SUPPORT

FROM TRAINED VOLUNTEERS AND STAFF

From parents facing a new diagnosis to adults considering going back for more treatment, the cleft journey is full of ups and downs. Having someone on hand who understands exactly what you're going through can make all the difference.

CLAPA has a network of parent, grandparent and adult volunteers trained to support others one-on-one. These volunteers use their wealth of personal experience and knowledge of the cleft treatment pathway to reassure those in need that they can cope with whatever lies ahead.



61 enquiries in
2023/24



39 matched with a Peer or
Parent Supporter



22 supported to access a
service from CLAPA,
another organisation,
or the NHS



The most important step of any journey is the first one. Having a peer that understands exactly what you have gone through is a big help, maybe at the time you can't see it but the more you engage and talk the easier problems will sort themselves out.



I would like to express my gratitude for the insightful conversation I had with the assigned Peer Support member. I am eager to continue the discussions, work towards my dreams, and achieve personal and professional goals.



Peer Supporter Training

CLEFT++

September saw the launch of 'Cleft++', a new service which uses a specialist online platform to safely connect 10-17-year-olds born with a cleft to a trained mentor, all of whom are young adults born with a cleft. Since the launch, the four trained mentors have supported seven young people, with most of these mentorships continuing into 2024/25.



The support I received in mentoring was incredible! I really appreciated being able to talk to someone who understood what I was going through. ...]
I have become much more confident when it comes to my cleft and a lot less worried about the future. [...] My Cleft++ mentor helped me feel so much less isolated than before.



COUNSELLING

Using student counsellors on placement, CLAPA provided structured, in-depth support to 13 people in need (ten adults, three parents) through a pilot of a new service which finished in October 2023. New student counsellors have been recruited and trained, ready for this to become a core service next year.

SUPPORTING PEOPLE TO ACCESS CLEFT CARE

CLAPA offers tailored, consistent support and information to those getting in touch with complex enquiries. This year, 84 people contacted CLAPA for support with a variety of concerns, the most common being about dental and orthodontic care (34%) or accessing specialist NHS cleft treatment (27%).



With thanks to the National Lottery Awards for All England and the Michael Josephson MBE Charity Ball for funding Cleft++, and the National Lottery Community Fund for supporting the our Counselling service this year.

UNDER 18S

SERVICES FOR CHILDREN AND YOUNG PEOPLE

For children and young people born with a cleft, connecting with others who look and sound like them is crucial to building self-esteem and knowledge so they can grow into adults who feel confident about their future.



If you or someone you know has a cleft, remember, you're not alone. CLAPA is a friendly club where everyone understands and supports each other. It has been amazing for my confidence.



A CYPC member in an article she wrote for the CLAPA website



CLAPA Christmas Social 2023



[CLAPA.COM/CYP](https://www.clapa.com/cyp)

CHILDREN & YOUNG PEOPLE'S COUNCIL (CYPC)

The CYPC is a group of 12-17-year-olds born with a cleft who took a key role in developing Cleft++ (pg. 9) and a new Pen Pals service launching next year. They contribute to articles, stories and suggestions to 'Cleft Youth' magazine and social media, and feature in content for Cleft Lip and Palate Awareness Week.

Their suggestions and feedback have fed into new resources around young people's surgery and getting braces. These young volunteers also hosted two 'Chat and Chill' events to support other young people, and shared their stories at a webinar for cleft health professionals.



ADULTS

SERVICES FOR ADULTS BORN WITH A CLEFT

Around 90,000 adults in the UK were born with a cleft. Many are unaware they can access specialist treatment on the NHS for ongoing issues, and those who try to get back into treatment often face barriers along the way. CLAPA provides research-driven resources and services to tackle the issues that matter the most to adults and help them feel in control of their cleft care.



EVENTS FOR ADULTS

Twelve 'CLAPA Lounge' support group events this year welcomed 97 attendees to talk about adult-specific topics hosted by trained volunteers. Adult volunteers also took part in Live Q&A Events and wellbeing events.

"I always enjoy meeting up with others like me, and sharing our experiences and just talking freely about stuff with no judgement. It's always nice when new people come along and you can hear about their situation and hopefully reassure them."

Adult who attended a CLAPA Lounge event

'RETURNING TO CLEFT CARE'

Over the year, CLAPA sent 'Returning to Cleft Care' packs to 84 adults and 430 further packs to NHS Cleft Teams for their patients. This pack answers common questions and includes helpful resources for adults hoping to return to NHS cleft treatment.

"It has made me feel a little more proud of who I am and helped me to see things differently."

Feedback from a recipient of the Returning to Cleft Care Guide



Special thanks to the National Lottery Reaching Communities Fund for funding our Adult Services for three years from July 2023

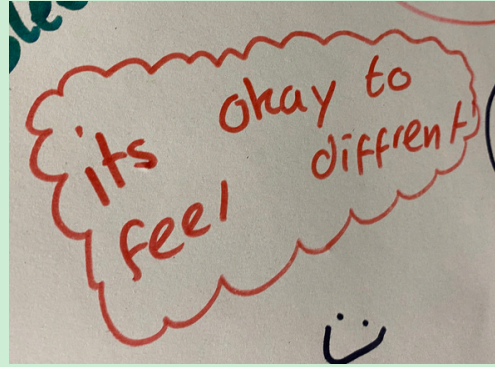


CAMP CLAPA

ADVENTURE WEEKENDS FOR CHILDREN AND YOUNG PEOPLE

Camp CLAPA Adventure Weekends (previously called 'Residential Weekends') take 8-15 year-olds born with a cleft on a two-night stay at an activity centre where they enjoy outdoor games, team-building activities like climbing and kayaking, and lots of time to share their experiences and make lifelong friendships. The weekends are supported by specially trained adult volunteers who were also born with a cleft and can act as supportive role models for young people.

In 2023, CLAPA ran three Residential Weekends in Doncaster, Milton Keynes and Stirling, welcoming 37 young people born with a cleft.



[At Camp CLAPA]

I know I'm safe to share my experiences without fear of being judged or them simply not understanding. Moreover, when I'm with other young people with a cleft, I automatically feel like I fit in.



Each Camp CLAPA Activity Weekend costs around £5,500

Special thanks to St. James' Place Charitable Trust, Walter Guinness Charitable Trust and the High Fraser Foundation for their support.



After the Camp CLAPA Weekends, parents and carers were asked if they noticed a positive difference in their child:

100%

Felt more positive about being born with a cleft



Knew others they could talk to about their cleft



Were more confident



Had learnt new skills



This made a hugely positive impact on our 11-year-old. He faced all sorts of situations that he would not have otherwise. His confidence was notably improved and we feel like this is a crucial time for confidence building [as he's about to] transition to senior school.



Scan to watch a special video thank-you message featuring footage from Camp CLAPA



THE ONLINE CLEFT

CONNECTING PEOPLE AFFECTED BY CLEFT IN THE UK

In a digital age, CLAPA's social media presence is critical in reaching the one-in-700 people born with a cleft and their families all around the UK. As well as forming the cornerstones of the 'cleft community', it helps us to promote our life-changing support services, raise awareness, celebrate accomplishments, and share stories from people affected by cleft.



@clapacommunity



 **1,921,665**

people reached by CLAPA's social media posts this year



6%

follower growth
across platforms



7%

engagement rate



+590

new members in our online support
groups for parents/carers and adults
born with a cleft

3,662

people interacted with the groups
each day by posting updates,
asking questions and supporting
each other



“I have also joined the CLAPA Adult Facebook group which is really helping. I have felt incredibly alone all these years and now I've found out there are safe spaces and people like me who go through the same situations and feelings it feels like I am part of something amazing with amazing people.”



COMMUNITY

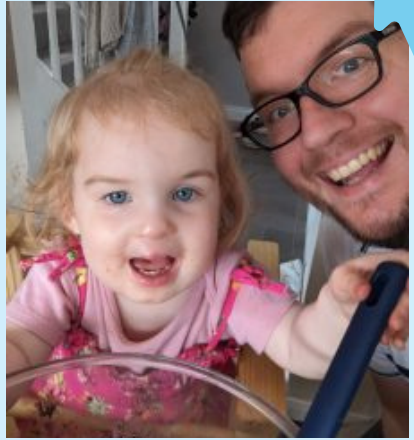
CLAPA.COM/STORIES



Oscar at 2 months

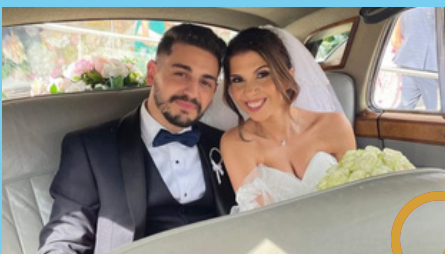


Oscar at 3 years



Matt shared his story to encourage other dads to reach out and get support through CLAPA.

Oscar's mum Ruby said, "If you've recently found out that your baby will be born with a cleft and you're feeling the same overwhelming feeling, please know that you've got this and everything really will be OK."



Just Married

CLAPA Volunteer Stavroulla was born with a cleft lip and palate. When she got married this year, she gave out CLAPA pin badges as wedding favours and shared her story online.



We shared nearly 100 photos of babies' first Christmas!

CLEFT RESEARCH

INVOLVING THE COMMUNITY IN RESEARCH PROJECTS

Even for those with lived experience, medical research into conditions like cleft can often feel inaccessible. CLAPA believes that everyone affected by cleft should have the chance to learn about current research and that opportunities to get involved should be available to all. We support research projects to recruit participants, gain feedback, and even run ongoing steering committees.



"[I have really enjoyed] being able to influence research programmes and seeing how my input makes a difference with cleft treatment."

Patient Representative taking part in a research consultation group



225



people on the dedicated 'CLAPA Voices' mailing list receiving invitations to take part in or give feedback on relevant research projects

95%



In CLAPA's Annual Survey, 95% agreed it was 'important for cleft researchers to get feedback about their projects from people affected by cleft'.

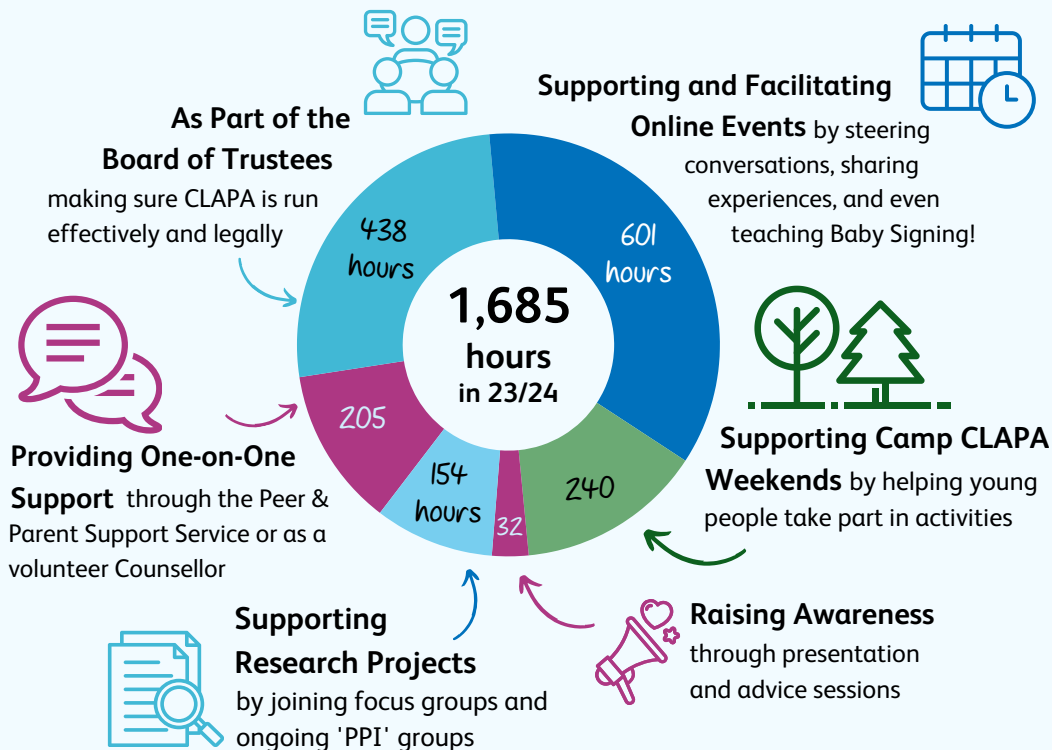
GUIDING NHS CLEFT SERVICE DEVELOPMENT

CLAPA now runs the Patient Engagement Group for NHS cleft services, ensuring the cleft community has a seat at the table when decisions are made about the future of cleft treatment. This year, the group has worked on important issues in cleft care such as self-referral for returning adult patients.

VOLUNTEERING

EMPOWERING THE CLEFT COMMUNITY

Volunteers and patient representatives are the backbone of CLAPA as a charity, and with digital-first service delivery, there are more opportunities than ever for volunteers to use their skills and experiences to support CLAPA's work. This year, volunteers and patient reps spent...



“Being born with a cleft lip and palate, CLAPA has been an integral part of my individual development of confidence in my appearance and experiences, as well as being a support to my parents when I was younger. Being a member of the CYPC was a really rewarding experience for me, as I found sharing my personal experiences helpful in raising awareness and supporting other young people.”

-Young CLAPA volunteer who supported a 'Camp CLAPA' adventure weekend

FUNDRAISING

OUR INCOME IN 2023/24

Donate to support our work



With no government or NHS funding, CLAPA relies on the UK cleft community as well as Charitable Trusts and Foundations to support our vital work.



In November, our wonderful Patrons and Ambassador took to social media to encourage donations to CLAPA's Big Give Appeal, which raised over £30,000!



Keiran celebrating after the Barcelona Marathon



Julia was one of 142 fundraisers who 'Stepped Up for CLAPA'



Chelmsford Golf Club chose CLAPA as Charity of the Year



Eight fundraisers donned tartan in the Kiltwalk



Valeri raised funds with sub-zero wild swims over the winter



Matt took on the London Landmarks Half Marathon

CHARITABLE TRUSTS & FOUNDATIONS

In 2023/24, 21 Charitable Trusts and Foundations donated to CLAPA's work.

- 29th May 1961 Charity
- The Anson Charitable Trust
- Awards For All
- Benefact Group (Ecclesiastical)
- The Boshier-Hinton Foundation
- The Croda Foundation
- The Clover Trust
- The D.C. Moncrieff Charitable Trust
- Edward Gostling Foundation
- G.M. Morrison Charitable Trust
- The Hamilton Wallace Trust
- The Highway One Trust
- The Hugh Fraser Foundation
- The Ian Askew Charitable Trust
- Joseph Strong Frazer Trust
- The Lillie Johnson Charitable Trust
- The Marsh Charitable Trust
- The Michael Josephson MBE Charity Ball
- The Misses Barrie Charitable Trust
- Nancy Roberts Charitable Trust
- The National Lottery Community Fund
- Ocado Foundation
- The Patrick & Helena Frost Foundation
- Rest-Harrow Trust
- The Reed Foundation
- Sir Jules Thorn Charitable Trust
- Smile Train USA
- Souter Charitable Trust
- Squire Patton Boggs Charitable Trust
- St James's Place Foundation
- The Swann-Morton Foundation
- Tesco Charity Trust Community Awards
- TK Maxx and Homesense Foundation Trust
- The Vassiliou Charitable Trusts
- The VTCT Foundation
- The Walter Guinness Charitable Trust



Figures in this report are unaudited. A set of full, audited accounts for the year 2023/24 will be available from October 2024 at CLAPA.com/finances

FOR EVERY £1 RAISED, CLAPA SPENDS...



69p on delivering and supporting services

like events, information, support, enabling research, and more

10p on our office, IT and phones

to keep our small team connected and run our feeding service

21p on fundraising

to ensure we have the money to run our services next year

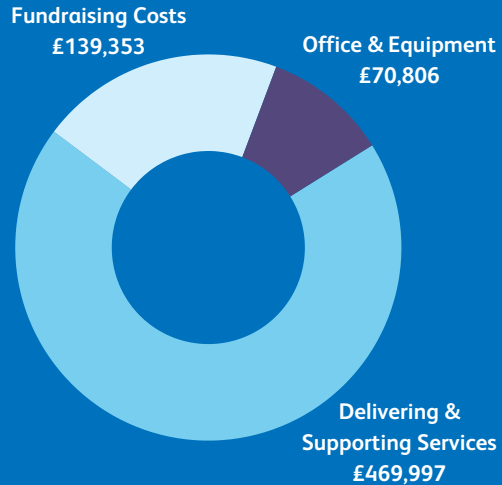
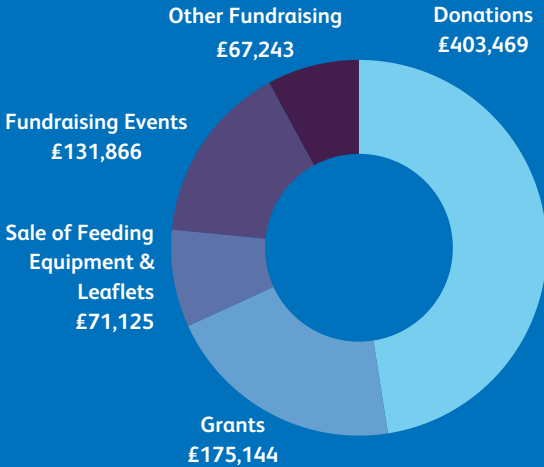


FINANCES

2023/24

INCOME: £851,028

EXPENDITURE: £680,155



The above figures are unaudited. Full audited accounts will be available from October 2024 at clapa.com/finances. Expenditure in this period included funds from grants received in the previous financial year. Unrestricted free reserves at the end of the year totalled £324k, or 5.7 months.

   @clapacommunity  www.clapa.com  info@clapa.com

 The Green House, 244-254 Cambridge Heath Road, LONDON, E2 9DA

Registered Charity in England and Wales (No. 1108160) and Scotland (SC041034). Company No. 5206298.