

Cleft Lip & Palate Association  
**Impact Report**

2022 - 2023



Registered with  
**FUNDRAISING  
REGULATOR**

**CLAPA**   
Cleft Lip & Palate Association



# ABOUT CLAPA

THE CLEFT LIP AND PALATE ASSOCIATION



CLAPA is the national charity for people affected by cleft lip and palate in the United Kingdom.

We support people to take control of their cleft journey, connect with others, and use their voices to impact the future of care.

Our vision is that no one affected by cleft lip and palate in the United Kingdom will go through their journey alone.



## CLAPA IN 2022/23

"I am delighted to introduce this latest Impact Report, a snapshot of how CLAPA has changed lives and connected communities in 2022/23. In April, our new vision proudly proclaimed that 'no one affected by cleft in the UK will go through their journey alone', and with our social media posts reaching over 2 million people this year, this future feels brighter than ever.

"Our 52 online events welcomed 763 attendees from all over the UK to share their experiences, learn new skills, and find their 'cleft community'. 'Residential Weekends' returned, with 43 young people given a transformative time away. A pilot counselling service helped 11 adults to better cope with having a cleft. We shared nearly 40 opportunities to help shape the future of cleft care and support. And so much more!

"To all of our dedicated volunteers, fundraisers and donors, I truly hope you enjoy reading about the difference your kindness and generosity has made this year."



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 Cleft 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.



IN 2022/23 



726 Welcome Packs  
sent to new families



11,457 bottles and  
teats sent out



162 extra items for  
vulnerable families

"We were given some CLAPA 'Dr Browns' bottles when our son was born. He took to them straight away, and it meant he fed really well despite his cleft. The specialist bottles look just like normal bottles, not like a specialist feeding device. They are quite pricey to buy so we are ever so grateful that we got some funded by CLAPA."

Family who received a CLAPA Welcome Pack

Each  
Welcome Pack  
costs CLAPA

£50



# 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. At times like this, having someone on hand who truly understands what you're going through can make all the difference.

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



matched with a Peer or Parent Supporter

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

“Support came quickly, post-diagnosis as the moment most in need of support. [Our Supporter] gave us lots of background on her experience and made us feel less alone, provided better understanding of the day-to-day challenges and how her family dealt with them. She was sweet caring and genuine, a real support in time of need.”

The quote is enclosed in a light blue rounded rectangle with a white border. There are decorative icons of speech bubbles and a paper airplane at the corners.

Parent giving feedback on this service

Each Match Costs  
CLAPA  
£315

A purple price tag with a white outline and a white ring at the top. The text is in white.

Each Information Enquiry costs  
£90

A light blue price tag with a white outline and a white ring at the top. The text is in white.





## PILOT PROJECT: COUNSELLING

This year, CLAPA welcomed two volunteer student counsellors who used their time on placement to provide structured, in-depth support to the cleft community.

Both student counsellors were born with a cleft and received training and support from CLAPA alongside clinical supervision

FROM JULY - MARCH



11 People



57 Hours



"The client [...] presented with issues with self-esteem, depression and anxiety, which she felt was a result of being born with a cleft lip and palate. Using a clinical scoring measure (CORE-10) her initial score was 25, which suggests severe levels of distress.

"After completing a number of counselling sessions, she has now scored herself a '7' which is a low level of distress and pretty much the opposite end of the scale! Goal-wise, she had met all of the original ones she set for herself bar one, which she feels she is on her way to achieving."

Report on a referral to the service from a clinical supervisor

## SUPPORTING PEOPLE TO ACCESS CLEFT CARE

CLAPA's Advocacy Service offers tailored support and information to the cleft community to help them access NHS and other services. This year, the key themes from adults born with a cleft were about returning to cleft treatment and accessing NHS care for complex dental issues. For parents and carers, enquiries mostly concerned surgery, ongoing delays to their child's cleft treatment and private healthcare.



"When we contacted CLAPA we found more than just a sympathetic ear; they provided expert advice on the options available to us and also had really useful insights [...] We are eternally grateful for the work of CLAPA, and we don't know how we would have navigated this difficult period without them."

Parent using the Advocacy Service



# ONLINE EVENTS

BRINGING THE CLEFT COMMUNITY TOGETHER

CLAPA's online events allow people at all stages of their journey to share their experiences, receive practical advice, and find their 'cleft community'. The formats and topics of these events are led by feedback and surveys to ensure they continue to be relevant and engaging.

In 2022/23, a strong focus on improving procedures and training meant more events could be hosted by volunteers with personal experience of cleft who could use their knowledge to steer the conversation and create meaningful connections with attendees. This year, volunteers spent over 100 more hours supporting CLAPA's events than the previous year!

52



Online Events such as support groups, skill workshops, family events, and wellbeing events.

763

Attendees

63%



Came to more than one event

2

Live Q&As on Dental Hygiene and Bullying

521



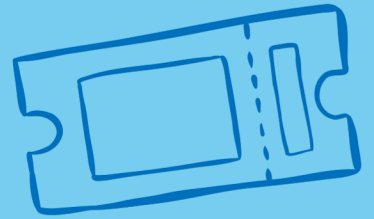
Watchers during and after



"The practical, straightforward advice given by the Speech & Language Therapists will make a real difference to how I support my baby's speech development."



Baby Signing Workshop



Across all areas, these events scored an average of 4.3 out of 5

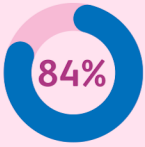
**AFTER THIS EVENT, I FEEL...**



More connected with others in the cleft community



More confident about coping with cleft-related challenges



More positive about my connection to cleft



More knowledgeable about the topic of the event



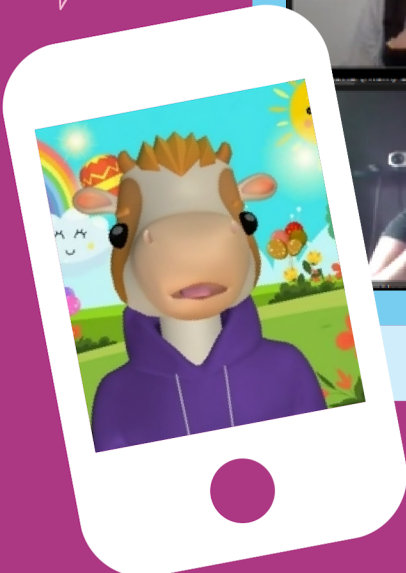
"[The Adults'] group really helps in actually getting me to talk about my cleft journey in a comfortable environment. [Hearing] others' experiences and sharing information is so valuable."

Adult after a 'CLAPA Lounge'



"I got so much more than I was expecting. Just listening to the volunteer's experiences and having our questions answered was a huge help. Everyone was so friendly and supportive as well. Just having a platform where we could talk about it was so helpful."

Parent who came to a 'Coffee Club'



Nursery rhyme 'Sing and Sign' event

Each Event Place Costs CLAPA  
**£42**

A 'Coffee Club' Support Group Costs CLAPA  
**£600**



# SOCIAL MEDIA

## BUILDING AN ONLINE CLEFT COMMUNITY

In this 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 services, raise awareness, and celebrate accomplishments.



# 2,098,099

people reached by CLAPA's social media posts this year



# 13%

follower growth  
across platforms



+1,104



+1,119

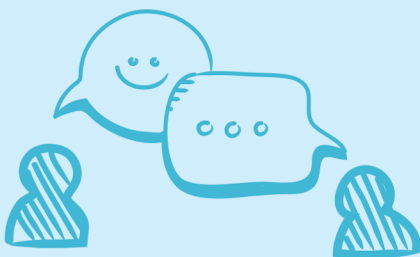


+306



# 8%

of people who saw a post  
commented, liked or shared



## FACEBOOK SUPPORT GROUPS

CLAPA's online support groups for parents/carers and adults born with a cleft gained 616 new members in 2022/23. An average of 3,395 members actively visited the group daily to post updates, ask questions and support each other.



"I have never met anyone else with a cleft in real life, but seeing your posts with the beautiful photos and amazing stories from people with cleft makes me feel so 'normal'! It's nice that you have adults too because I never see people who look like me. It's incredible to have this whole community in my pocket, it makes me proud to tell people I'm part of an exclusive 'one in 700' club!"

Message received in July 2022

## STORIES SHARED

118 people submitted their stories and photos to be shared with the cleft community on social media on CLAPA's social media channels.



### PUPPY LOVE

Marley (aged 11) was born with a cleft. When his family dog had a puppy with a cleft just like his, Marley adopted the puppy as his own.



### MISS SCOTLAND

Lauren, a 2022 Miss Scotland finalist, selected CLAPA as her chosen charity and visited the Cleft Team in Glasgow to raise awareness.



### ELLIE'S STORY

Phoebe was born with a unilateral cleft lip and palate. Mum Ellie says, "I have been so lucky to have made many lovely friends through [CLAPA's] community. We love seeing our babies develop, supporting one another through those big milestones, offering advice around surgery time, and sharing ideas for feeding, scar care, and anything related."





# CLEFT RESEARCH

## INVOLVING THE COMMUNITY IN RESEARCH PROJECTS

For cleft researchers, CLAPA acts as the gateway to the cleft community, supporting projects by recruiting participants and arranging 'Patient and Public Involvement' (PPI) opportunities. These opportunities can range from simple feedback forms about an information leaflet to CLAPA running a steering committee of people affected by cleft for an ongoing project.



128

people on the dedicated 'CLAPA Voices' mailing list



38 opportunities shared

28 from external projects  
10 from CLAPA



131

21/22

245

22/23

Hours spent by patient and parent reps on PPI activities

7

ongoing PPI groups for large projects such as the Cleft Collective and SLUMBERS II

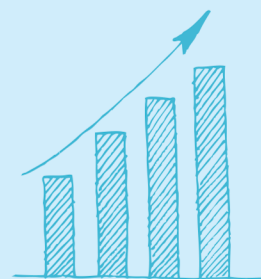
55

group members (made up of 43 individuals as some sit on multiple groups)



Researcher who used CLAPA Voices

"CLAPA have been incredibly helpful and supportive in promoting our research. Through their assistance, our research team have been able to recruit members of the cleft community for our study with ease. I would highly recommend CLAPA's consulting services to fellow researchers."



95%

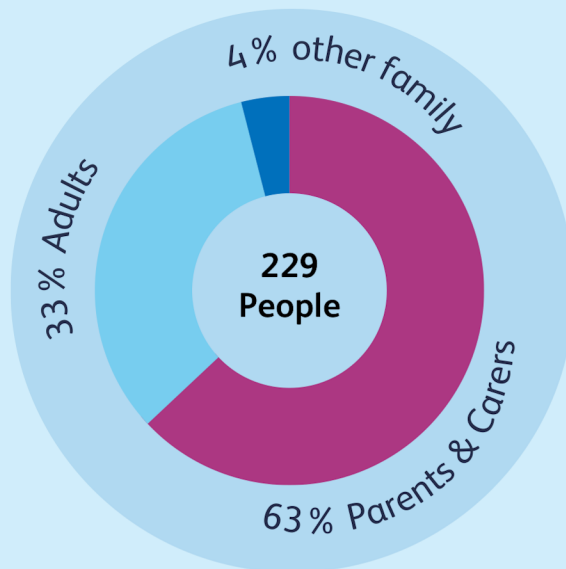
In CLAPA's Annual Survey, 95% agreed it was 'important for cleft researchers to get feedback about their projects from people affected by cleft'.


# ANNUAL SURVEY


TAKING THE PULSE OF THE CLEFT COMMUNITY




One of many ways CLAPA gathers feedback to help shape its plans for the future is through an Annual Survey which provides a snapshot of the cleft community's needs, priorities and concerns.

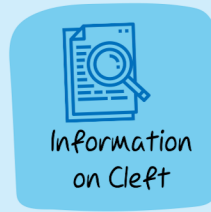


**15%**  had a disability or long-term health condition (not cleft)

**13%**  said their household was in financial hardship

**86%**  agreed CLAPA values accessibility, inclusion and diversity

## YOUR MOST-VALUED CLAPA SERVICES



## YOUR TOP CONCERNS

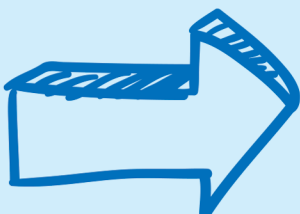
We asked respondents what their top concerns were surrounding their or their child's cleft and cleft care

### PARENTS & CARERS

- Ongoing impact of the pandemic on cleft care
- Lack of awareness amongst teachers and health professionals
- Supporting children when starting or changing schools

### ADULTS BORN WITH A CLEFT

- Lack of affordable, accessible dental care
- Long delays in accessing adult cleft care
- Lack of knowledge and sensitivity from generic health professionals



Full results are available on the CLAPA website [clapa.com/surveys](http://clapa.com/surveys)  
These results directly feed into CLAPA's plans for the next 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. This year, we continued with our '**Children and Young People's Plan**' in consultation with our community.

## CHILDREN & YOUNG PEOPLE'S COUNCIL (CYPC)

This year, CLAPA's focus group of 12-17-year-olds born with a cleft helped to create and launch Cleft Youth, contributed to lots of content for CLAPA's social channels and leaflets and gave feedback on several research projects.

“It was really nice to meet people who had been through the same experiences as me. It was also good to be able to pass on my experiences to younger members who were about have their bone graft operations. [...] Being involved in the CYPC has boosted my confidence in talking about my cleft and the experiences associated with it.”

A new member of the CYPC reflecting on their experiences in July 2022



## CHILDREN & YOUNG PEOPLE'S PLAN (2022-25)

### What do we want?

A world where young people feel confident and positive about having a cleft

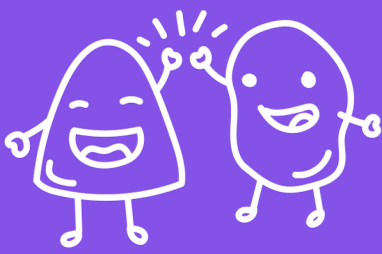
### How will we get there?

Bring young people together to build confidence and increase self-esteem; create community-led resources aimed at young people around three key milestones:

- Bone graft
- Changing schools
- Jaw surgery

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





# CLEFT YOUTH

A new 'Cleft Youth' brand was launched in 2022 to reach more under-18s born with a cleft with content created 'by and for' them. Instagram channel @CleftYouth is aimed at 13-17-year-olds, while a hard copy magazine is aimed at 5-12-year-olds. The content features stories, facts and engaging, accessible advice from other young people.



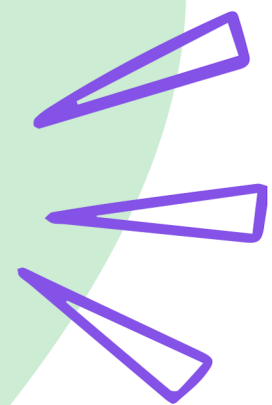
@CLEFTYOUTH



FRIENDS  
SMILE  
CLAPA

KIND  
BRAVE  
CARING

CLEFT  
PALATE  
GOAL





# WEEKENDS AWAY

RESIDENTIAL WEEKENDS FOR CHILDREN AND YOUNG PEOPLE

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. In 2022, CLAPA ran four Residential Weekends in Buckinghamshire, Yorkshire and Perthshire, welcoming 43 young people born with a cleft.

“It was very special because everybody was born with a cleft like me.

“I had an operation the week after the Residential and it was really nice to see other children who have operations. I made three really good friends.”

“[My daughter] was really uncertain about going away, meeting other children with clefts and just wasn't sure she would enjoy herself. She came home asking to go again in future. She has benefited from talking to others who have experienced similar things to her, e.g. operations, dealing with bullying. It's given her the confidence to stand up for herself and challenge others when they've been cruel. The change in [her] confidence has been great to see.”

After the Residential Weekends, parents and carers were asked if they noticed a positive difference in their child.

73%



Felt more positive about being born with a cleft

63%



Were more confident

67%



Knew others they could talk to about being born with a cleft

70%



Had learnt new skills

A young person who attended a Residential Weekend in May 2022

A parent whose child attended a CLAPA Residential Weekend in October 2022



Each Place on  
a Residential  
Weekend Costs

CLAPA  
**£360**



TRA 400





# ADULTS

## SERVICES FOR ADULTS BORN WITH A CLEFT

Around 90,000 adults in the UK were born with a cleft. They often face barriers when returning to cleft treatment, and many aren't even aware it's an option. CLAPA provides resources and services driven by research and community input to help adults born with a cleft feel in control of their cleft care.

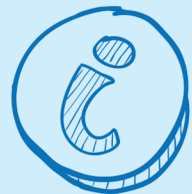
Four 'CLAPA Lounge' events aimed at adults took place over the year, welcoming record numbers of attendees coming to their first-ever CLAPA event. The Adults' Focus Group continued to meet regularly to give feedback on various areas of service and resource design as well as wider policy.

Nathan shared his story on our website



"The support from CLAPA has given me hope - thank you so much. I've contacted a cleft care team directly, had an appointment with my GP and got the referral done, plus I've made contact to get peer support too. I have also told my boss at work - only the second person outside of family that I have spoken to about my cleft in 30 years!"

Over the year, CLAPA sent 'Returning to Cleft Care' packs to 94 adults and 270 further packs to NHS Cleft Teams to distribute to the patients leaving their care.



Feedback: "After receiving a 'Returning to Cleft Care' guide, I feel more confident about..."

93%

accessing treatment

80%

talking to friends and family about cleft

71%

talking to my GP or Dentist about cleft

100%

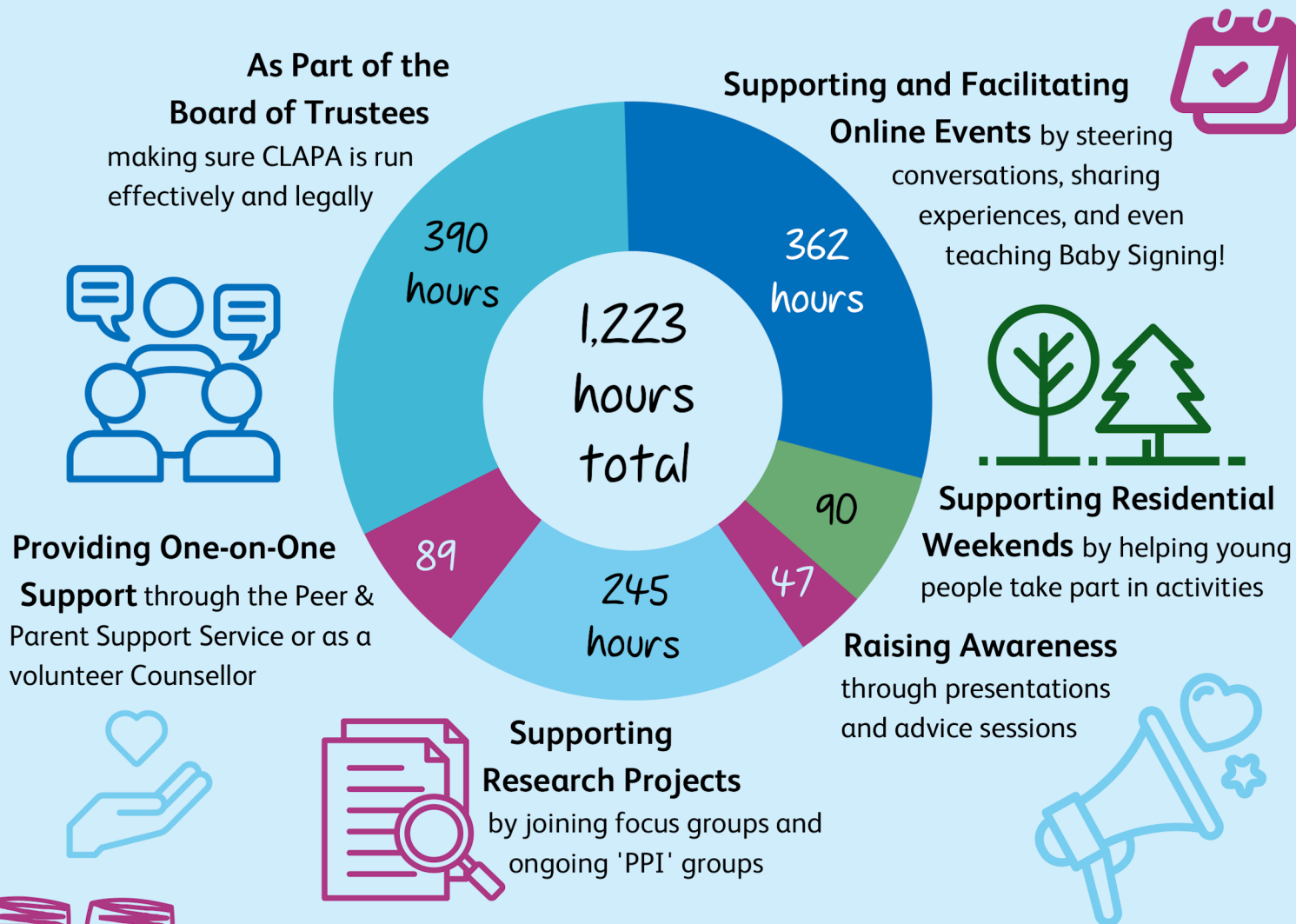
accessing support from CLAPA

# VOLUNTEERS

EMPOWERING THE CLEFT COMMUNITY



Volunteers 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...



"I have recently [volunteered with] the Baby Sign classes, Antenatal Support Group, and listening in and supporting my son with his CYPC work. I want to make a positive impact to families going through similar circumstances to my own, and especially to families at the start of their cleft journeys.

"It is really rewarding to get feedback from parents and have a sense of making a positive difference to someone's life. CLAPA supports their volunteers really well - with regular contact and celebrating our involvement. It has been a really beneficial experience, both personally and professionally."



# FUNDRAISING

OUR INCOME IN 2022/23

With no government or NHS funding, CLAPA relies on the the UK cleft community as well as Charitable Trusts and Foundations to support our vital work. In 2022/23:



**66%**

of our donations came through online platforms like JustGiving



**45%**

of donors were making their first donation to CLAPA



**33%**

of 'challenge event' income came from marathons



**£65k**

donated to our #SaveCLAPA appeal by individuals



**292**

new people joined 'CLAPA Champions' by signing up to give regular donations

**£64k**

donated by regular givers - nearly £20k more than the previous year!

## CHARITABLE TRUSTS & FOUNDATIONS

In 2022/23, 21 Charitable Trusts and Foundations donated to CLAPA's work.

- The Anson Charitable Trust
- The Clover Trust
- The D.C. Moncrieff Charitable Trust
- The D'Oyly Carte Charitable Trust
- Ecclesiastical (Benefact group)
- Fat Face Foundation
- G.M. Morrison Charitable Trust
- Highway One Trust
- The Hospital Saturday Fund
- Joseph Strong Frazer Trust
- The Lillie C. Johnson Charitable Trust
- Maximus Foundation UK
- The Misses Barrie Charitable Trust
- National Lottery Awards for All England
- The Patrick & Helena Frost Foundation
- Roger and Douglas Turner Charitable Trust
- Sir Jules Thorn Charitable Trust
- SmileTrain
- TK Maxx and Homesense Foundation
- The Vassiliou Charitable Trusts
- The VTCT Foundation

Figures in this report are unaudited. A set of full, audited accounts for the year 2022/23 will be available from October 2023 at [clapa.com/finances](https://clapa.com/finances)

## FUNDRAISING STORIES

Budding artist, Stanley, aged eight, designed his own Christmas cards to raise money for CLAPA. With his mum's help, he sold 78 cards through his Instagram @stansmithart.



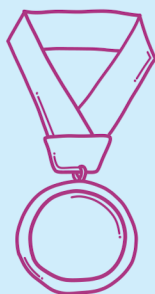
### In Memory: Tunes4Will

Will was a young CLAPA volunteer and fundraiser who tragically lost his life in May 2022. Will's parents organised a 24hr DJing marathon which raised an incredible £20k for CLAPA. The funds will help support a project in Will's memory.

Jonathan and Kenny cycled 140 miles to raise funds for CLAPA after Jonathan's granddaughter was born with a cleft lip and palate.



Lil, aged six, completed the Mini Great North Run



## #SaveCLAPA

After a tough few months, the #SaveCLAPA Appeal launched in October with an inspiring call to action to rally the cleft community to support our life-changing work. The appeal saw instant success, raising over £100,000 by January, putting CLAPA back on track! It also kickstarted rapid development in CLAPA's fundraising practices and platforms, work which will continue in our new three-year Income Generation Strategy.

## FOR EVERY £1 RAISED, WE SPEND...



**67p on delivering and supporting services**  
like events, advocacy, research support and more

**10p on our office, IT and phones**  
to keep our small team connected and run our feeding service

**23p on fundraising**  
to ensure we have the money to run our services next year



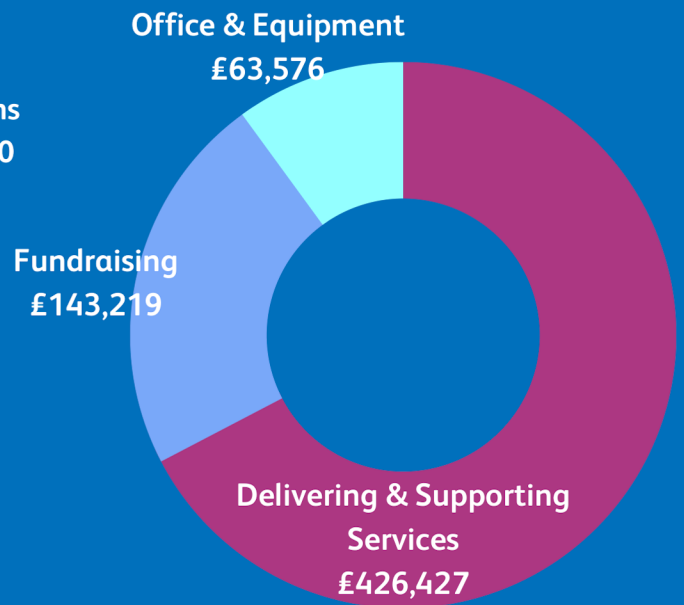
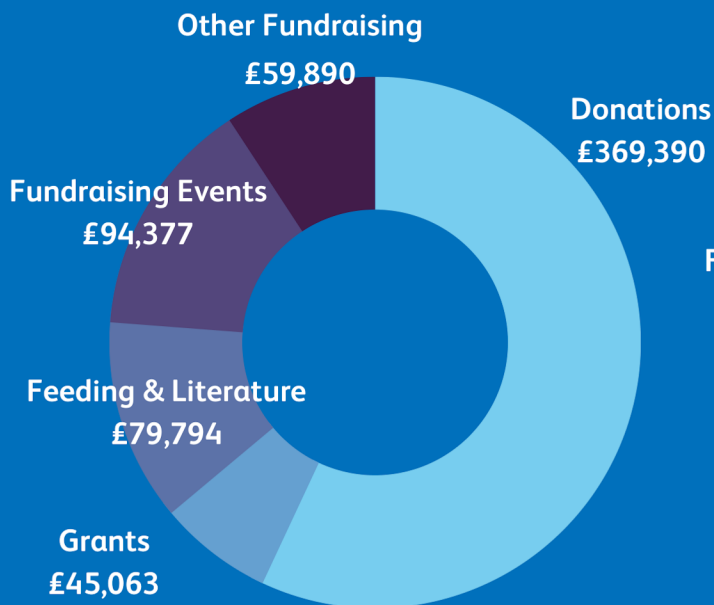


# FINANCES

## 2022/23

**INCOME: £648,624**

**EXPENDITURE: £633,222**



The above figures are unaudited. Full audited accounts will be available from October 2023 at [clapa.com/finances](http://clapa.com/finances). Expenditure in this period included funds from grants received in the previous financial year such as COVID resilience grants. Reserves at the end of the year totalled £224k, or 4.7 months.




 @clapacommunity
 
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