

Cleft Lip and Palate Association

Impact Report

2021 - 2022



CLAPA 
Cleft Lip & Palate Association

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

CLAPA'S IMPACT

2021-22

OUR VISION

No one affected by cleft lip and palate in the United Kingdom will go through their journey alone.

OUR PURPOSE

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 journey, connect with others, and use their voices to impact the future of care.

CLAPA IN 2021-2022

During the global pandemic, we had to rethink and reimagine how we could continue to serve our community across the UK in a meaningful way.

After a great deal of experimentation and learning, a new one-year digital-first strategy was launched in March 2021. This strategy aimed to redevelop CLAPA's digital presence, expand our online events programme, and provide crucial resourcing to two key areas of service delivery: advocacy and research involvement. This strategy launch coincided with a significant staff restructure to enable faster and more purposeful development of services.

What followed was a year where, despite ongoing disruption, CLAPA grew into a more focused, flexible organisation which is far better placed to deal with the challenges of a changing world.

We are immensely proud of all we have achieved in 2021/22 and the foundation this has created for our work over the next few years. To learn more about our future plans, visit clapa.com/strategy.



CLAPA'S TEAM

CLAPA has a team of 15 staff based all around the United Kingdom. Most of our staff are part-time, working 2-4 days per week.

We have a small office in London which is mostly used to run the feeding service.



BOARD OF TRUSTEES

Our Board of Trustees is made up of 12 volunteers. These include 6 parents of children born with a cleft, 2 adults born with a cleft, and 4 current or former NHS Cleft Team Clinicians. They use their skills and experience to work closely with CLAPA's senior staff to make sure the charity is run well.

BOTTLES & TEATS

FEEDING BABIES BORN WITH A CLEFT IN THE UK



FEEDING SERVICE

Many babies born with a cleft are unable to breastfeed or use regular feeding equipment. For over 30 years, CLAPA's feeding service has supplied specialist bottles and teats to new parents and carers so they can feed their babies. We are the only UK supplier of this feeding equipment, some of which are manufactured specifically for us.

As well as free 'Welcome Packs' sent to new families, we provide additional free-of-charge equipment to families in need who are referred by an NHS Cleft Nurse Specialist. Rising costs are making this service increasingly difficult to run, but we are determined to ensure there are affordable options for all 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."

Parent of a child born with a cleft,
August 2021



733 Welcome Packs of bottles and teats sent to new families



10,671 bottles and teats sent to families



115 extra items sent free of charge to vulnerable families

CONNECTION

BRINGING THE UK CLEFT COMMUNITY TOGETHER

ONLINE EVENTS

Regular events allow people to talk about their experiences and worries and hear from others at all stages of the cleft journey. In 2021/22, we hosted:

59 Events on Zoom, including support groups, skill workshops, family fun events, and wellbeing events.

1,049 Attendees from the cleft community



These events gained an average score of 4.3 out of 5



83% Of respondents saying these events helped them feel more connected with others in the cleft community



94% Said these events helped them feel more positive about their ability to cope with cleft-related challenges in the future



"My son was born with a cleft lip and palate, and I have received so much support antenatally and post-birth. From meeting other parents to sharing advice it has been an invaluable asset for us. CLAPA ran a 6-week BSL course for infants. The classes were engaging and really set the foundation for some of the signing we use day to day. As my son has hearing and speech issues associated with his cleft, learning the BSL basics have resulted in us being able to communicate."

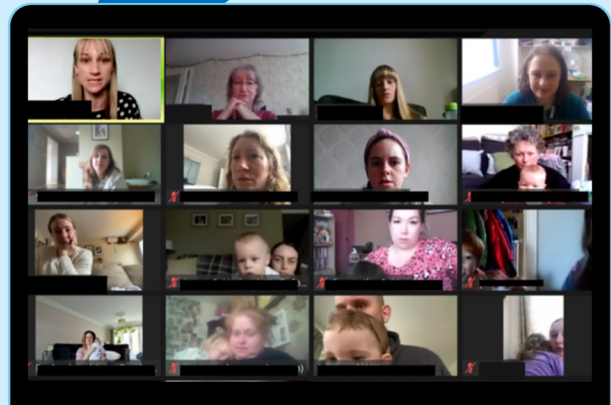
Parent at a 'Baby Signing' session

10 Facebook Live Q&As on topics from dentistry to hearing and glue ear.

925 Watchers online

"The interesting information and openness of the participants. Everyone was so caring. It was very emotional hearing people's experiences and concerns [...] The attitude of everyone present was so caring and heartfelt. It was amazing."

Adult at a 'CLAPA Lounge'



"This charity is a vital service for all parents and those cleft affected. When there are so many restrictions an online community is essential to promote and share good practice, promote positive mental health and reduce the feeling of isolation."

Parent after a 'Dealing with Diagnosis' Support Group

SOCIAL MEDIA

Channels like Facebook, Twitter and Instagram are some of CLAPA's primary tools for reaching people affected by cleft in the UK. Through social media, we promote services, raise awareness and spread our messages. CLAPA's reach on social media is the highest for any cleft support charity worldwide.

In 2021/22, followers on CLAPA's accounts grew by 6% across the board, and there were nearly 170k engagements (reactions, shares and comments) on posts throughout the year. Throughout the year, our posts reached 1.65 million people.

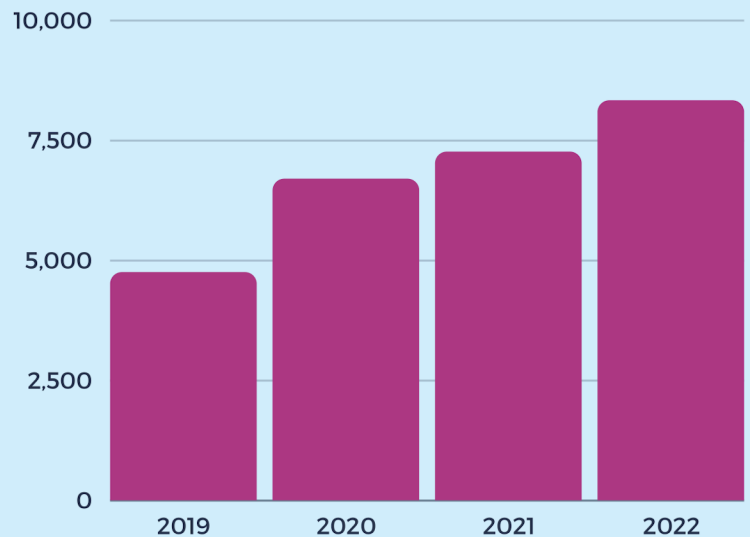
SUPPORT GROUPS

CLAPA's online support groups for parents/carers and adults born with a cleft gained 396 new members in 2021/22. An average of 3,500 members actively visited the group daily to post updates, ask questions, support each other with comments, or just check-in.

STORIES SHARED

Over 100 people submitted their stories and photos to be shared with the community on social media.

DAILY REACH ON SOCIAL MEDIA



"Without [CLAPA's] help and support from the first day of our little boy's life, who knows where we'd be? When we were worried sick and confused, not knowing why and what the future held, you were there. Words cannot express how much your work is valued!"

Comment left on a CLAPA post



CLAPA prides itself on involving the UK cleft community at all levels of its work, including asking volunteers to feed into and help run services wherever possible. This year, volunteers gave up 236 hours of their time to support and host online events.

"I volunteer for CLAPA because I want to give back after all the amazing support I've received myself over the years. [...] CLAPA has helped me to feel proud of having a cleft, and I want to be able to help them make others feel the same."

REASSURANCE

HELPING PEOPLE COPE WITH CLEFT-RELATED CHALLENGES

"I honestly cannot thank [...] CLAPA enough for the positive support I've received. [...] CLAPA have enabled me to reach out to other mums across the UK and not feel so alone. I can't tell you how much that has helped me in what I look back on as such a sad time in my life - only weeks ago! Something I never expected when I thought about having my first baby. I'll be forever grateful."

New parent receiving support in 2021



ONE-TO-ONE SUPPORT

CLAPA's Parent and Peer Support Service provides confidential one-to-one support to people affected by cleft, delivered by trained volunteers. Their lived experience and knowledge of the cleft care pathway can reassure those in need that they can cope with whatever lies ahead.

"[My Supporter] has just been wonderful. I really appreciated her guidance and advice. [...] I honestly couldn't recommend this enough. It made such a difference in the first few weeks following diagnosis."

Expectant parent receiving support in 2021

ADVOCACY

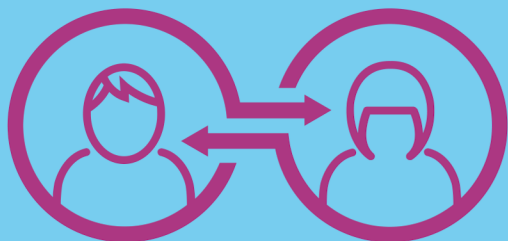
Our Advocacy Service ensures people getting in touch with questions and concerns get the expert help they need. With the pandemic's devastating impact on the NHS causing ongoing uncertainty and delays for cleft patients and their families, this service has had a busy first year!

"We found CLAPA to be highly influential and after their engagement with our local NHS team an action plan was developed which finally delivered overdue surgery for 20 or more children including our son. We are eternally grateful for the work of CLAPA and we don't know how we would have navigated this difficult period without them."

Family who contacted CLAPA in 2021

PARENT & PEER
SUPPORT
SERVICE

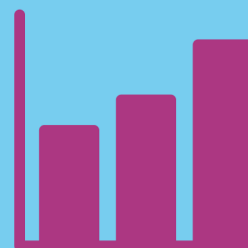
73 Enquiries led to
39 Matches



100% of the people giving feedback said the service made them feel:

- Less isolated
- More positive
- More confident

in coping with the concern they got in touch about



CLAPA VOICES

INVOLVING THE COMMUNITY IN CLEFT RESEARCH

RESEARCH

CLAPA believes it is vital for people affected by cleft to have a say in cleft research. We also believe that everyone should have the chance to use their lived experiences to positively impact the future of cleft care.

We provide a consultancy service for researchers which connects their work with the cleft community and promotes the patient voice at all levels. In 2021/22, our new structure saw this service getting the resourcing it needs, and some exciting leaps forward have been made.

'CLAPA Voices' was launched in the summer of 2021 to help connect people affected by cleft with research. Just over 100 people joined last year, and 22 opportunities were shared, including four opportunities created by the CLAPA Staff team to gather feedback on initiatives and policy changes within the charity.



22 opportunities shared

18 external research

4 internal surveys

41 people from the cleft community volunteered in PPI Groups

131 Volunteer hours spent

In the past year, CLAPA supported 41 people from the cleft community to spend 131 hours volunteering in 'Patient and Public Involvement' (PPI) groups for projects and organisations such as SLUMBRIS II, the Cleft Development Group, Cleft Care Scotland, and more. Twenty-four others attended one-off focus groups to help researchers by giving valuable feedback about their studies.

"It's a privilege to be involved in something like this, and it was quite simply inspiring to see how engaged everyone was. Both [facilitators] made clear that [the researchers] really heard, not only the points made, but the bigger picture for each contributor. That's so validating."

Participant in a research consultation group organised by CLAPA



"CLAPA have been invaluable in helping our research to reach the wider cleft community. Their enthusiastic support in sharing information about our research has contributed significantly to our research's recruitment and I would hope that their consultancy will be able to help shape the research activity of my team and wider colleagues in the future."

Researcher who used CLAPA Voices

UNDER-18S

SERVICES FOR CHILDREN AND YOUNG PEOPLE

This year, a significant focus was on better understanding the needs of children and young people in a changing world and evaluating what CLAPA's response to this should be.

This resulted in the creation of a Children and Young People's Plan for the next few years, which has a vision of a world where young people feel confident and positive about having a cleft.

CHILDREN AND YOUNG PEOPLE'S COUNCIL (CYPC)

CLAPA's Children and Young People's Council (CYPC) are a group of 12 to 17-year-olds born with a cleft who meet regularly to help us better support others like them. In 2021/22, the CYPC:

- Helped to create the Young People's Plan
- Created content for the CLAPA website and social media and newsletters, including for Children's Mental Health Week and Cleft Awareness Week.
- Helped design a CLAPA survey suitable for young people alongside the main Summer Survey
- Improved the process for recruiting new CYPC members and made some changes to how the CYPC was run
- Gave feedback on research projects, including FaceIt
- Put together tips for other young people having Bone Graft surgery
- Hosted events for other young people in the cleft community



ONLINE EVENTS

Online events for young people this year included an online quiz hosted by the Children & Young People's Council, a Summer Social, and a workshop on 'Confidence, Empowerment and Being Me'.



Since its inception, many CYPC members have now grown into young adults who look back fondly on their time with the group and the friendships they made with other young people born with a cleft. Recently, some former members met up and shared this photo with us.

They said: "We had a good catch-up and talked about upcoming things in our lives, both cleft related and non-cleft related. It was so nice to meet everyone again after almost 2 years and just have fun together!"



ADULTS

SERVICES FOR ADULTS BORN WITH A CLEFT

The VTCT-funded Adult Services Project, launched in 2019, was left with an underspend due to the pandemic. This past year has seen this funding put to good use to meet the new and emerging needs of adults born with a cleft in the UK.

"As a 56 year old, discharged from cleft care at 21 I thought this was what I had to live with for the rest of my life, and I am struggling big time. The support from CLAPA has given me hope - thank you so much.

"I have contacted my GP about further treatment. 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!"

Feedback from an adult after receiving the Leavers' Pack



RETURNING TO CLEFT CARE

The 'Returning to Cleft Care' guide for adults was given a refresh and is now regularly requested by Cleft Teams around the UK to give to those leaving cleft services. This year, the guide was put online at clapa.com/adults to make it easier to access.



ONLINE EVENTS

Several new online events for adults were run with the help of volunteers. These included a Christmas social and a new 'CLAPA Lounge' event type which brings adults together to share experiences around specific topics.

After suggestions from the cleft community, volunteers ran a 4-part webinar around different aspects of employment for those with a visible difference or with other cleft-related concerns.

"It was lovely to be with such a caring group of people. A very informative get-together. I look forward to catching up again at the next CLAPA Lounge."

Adult who attended a CLAPA Lounge

ADULTS' FOCUS GROUP

To ensure that the voices of adults continued to be represented when planning and running this work, an Adults' Focus Group was created. This group have since met regularly to discuss adult services and wider policy, and will be instrumental in the coming years as we continue to work to implement the findings of the 'Whole of Life' survey.

FUNDRAISING

OUR INCOME IN 2021/22

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



£7,320

more was donated by regular donors this year than the year before. For the first time, the average annual commitment for regular donors rose over £100.

+150%



Thanks to the popularity of Step Up for CLAPA, income from walking events increased by 150% this year, with 125 people lacing up their walking boots



82%

of our donations came through online platforms like JustGiving



207

people joined #TeamCLAPA by taking on a challenge like a marathon or trek. They raised an average of £357 each

f 533

people started Facebook Fundraisers, which raised £35,594 over the year



£55,384

raised by fundraisers on JustGiving

CHARITABLE TRUSTS & FOUNDATIONS

In 2021/22, 18 Charitable Trusts and Foundations donated to CLAPA's work. Our sincere thanks go to:

- 29th May 1961 Charitable Trust
- Anson Charitable Trust
- BBC Children in Need
- Boshier-Hinton Foundation
- Clover Trust
- Dyers' Company Charitable Trust
- Earl Fitzwilliam Charitable Trust
- Edward Gostling Foundation
- Four Acre Trust
- Fuellers Charitable Trust Fund
- G.M. Morrison Charitable Trust
- Joseph Strong Frazer Trust
- Lillie Johnson Charitable Trust
- Marsh Charitable Trust
- N Smith Charitable Settlement
- Patrick & Helena Frost Foundation
- Pears Foundation/DCMS
- Smile Train USA

Full audited accounts for the year 2021/22 are available at clapa.com/finances

FUNDRAISING

STORIES FROM THE CLEFT COMMUNITY

Oscar and brother Josh took part in a cross-country motorbike trial event to raise money for CLAPA.

Mum Claire said, "Oscar was born with a unilateral cleft lip and palate and CLAPA have supported us as a family for 9 years now. When we had the diagnoses at our 20 week scan we didn't know what to expect. CLAPA gave us support and helped us understand what to expect when Oscar arrived. The support carried on through parent groups and events where Oscar could meet other children and we could meet other families going through the same experience as us."



Oscar's Motorbike Trial

13-year-old Ellie wanted to raise money for CLAPA so she could help other children like her who were born with a cleft lip and palate.

Ellie decided to do something extraordinary and has managed to raise just over £400 by shaving off her hair!



Ellie's Head Shave

Andy took on the incredible challenge of running a huge 100 miles on Christmas Day, raising £1,320 for CLAPA. He was inspired after his best friend's baby was born with a cleft palate.

Andy said, "I feel awareness of these conditions is not high enough considering over 1,200 babies are born each year with a cleft, which can also link to these other conditions. Therefore, my aim with this run was to make people much more aware of these conditions and to raise money for CLAPA to support their work for the UK cleft community."



Andy's 100 Mile Run

FOR EVERY £1 RAISED, WE SPEND...



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

12p 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



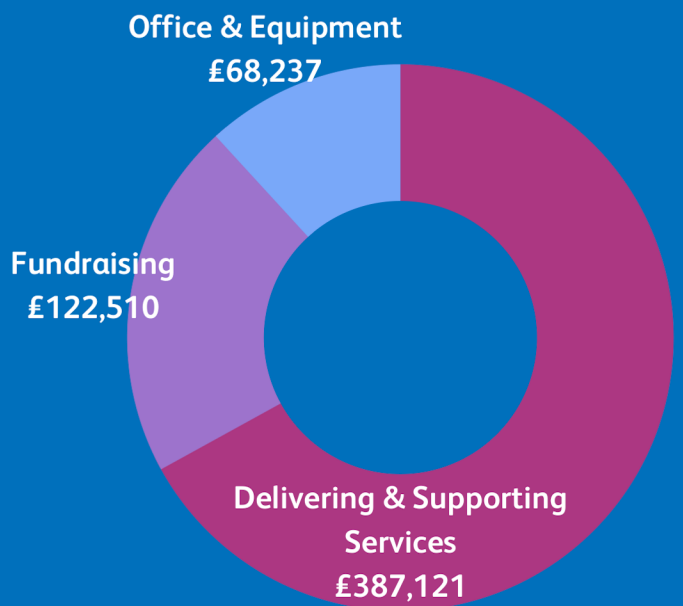
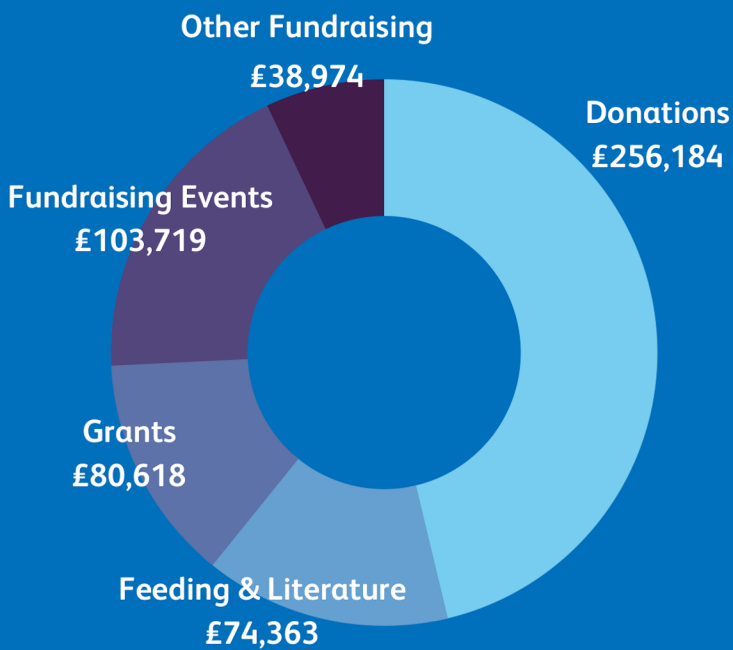


FINANCES

2021-22

INCOME: £553,858

EXPENDITURE: £577,868



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.

FULL AUDITED ACCOUNTS AVAILABLE AT [CLAPA.COM/FINANCES](https://www.clapa.com/finances)




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