Annual Review

2017-2018

CLAPA
Cleft Lip & Palate Association

In This Review

Visit www.clapa.com for all the latest news and information about our projects and services. Make sure you join our Community at www.clapa.com/community to be the first to find out about events and opportunities near you!

About CLAPA

The Cleft Lip and Palate Association (CLAPA) works to improve the lives of people born with a cleft and their families in the United Kingdom.
We are a 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.

Support, Connect, Empower

2017 THE CHARITY IMPACT AWARDS WINNER

CLAPA is the winner of the Charity Impact Awards 2017 Health Category.

This award recognised our "stunning achievement of making a massive and sustainable difference to our world and the lives of people in it."
We're thrilled to be recognised in this way, as making a difference that can last a lifetime is at the heart of the work we do with people of all ages affected by cleft.

Beth's Story

Like most parents, Shirley-ann's first concern when her baby was born was; "Is she healthy?"

Before meeting baby Beth, she and her husband Mitchell didn't know anything about cleft lip and palate, and certainly didn't think it was something that might affect their daughter.

"I got over the shock quickly, but I think it would have been good to know more information about what cleft was so that I could have been more prepared."

The family first found out about CLAPA from the Glasgow Dental Hospital. Staff there put them in touch with Gillian McCarthy, CLAPA's Scotland & Northern Ireland Manager, when Beth was eight-years-old.

During the first years of hospital visits, Beth was still so small and, while it was a hard time for the rest of the family, Beth was too young to understand or remember her surgeries. By the time it came to her alveolar bone graft surgery to help her adult teeth grow properly, Beth was older and more aware of what was happening.

Her parents worried that this was frightening for her, but were grateful to have met other families through CLAPA

> "When I was younger I thought I was the only one and I'd think 'Why have I got this?' Meeting other people like me makes me happy and feel not alone."

so Beth knew other children in similar situations. This meant that Beth had someone to answer her questions, like what she would be able to eat after surgery and what to expect. Attending CLAPA events during the past few years helped Beth to make friends from different parts of Scotland who were also born with a cleft. Visiting from Glasgow and Aberdeen, these friends come to her home for sleepovers, often chat over the phone, and regularly write to each other as pen-friends.

"When I was younger I thought I was the only one and I'd think 'Why have I got this?'" Beth explains. "Meeting other people like me makes me happy and feel not alone."

Her favourite CLAPA activities are the Residential Weekends.

"They're always a lot of fun!" she says. On these trips she gets to take part in teambuilding activities, make campfires, toast marshmallows, and spend time with her friends.

"All the children involved with CLAPA are very caring," Shirley-ann notes.

She has also made friends with a group of fellow parents through CLAPA events. They share experiences and pass time together around town while their children catch up at CLAPA events for young people nearby. Their support extends online as well and Shirley-ann knows she can always pick up the phone when she needs someone to speak to.

Its two years now since the family attended their first CLAPA event. They met other families affected by cleft and spent the day sledging and playing in the snow. Beth's brother went with her too and it helped him understand what she was going through.

"They're really close," Shirley-ann says. "He gets very worried about her operations. This kind of support really does help the whole family."

"[CLAPA] does so much for us. Beth went to a residential weekend last year and the children have a Christmas party too and family days out too with other families. We'd be lost without them."

Speaking to Beth, now ten, it's clear that her cleft has not held her back. "I'm fine to talk about it at school if people ask," she says. "I don't worry about explaining everything. I just tell them this is something I was born with."

We asked Beth if she has any advice she would offer to other children affected by cleft, and she is quick to reply: **"Stay positive, remember you're not alone. Stay strong. 'CLAPA strong', I like to say!"**

Do you have a great story to share with the cleft community? Contact info@clapa.com to learn more!

Is your child starting school?

Schools have a duty to make sure every child gets the most out of their education, but you can help by letting your child's teachers know about any issues they should look out for, and ways they can help your child succeed. This might include supporting their speech development, knowing how to spot the signs of hearing loss, and helping them catch up on lessons missed for hospital appointments. You might also suggest they talk about diversity and differences in the classroom to promote understanding and acceptance.

Visit www.clapa.com/schools for more information

Parent and Peer Supporters

Our Parent and Peer Supporter Service sees trained volunteers providing one-to-one support to people affected by cleft.

This contact can be one-off or ongoing, over phone or email, and aims to give people reassurance and a sympathetic ear when they're going through a tough time.

"Thank you for being there when I needed you the most."

In late 2016, we re-launched this service to make it easier to access, more secure, and more focused on safeguarding. We currently have 33 active volunteers providing this service. Volunteer training and expenses are funded by a Big Lottery Awards for All grant, with staff support time funded by the The Big Lottery.

Find a Supporter

If you need to talk, CLAPA's trained Parent and Peer Supporters are here to listen. Visit our website to fill in a simple form, or give us a call on 020 7833 4883 to be connected with a volunteer within 48 hours.

Parents: clapa.com/parent-support
Adults: clapa.com/peer-support

Raise Awareness at School

Combining an awareness-raising talk with a fundraising event like a cake sale is a great way to get the whole school on board. You can use one of CLAPA's ready-made presentations about cleft, or use one of our templates to create your own.

Visit www.clapa.com/schools to find resources including:

- Tell Your Story PowerPoint Template
- Little Guide to Fundraising at School
- Information for Parents and Teachers
- Schools PowerPoint Presentation

In the first year of this new service, 37 adults born with a cleft got in touch for support. 34 % asked about surgery and returning to treatment as an adult patient, while 30 % wanted to discuss feelings of isolation and learn about getting psychological support. Other topics raised included concerns with speech, appearance, delayed diagnosis, access to information, and decisions around becoming a parent.

92 parents used the service to find one-to-one support. 42 % of these parents were dealing with a recent diagnosis (26 % of parents contacting the service were still pregnant), while 18 % needed support with an upcoming surgery, and 15 % wanted to speak about feeling. Other topics included concerns with bullying, speech, other conditions and syndromes related to cleft, and appearance and scarring.

> "I found this service very prompt and useful especially for myself who is very anti help pages. The lady was honest and helped to stay on track and tackle some issues when and if they arrive." - A parent who used the support service

After the support ends, both the supporter and the person who contacted the service are invited to give anonymous feedback:

- At least 80 % of adults and parents feel more positive about dealing with cleft related challenges following support from CLAPA volunteers.
- At least 80 % of adults and parents feel less isolated after using this service.
- At least 80 % of adults and parents are better able to cope with the challenge/s they first contacted us about following support from a CLAPA volunteer.
- At least 80 % of peer/parent support volunteers have gained related skills and/or experience through being part of the service.

CLAPA's Commitment to Safeguarding

CLAPA is committed to the safety and wellbeing of everyone who uses our services. Find out more at www.clapa.com/safeguarding.

Volunteer With CLAPA

Could you be there for someone in need with a listening ear and open mind?

Our Parent and Peer Supporters are trained to use their own experiences with cleft lip and palate to help people in the same sort of position going through a tough time. Sometimes it's a single email exchange or phonecall, sometimes it'll be a longer conversation over several weeks. You'll be there to support them to talk through their worries and questions without judgement, and refer them on to other services as appropriate.

This volunteer role comes with full training, and an annual refresher day to keep you in the know. You'll also be supported every step of the way by your key contact at CLAPA. Budget constraints mean training events are run on a semi-regular basis, so get in touch to register your interest and we'll let you know when an opportunity comes up.

Find out more about this and other volunteering roles at CLAPA at clapa.com/get-involved/

Local Support Groups

Spotlight On: Barnsley

Last year, we reported on a new style of local cleft support groups being rolled out across Central England. Since then, these groups have gone from strength to strength, with Barnsley paving the way for new groups to emulate this model.

The group meets monthly and sees an average of four families each month. Over 30 people attended their small Christmas party, and the 50 members of their Facebook Group regularly chat together between meetings. What makes these groups special is the attendance of a local Cleft Nurse Specialist from the Trent Regional Cleft Network.

Group leader and CLAPA Volunteer, Alison, says she “loves” having the nurses attend. “They provide a service that I can't from a medical point of view. When new

"It can be very isolating having a child with a need that is different to the majority of children and CLAPA provides support and guidance on feeding and how to prepare for surgery to name but a few examples. They also fund support group meetings that allow cleft affected people to come together and share knowledge and support to others. It is a fantastic charity."

Mother of a child born with a cleft, responding to a 2018 survey.

parents have turned up with babies in arms the nurses have been able help with feeding techniques, make suggestions about any issues that a GP should be able to help with like reflux issues, as well as weighing [babies] and reassuring parents." Different nurses will attend the group meetings, which is helpful for parents as when it comes to official clinic appointments, they'll be sure to know the nurse by their side at what can be an emotional time. It is an amazing honour to know the Nottingham Cleft Team ensures my meetings have these valuable team members present."

> "I really appreciated seeing the nurses in a more sociable setting rather than in purely medical ones […] I felt I had a friend there with me, not just Ben's Cleft Nurse."

As a parent, Alison has also personally benefited from the presence of a nurse.
"It was useful to get Ben weighed when he was little and I really appreciated seeing the nurses in a more sociable setting rather than in purely medical ones, so when I was in the busy Multi-Disciplinary Team meetings I felt I had a friend there with me, not just Ben's Cleft Nurse."

Mags, a local Cleft Nurse Specialist who regularly attends meetings, added, "We, as nurses, love being involved with the local groups. Those of us that cover the north of the region tend to take it in turns covering the Barnsley group. […] It is really valuable for some of our antenatal couples to meet other families and babies /children with cleft. Other parents are generally very welcoming and enjoy sharing their cleft journey with other people. Antenatal couples tend to appreciate the honesty of the experienced parents. As experienced nurses, we also enjoy seeing 'our' babies' progress. It is also great to see their parents' progress in terms of their confidence, etc."

Find a Group Near You

There are local support groups all around the UK to help new and expectant parents find a supportive community. We're also on the lookout for enthusiastic volunteers to help us set up groups in new areas.

Find your nearest group or the details of your local CLAPA contact by visiting clapa.com/in-your-area/

Covering the Country

CLAPA's Regional Coordinator Project

A Residential Weekened in 2017

This year saw CLAPA recruiting local staff to support all 8 UK regions, bringing us one step closer to equal access to events and opportunities for the entire cleft community.

> "If CLAPA didn't exist I really don't know how I would have managed from diagnosis 6 years ago until now. It has the most important role for a family expecting a cleft baby. The support is amazing."

The aim of our long-term Regional Coordinators Project was to make a tangible, positive impact on the lives of people affected by cleft around the UK by generating local activity and empowering volunteers to support others. This independently-evaluated project saw fantastic outcomes in regions where we were able to secure funding, but without local staff members working on the ground in other regions, it's been tough to replicate these results.

CLAPA is committed to working towards equal access for our services across the UK. That's why, in 2017, we invested in the future and restructured our regional team to add four new part-time, home-based Engagement Officer roles to cover the four remaining regions.

This meant that, for the first time in CLAPA's history, everyone affected by cleft in the UK would have one of our staff dedicated to supporting their local area.

"CLAPA have been an amazing support through my pregnancy, immediately after my son was born and also as my son is growing up. The family days are supportive not only to parents for support from other parents, but also for the children as they mature to give them opportunities to play with and talk to other children with a cleft lip and/or palate."

It's still early days for this next phase of our project, but our staff have already started to accomplish fantastic things and reach out to make links in their region. This project gives incredible, proven benefits to families and individuals affected by cleft, but with limited funding our staff are still working very part-time, and we currently have no dedicated support for Northern Ireland. Getting more funding for our regional work is vital to ensure equal access across the UK and to avoid having to make further cuts on services.

Read more at clapa.com/about-us

Kath Allen,
Engagement
Officer for North
East England

"Parents like to feel that they have someone fairly local that they can approach, and be able to put a face to the name."

"It also means that more activities and events can be planned by someone who knows the area well and knows about local resources. I think it offers a more personal touch to the cleft community."

"[CLAPA Volunteers] all have a story to tell about how they became involved. I like to meet with our families from the Cleft Community and find out how they have been supported so far and how they feel we could help further."

"Working for just seven hours [per week] limits the difference that I can make in my area and the support that I can offer our families. It means that it's particularly important that I prioritise my workload and plan effectively."


KataKanu
CAN YOU EXPERIENCE
1

The Regional Coordinator Project

Lottery funding has helped us reach thousands of people in three England regions over the past five years. This independently-evaluated project has seen fantastic results in 2017/18 alone:

- ✓ **81% of young people attending a CLAPA event agreed they met other people they could talk to about being born with a cleft.**
- ✓ **87% of young people attending a CLAPA event said they felt more confident about themselves afterwards**
- ✓ **100% of parents attending a Happy Faces Group agreed that they'd met other people they could talk to about cleft-related issues.**
- ✓ **96% agreed they had access to support from others in the group**
- ✓ **94% felt more confident in supporting their own child with cleft-related issues after attending a Happy Faces Group**

"I loved meeting other people because I made new friends and learnt that other people are the same as me."

"My child has gained so much confidence by attending CLAPA events; he very much looks forward to them. I as a parent feel like I have a great support network."

"My son attended an activity day and he loved it. He is very insecure about his appearance so meeting with others helped him so much! He came out adamant that he would go to as many meet ups as possible!"

"[My daughter] LOVED today………. I forget she feels different from other kids because of her cleft as we don't notice it, but she said it was great to be with other children like her and she's looking forward to getting to know them better at future events. Thank you again."

North East England

northeast@clapa.com

Engagement Officer Kath Allan had a wonderful time at the North East and Cumbria Christmas Party, organised by local CLAPA Volunteers. Just over a hundred people attended.

Kath says, “[At the party], parents talked to me about how important it is that their children are able to meet other children who have shared similar experiences. Parents also said that it’s so helpful to meet, and have discussions with, parents who are all at different stages of their child’s treatment.”

South West & South Wales

southwest@clapa.com southwales@clapa.com

This region saw two Christmas parties organised by volunteers, and a Family Day in Trethorne Leisure Park which gave local children a chance to meet up and make friends in a fun, informal environment.

Engagement Officer Catherine Dougherty would love to hear from more prospective volunteers to help run events and organise meet-ups across this large region. Please get in touch if you’d like to learn more about volunteering opportunities to suit you.

"Happy Faces has been a Godsend. It has been a lifeline for our family, supporting us through the difficult times and celebrating the good times. We have received so much support, advice and guidance from other group members, I genuinely don't know how we would have coped with our son having a cleft lip and palate if it wasn't for this group."
- Parent attending a group in East of England

East of England

eastengland@clapa.com

66 people attended a family fun day at Wroxham Barns in Norfolk, including 34 young people born with a cleft.

Volunteer-run Happy Faces Groups in Norfolk and Essex gave local families a safe and fun place to meet up and share experiences, wherever they were in their cleft journey.

Regional Coordinator Daniel Richards is now in post, and we look forward to telling you all about the activities and events he's organised in next year's Annual Review.

North West & North Wales

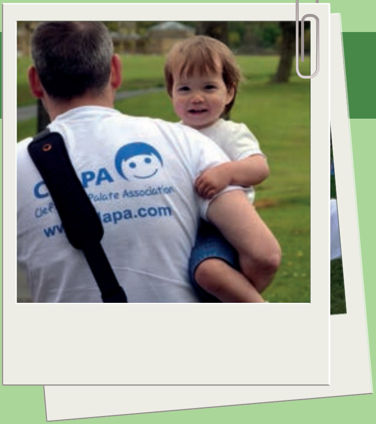
northwest@clapa.com northwales@clapa.com

A Family Fun Day at Bodafon Farm Park welcomed 33 people, and a Christmas Party run by volunteers in Merseyside brought 70 people together.

Engagement Officer Sarah Tinsley is keen to recruit new volunteers to help her run more events across the whole region - get in touch to find out more about opportunities in your area.

Northern Ireland

northernireland@clapa.com



CLAPA is keen to see more events and opportunities in Northern Ireland, but at the moment this is the only region without a local staff member generating activity, and due to funding cuts our Scotland and Northern Ireland Manager has reduced capacity.

Can you help us be there for people affected by cleft in Northern Ireland?

Do you know of any local funding opportunities that could help us put a staff member back in Northern Ireland? Could your company or organisation 'sponsor' an Engagement Officer to help us give people in Northern Ireland the local support they deserve? Please get in touch with our Scotland and Northern Ireland Manager at northernireland@clapa.com.

In the meantime, we need enthusiastic new volunteers interested in setting up local groups. If this could be you, please contact us to find out more about how you could help others like you in your area.

Why bring your child to a CLAPA event?

"Seeing other children with clefts, making friends"

"Meeting and socialising with other children who are cleft affected"

"To meet similar age children with experiences of operations"

"To meet with a child who has just had an operation that mine is due to have"

- Parents in a 2018 survey

South East England

southeast@clapa.com

Last year was especially busy in South East England, with two adventure days, a Residential Weekend, and three Family Fun Days across the region.

Local volunteer groups also ran some fantastically successful events, including four large Christmas parties which welcomed hundreds of families to celebrate together. The GOSH Events Group organised another Patient-Professional Forum which saw 35 people attending a Q&A with clinicians and former patients about jaw surgery (osteotomy). This gave young people considering this procedure a chance to ask questions in an informal environment and get honest answers from people who had been through it all already. A film of this event, including the Q&A, is available at vimeo.com/clapa

The South London and Surrey Events Group put on their annual Bockett's Farm day, where over a hundred people enjoyed a day out with animals and outdoor games.

Q. Why did you come to the family day?

A. "To meet people on the same journey as us to provide insight if they're ahead. Also, for my eldest to understand there are other children as special as her sister. Its lovely to be around people who have shared the same or similar experiences – to show the girls they don't look different from everyone else."

Work Skills Day

CLAPA has been the Charity of the Year for Crown Worldwide since 2017, and in that time their employees have been keen to use their skills to help people in our community however possible. For any young person looking to the future, entering the world of work can be a daunting prospect, but for a young person born with a cleft there may be extra worries about how others may react or how they'll cope in a new environment.

Crown Worldwide staff worked with CLAPA to put on a 'workskills' event for young people aged 6-19 born with a cleft to build skills and confidence. The day included information and workshops on CVs and interview techniques.

"I enjoyed meeting other teenagers with clefts as in my day to day life I don't know any. Through chatting with them it was good to find out that they were struggling with some similar things to me. The group exercise was the part of assessment days that I was most worried about. However, on the workskills day I found that it was quite enjoyable. It really improved my confidence and now I'm not so worried about any future assessment days I may attend."

- 18 Year old who attended the event

Visit www.clapa.com/in-your-area to find events near you

Central England

centralengland@clapa.com

Two fantastic Family Fun Days in Nottingham and Lincolnshire brought 187 people affected by cleft together to share experiences and make friends locally. Nineteen young people also had an exciting day out at one of our two Adventure Days in the region, and seven more attended a Residential Weekend in Sherwood.

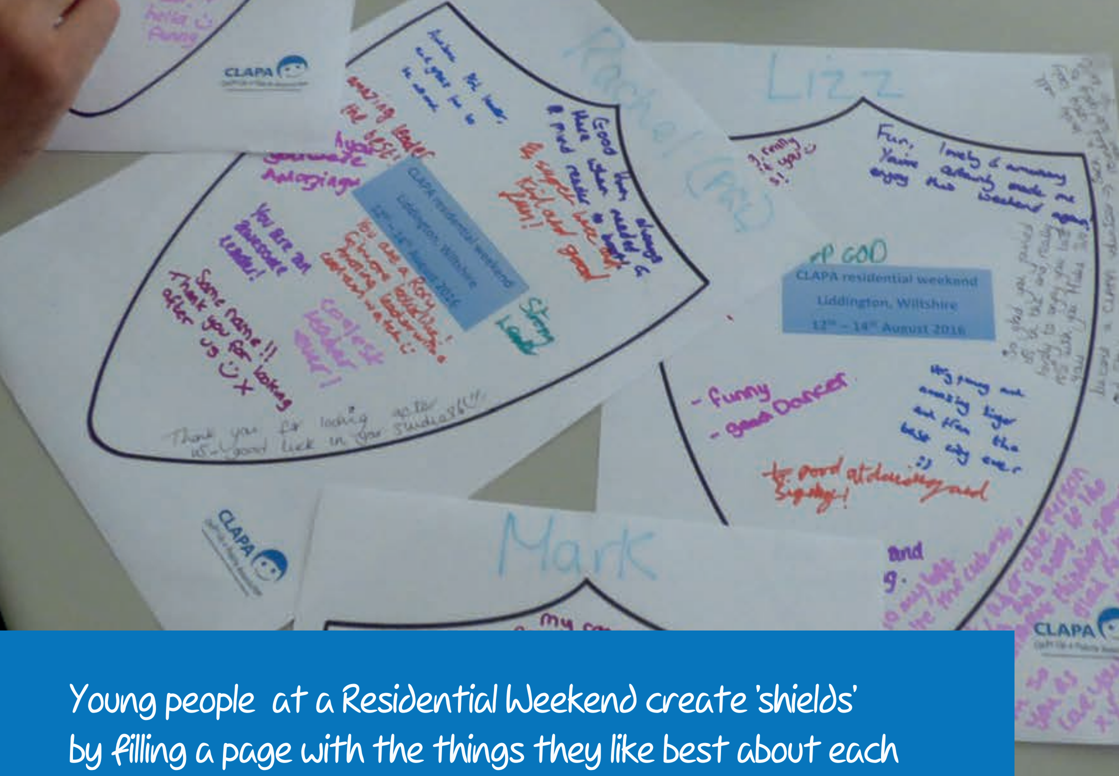
Central England has seen great success with its Happy Faces Groups in Warwick, Birmingham, Derby and Barnsley, with regular meetings of all three groups taking place throughout the year at soft play centres, parks and village halls. See page [??] for a closer look at how this has changed the kind of support available for parents in the area.

CLAPA's Patient Voices Group for Birmingham Children's Hospital meets quarterly to give the Cleft Team valuable insight into the issues faced by parents and patients using the service, as well as giving feedback and making suggestions for improvements. If you're passionate about improving Cleft Care in the West Midlands Cleft Service, get in touch to find out more!

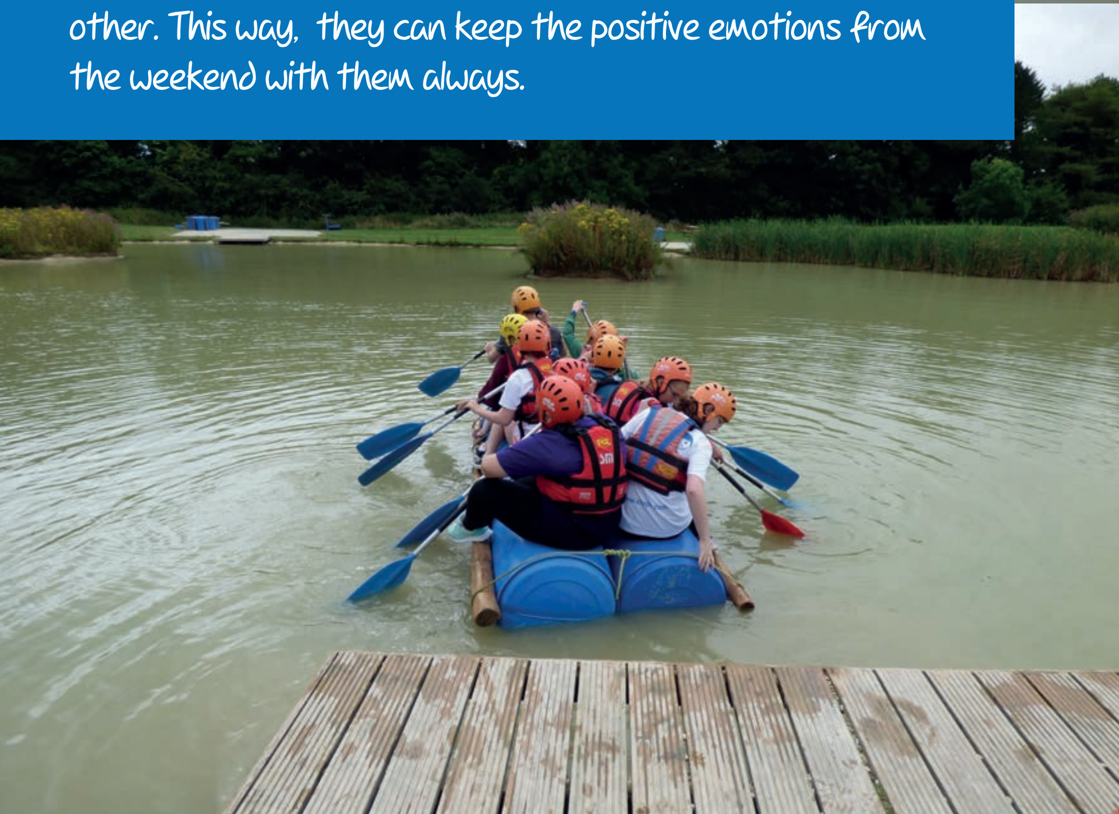
CLAPA Volunteers also organised local events to bring together families in their area, like the hugely popular Christmas Party in Birmingham which welcomed 117 people to an exciting day of celebration.

"I just wanted to thank you for organising the day out recently. We had a lovely time, and I didn't realise how much I needed it until I was there. I've found some of our recent difficulties with [my child]'s speech and hearing a bit isolating (as my friends find the subject uncomfortable), so it was nice to feel reassured by others going through the same journey and come away feeling a more positive about it all."

– Parent after a Family Day



Young people at a Residential Weekend create 'shields' by filling a page with the things they like best about each other. This way, they can keep the positive emotions from the weekend with them always.



Scotland

scotland@clapa.com

2017/18 was an extremely busy year for our Scottish community, particularly for older children born with a cleft hoping to meet others like them. As well as a popular Residential Weekend in Dalguise, six Activity Days throughout the year saw 175 young people come to local centres to enjoy adventures around climbing, water sports and more.

Three Family Days welcomed a further 110 people to build local connections, and Christmas parties in Aberdeen and Glasgow brightened up the winter for many others. Our staff also supported regular Happy Faces Group meetings in Fife, Aberdeen, Edinburgh and Forth Valley.

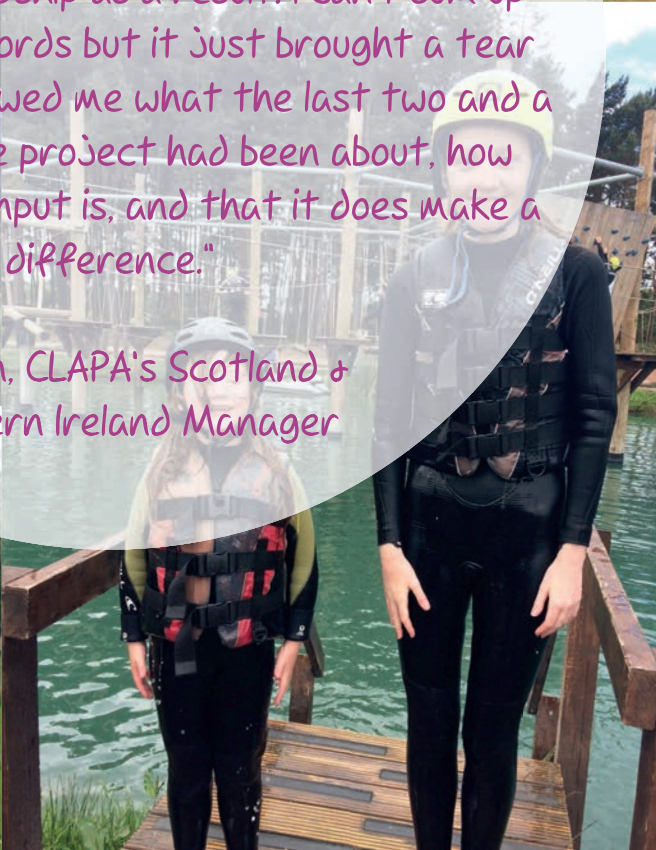
Spotlight On: Scotland

"It is clear from qualitative feedback collected during Year Three that the SRC [Scotland Regional Coordinator] Project offers crucial peer-support, which is not otherwise available to families through their engagement with the NHS cleft service. The role of the SRC is valued very highly by those who use CLAPA's services in Scotland and many have highlighted how much more challenging it would be for families to gain support if the SRC Project did not exist, or was not based locally."

- End of Year Project Report, evaluated independently by the Centre for Appearance Research

The Scotland Regional Coordinator Project aimed to provide a local support service for people affected by cleft in Scotland, including parents/carers, patients, and adults who have left the treatment pathway. This saw a number of targeted events run across the country, such as family days out, adventure activities for young people, and engagement opportunities for patients and parents.

A Scottish version of CLAPA's successful Children & Young People's Council was set up, called the SCYPC. This gave a group of Scottish 9-17 year olds a valuable chance to meet up 4 times each year to help CLAPA, the NHS and researchers make their work more accessible and relevant to young people born with a cleft, as well as giving Council Members a chance to make friends and share their own experiences. Volunteers have also been trained, and awareness-raising sessions were carried out at schools, community groups and with health professionals.



"My best memory of the project, probably the most emotional, was at a Christmas party in 2017 when I saw 3 girls joyfully running to the selfie mirror. They had attended several CLAPA events in my time as Regional Coordinator and had developed a friendship as a result. I can't sum up that moment in words but it just brought a tear to my eye as it showed me what the last two and a half years of the project had been about, how important CLAPA input is, and that it does make a difference."

- Gillian, CLAPA's Scotland & Northern Ireland Manager

Spotlight On: Scotland

Independent evaluators reported on the success of this project in May 2018. The key project outcomes included:

1: People affected by cleft are better able to cope with their condition.

Through their involvement with CLAPA, two-thirds of children and young people born with a cleft said they learned new ways of coping with cleft-related issues in a positive way. Three-quarters said they felt they could now offer help to their peers as a result of attending CLAPA events.

This is a fantastic result considering these events didn't specifically promote or teach coping skills beyond giving children a chance to meet and make friends in a non-medical environment. By building on what we've learned through these events, we hope to accomplish much more for children and young people in Scotland in the future.

2: People affected by cleft have increased confidence

86 % of children and young people born with a cleft attending a CLAPA event said it increased their confidence, showing the benefits of being around others who look and sound like them.

> "[It has] helped me really to be myself, and I'm not alone."
>
> – member of the Scotland Children and Young People's Council (SCYPC)

SCYPC Meeting

3: People affected by cleft feel less isolated

Four-fifths of young people born with a cleft attending one or more CLAPA events said they'd made friends they could talk to about having a cleft. We're extremely proud of this outcome, and hope to continue to help young people forge these vital supportive friendships that can last a lifetime. As our independent evaluators noted: "This outcome may be best achieved through continued attendance at events, since the development of trusting friendships is more likely to happen as children and young people advance further through their CL/P journey."

4: Parents of children with a cleft are better able to support their children with cleft-related challenges.

Three-quarters of parents and carers said their confidence in supporting their child born with a cleft had increased. 85 % felt more confident in connecting with other people for support with cleft-related challenges.

We were also thrilled to learn that as a result of attending a CLAPA event, 88 % of parents and carers said they now felt they had access to a local support network.

5. Adults

As the events organised as part of this project were largely aimed at families with young children and teenagers, we have limited numbers for adults. This is something we hope our new Adult Services Project will help change by directly focusing on this historically underrepresented group.

Raising Awareness in Scotland

Presentations about CLAPA and cleft were delivered by staff and volunteers throughout Scotland to dentists, community groups, schools, and more. 92 % of community dentists said the presentation had given them a greater knowledge of cleft and of the challenges people affected by cleft may experience. 85 % reported they felt more confident offering support to patients born with a cleft who came to their practice.

I think CLAPA's regional work is really important to the people we support. We ensure that there is a spread of activity across our areas and aim to reach as many families as possible within the restraints of budgets and geography. We can also get to know the local volunteers, without which we couldn't provide half of what we do, and work with them to help build a community within our areas."

- Gillian, CLAPA's Scotland & Northern Ireland Manager

Support Our Services

In August 2018, CLAPA announced that the funding for this service had come to an end and that due to a lack of continuation funding we would have to cut down on what we were able to offer in Scotland. Thanks to a number of small grants and the generosity of our Scottish community, we have been able to preserve a smaller service which will continue to provide fantastic support for at least another year.

But an increasingly difficult economic environment means this service, like all our services, are still vulnerable to cuts. The cleft community deserves a service they can rely on for years to come, which is why sustainability is at the heart of our strategy for the next three years. To keep these services going for years to come, we need your help.

If everyone on our Facebook page gave just £2/month, we could secure our frontline regional support services for an entire year, including local support groups, Christmas parties, family days and more. We could make real commitments to expanding the areas of our work under the most pressure, such as our feeding service, and make sure we never have to cut back what we can provide.

The cost of a coffee is all it takes to secure a future for the CLAPA Community. Can you help us be there for people and families in need all over the UK?

Help CLAPA make a difference that lasts.

Visit clapa.com/donate/

Youth Forward

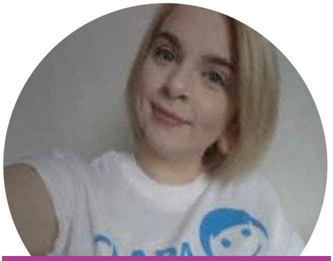
In summer 2017, we launched a new targeted service for under-18s born with a cleft: CLAPA Youth Forward. This quarterly newsletter is made up of submissions from our youth community, including stories, personal advice on everything from braces to bullying, and lists of local events. Since its launch we have had 97 sign-ups, with plans to promote it to Cleft Teams and at teenager-focused events in the future.

It is our hope that as sign-up grows this will become a flourishing community of young people born with a cleft who feel comforted by the stories of others and empowered to share their own. We want to ensure that no one goes through their cleft journey alone, and at this crucial time we know it's vital for young people to know there are others just like them all over the country, and that CLAPA is there to offer a listening ear whenever they may need it.

Under-18s with their own email address can sign up with permission from a parent or carer at clapa.com/youthforward

Once young people turn 18, they'll get one final email inviting them to sign up for our main CLAPA Community for adults, parents, family members, health professionals, and everyone else wanting to stay up to date with our latest events and opportunities.

The Children & Young People's Council (CYPC)



by Sally Carpenter, Children & Young People's Officer

The Children & Young People's Council (CYPC) is a group of 9-17 year olds born with a cleft who meet up four times a year (including one Residential Weekend!) to help CLAPA, Cleft Teams and Researchers make sure we're doing the best we can for the under 18s in our community.

There are currently 14 children on the CYPC aged between 11 – 16. We are recruiting for more and hope to have a full roster by the end of the year.

We currently run a schedule of three CYPC meetings a year and one adventure weekend away. We use these meetings as a way to evaluate and improve our services for under 18s, but also to train these young volunteers in new skills. Adults born with a cleft can give us valuable insight into what would have made their teenage experiences better, but the young people in the CYPC are having these experiences right now, and are best placed to tell CLAPA, researchers and the NHS alike what we should be doing to support others like them.

We started off 2018 with a meeting in February, held at CLAPA's small office in London, where we welcomed two new members to their first meeting. We held a workshop on development of the CYPC itself, talked about who we want to engage with in the future, what we want the CYPC to help with this year and what projects we are going to work on long term. We learnt about safeguarding, and how we can keep ourselves and each other safe at school, home and online

We also talked about our adventure weekend, where we go away as a group and have fun, learn new skills, and take part in teambuilding and confidence-boosting exercises. In April we had our Adventure Weekend in the Pioneer Centre in Staffordshire. There were lots of fun activities including indoor caving, abseiling, zip wires and even a search and rescue operation! We also took the time to complete some work for CLAPA by running

At a CLAPA CYPC Resedential 2018

workshops around what our new Young People’s hub on the website should look like and what we wanted to include in it. Fun was had by all!

We went into our second meeting of the year on August 11th where we welcomed another new member. This time, we took over CLAPA's social media accounts to show our community across the UK what the CYPC gets up to.

We started off the meeting creating our very own role profiles, so that everyone can find out about the CYPC whether on our website or in our new welcome packs, where these profiles will be available. We also recorded some fun videos and gifs to use on our YP hub. In the afternoon, we carried on with the film theme and created some content for the CLAPA website around a few important subjects voted on by our Under-18s Facebook Group. These included dealing with negativity, how to get involved with CLAPA, and advice on orthodontics. These short films will be available soon on our YP support page. Later on in the afternoon, the CYPC got the opportunity to go and break out of an Escape room! They had fun and everyone escaped safely.

You can find out more about what CLAPA does for young people born with a cleft at clapa.com/young-people

Feeding Service

"My son was [fed with a nasogastric tube] until we received the Dr Browns bottles, it literally changed our lives."

Since expanding our range of specialist bottles and teats last year, CLAPA has seen a huge 35% increase in demand for our free Welcome Packs for new parents, and a similar increase in orders from our subsidised shop.

This service is absolutely core to CLAPA as a charity, the parents and carers in our community, and the NHS Cleft Teams which rely on us as the only UK supplier of this specialist feeding equipment. With no government funding and a slowdown in donations, responding to this increase in demand has proven difficult, but we are determined to keep this crucial service running as smoothly as possible so no one is ever left without a way to feed their baby.

Can you help us protect this service?

With our costs increasing every year, it's only thanks to generous donations from people like you that we're able to keep subsidising this service for people in need.

Every pound you raise for CLAPA is an investment in the future of cleft support in the UK for people of all ages, and goes towards ensuring we never have to cut down on essential services like this.

clapa.com/donate

Online Support

CLAPA's online support groups for people affected by cleft have hit over 10,000 members this year, with new conversations, milestones, well-wishes and gorgeous photos posted every day. Find out more about how CLAPA can support you at clapa.com/support

For Parents & Carers:
facebook.com/groups/clapacommunity
For Adults:
facebook.com/groups/clapaadults
News & Updates
facebook.com/clapacommunity
twitter.com/clapacommunity
clapa.com/community

Research: How Online Groups Help

The Centre for Appearance Research (CAR) is a research centre based at the University of the West of England, Bristol, who strive to make a real difference to the lives of the millions of people worldwide with appearance-related concerns.

CLAPA has worked with researchers from CAR on many studies over the years, including several papers published this year about parents' experiences of a cleft diagnosis.

Last year, CAR carried out a study on CLAPA's Facebook Support Groups to learn more about the benefits and drawbacks of groups like these, and what organsations like CLAPA can do to make them more helpful and reliable.

This study examined survey data and analysed posts collected by one trusted researcher from two CLAPA Groups: one for parents and carers, and one for adults born with a cleft.

39 parents/carers and 22 adults born with a cleft took part in an online survey about their use of CLAPA’s Facebook Groups. 67 % of parents and carers found out about the group shortly after receiving a diagnosis of cleft

They found in the parents’ group, 42 % of posts were about sharing experiences, with a quarter of these relating to “sharing of good news, or positive messages”. A further 40 % of posts were from people asking for advice from others on topics from post-operative care to dental hygiene. The adults’ group was similar, with 52 % of posts related to sharing experiences, and 31 % asking for guidance.

While many people found their conversations helpful and reassuring,there was a worry that advice given was based on opinion rather than fact. This is something to be aware of on any social networking site: everyone’s situation is unique, so what works for someone else may not necessarily be a good solution for you. Information from other parents or patients, or even from CLAPA’s website, should never replace the advice given to you by your doctor or Cleft Team.

This study concluded that, when appropriately managed, social networking sites like CLAPA’s groups are a helpful source of health-related information and peer support.

Three Things We're Proud Of This Year

1. After nearly 40 years of CLAPA Branches, a full review has revolutionised the way our volunteers can work together to provide the best possible support to their local cleft community. Visit clapa.com/get-involved to find out more.

2. At CLAPA we believe that every smile tells a story, and in the past few years we've been excited to add World Smile Day to our calendar of celebrations. Falling on the first Friday of October, this international campaign aims to bring smiles to the world with acts of kindness, and we played our part by celebrating smiles at all stages of the cleft journey.

3. This year saw CLAPA reach a long-term goal of creating a staff position in each region of the UK to support local activity. This brought us one step closer to giving everyone in the UK equal access to our life-changing services.

Three things we've learnt

1. A grant-funded organisational strengths assessment gave us an inside look at what CLAPA's volunteers, trustees and staff really thought of the charity, and gave us a clear direction for internal development.

2. A survey of children and young people using CLAPA's services last year has helped us put together a strong strategy for this area of our work, with a focus on facilitating one-to-one contact between young people, and creating more engaging content for all ages.

3. GDPR may be a buzzword now, but it's been part of CLAPA's vocabulary since May 2017 when we began serious preparations. Since then, a programme of updates and staff training has ensured we are doing everything we can to exemplify best practice in how we treat our community's data.

Three Things We're Looking Forward To

1. 2019 will see CLAPA turn 40 years old! We look forward to inviting everyone in our community to join in the celebrations with birthday parties up and down the UK.

2. Our Adult Services Project, funded by the VTCT Foundation, kicked off in March 2018. Make sure you get our next Annual Review to read all about the ways in which this fantastic project has been making a difference to the lives of adults born with a cleft throughout the UK.

3. While safeguarding concerns mean we won't be adding any under-18 volunteers to our network of Peer Supporters, we're still keen to find ways for these young people to start supporting others like them. Check our website soon to find out how we're helping to make sure that everyone who needs a listening ear can find one with CLAPA.

In Your Area

CLAPA has events, opportunities and groups all over the UK. Find out what's on near you by visiting clapa.com/in-your-area, or give us a call on 020 7833 4883.

Join the Community

Visit clapa.com/community to join the CLAPA Community and get regular updates over email about news and events.

CLAPA
Cleft Lip & Palate Association

Registered Charity England & Wales (1108160)
and Scotland (SC041034)
The Green House, 244-254 Cambridge Heath Road
LONDON, E2 9DA
☎ 020 7833 4883 ✉ info@clapa.com
@clapacommunity @clapacommunity
facebook.com/clapacommunity