CLAPA NEWS

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CLAPA
Cleft Lip & Palate Association

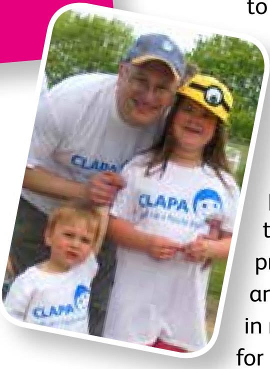
Welcome to CLAPA News

In this issue:

The Children & Young People's Council (CYPC) on a Residential Weekend in August 2016

Foreword

Dr. David Stokes joined CLAPA in May 2016, taking over from Rosanna Preston who stepped down as our CEO after nine years in post.



Joining CLAPA has been an absolute privilege for me. As a parent of two young children, and having spent years working and volunteering with family charities, I am acutely aware of how important peer support is.

CLAPA belongs to and is led by its community; they shape our services, keep us informed and tirelessly fundraise to keep CLAPA's services going. They run the Branches and groups and support networks that are so essential to connecting our entire community, and even direct our strategy through the Trustee Board. Three new families every day welcome a new baby with a cleft, and enter a whole new world of medical terms and decisions that can be both bewildering and terrifying. Supported by the highly dedicated team of CLAPA staff, it is the hard work of our volunteers which ensures that no-one has to face this alone.

However, the landscape that we exist in is not without its challenges. Ensuring that medical services remain world-class requires constant vigilance, as the recent surgical review of services in Scotland has highlighted. Long waiting lists continue to be an issue for some patients, and there are still some issues around diagnosis, whilst the tough economic conditions have made fundraising even more of a challenge. Despite this, we are dedicated to keeping up the good work even as we make the most out of every penny, ensuring that we make the most of opportunities offered by new technology and practices.

These challenging conditions do provide an opportunity for the charity to develop, and CLAPA is successfully progressing with a wide variety of great and essential work - but there are still areas in need of improvement. 2016/17 is a time for us to take a careful review (in consultation with the whole CLAPA family) of how we deliver our services in order to provide the best outcomes for our community wherever they are in the UK.

Our vision is to realise a world where having a cleft is no barrier to achieving desires and ambitions; a world where those born with a cleft are fully supported and receive the best possible care at every stage, where awareness and education have replaced stigma, and where the cleft community has a strong, diverse and representative voice. What heartens me most about joining CLAPA is that everyone shares this vision – from our trustees and volunteers to our paid staff and funders. This vision is reflected in everything we do, and everything you will read about in this edition of CLAPA News.

Dr. David Stokes

News from CLAPA

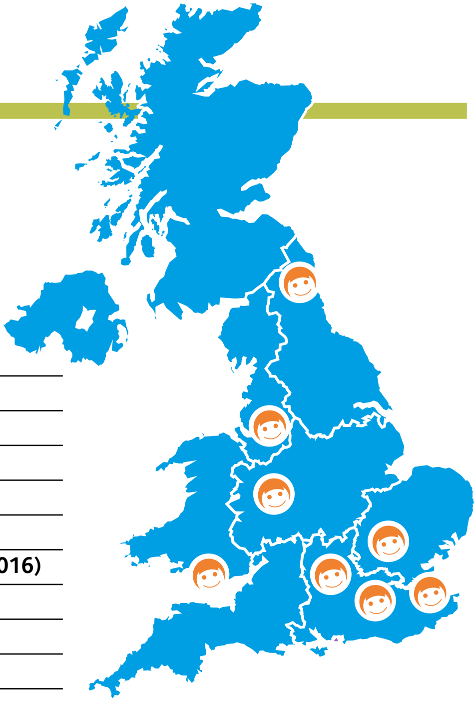
The past year has seen a lot of big changes to almost every aspect of our work, including our feeding service, our website, volunteering, fundraising - the list goes on! These changes are based on feedback from our community and are geared towards making everything, simpler, more enjoyable, and more cost-effective. This is why the 27th edition of CLAPA News is in A5 format: not only is it cheaper for us to print and send, it will also fit nicely with our new compact Welcome Packs launching in 2016/17.

For the latest news from CLAPA National, sign up to our mailing list at www.clapa.com

New Branches & Groups

The giant map up on our office wall has had a number of new features added this year as we've welcomed more groups than ever before to the CLAPA Community. Visit www.clapa.com/in-your-area to find events and activities near you.

- **North East & Cumbria Branch (August 2015)**
- **Manchester Happy Faces (August 2015)**
- **Glasgow Branch (September 2015)**
- **Isle of Man Happy Faces (February 2016)**
- **Leicester Happy Faces (May 2016)**
- **Wigan and Leigh Happy Faces (June 2016)**
- **Buckinghamshire & Bedfordshire Branch (June 2016)**
- **Berkshire Happy Faces (July 2016)**
- **Kent Branch (July 2016)**
- **Northern Ireland Branch (July 2016)**



Scotland Cleft Community and Family Support Programme

January 2016 saw the official launch of our project to provide activities and services for everyone all across Scotland. Regional CLAPA Staff hosted a fun-packed afternoon which included circus skills and tricks from Adventure Circus in Perth. We were lucky enough to be joined by representatives from two of the project's funders, The Sick Kids Friends Foundation and Glasgow Children's Hospital Charity. It was great to see so many familiar and new faces!

New Happy Faces groups have sprung up all across Scotland in the past year, and we look forward to continuing to work with the local cleft community even more in the coming years..

Funding this Project

The Big Lottery Fund in Scotland has:

- Donated £199,838 under their Investing in Communities Programme.
- The **Sick Kids Friends Foundation** has donated £24,458.
- The **Robertson Trust** has given us £30,000.
- **Glasgow Children's Hospital Charity** has donated £24,458.
- The **Scottish Government Health and Social Care Directorate** has given us two grants for our work in Scotland under Section 16b of the National Health Service (Scotland) Act 1978.

CLAPA CONFERENCE 2015 – 'TAKING CONTROL'

November 2015 saw over 300 people coming together – both in person and online – to take part in our latest national conference around the theme of 'Taking Control'.

We looked at the different ways in which people had taken control of their – or their child's – cleft care, and how this had changed their perspective. We heard from adults who had gained confidence by speaking up for themselves in clinics, parents who had joined research panels to help benefit others, and a number of health professionals speaking about the ways they were helping to empower patients and families around the UK.

We learnt a lot from the day's group discussions, particularly around services for adults and the need to raise awareness. Watch videos from the CLAPA Conference 2015 at vimeo.com/clapa

Our next conference will be in 2017! Rather than holding one this year we decided to focus on building CLAPA's first ever national campaign to improve care for cleft lip and palate. The campaign will launch in 2017 and will be focused on issues surrounding diagnosis. See page 14 for more information.

How Much Do Dentists Know About Cleft?

Andrew Dixson-Smith
Co-Chair,
Adult Voices Council

I met with Dr Nikhil Gogna, a volunteer ambassador for dentists, at the 2015 CLAPA conference and since then we have discussed doing some joint presentations to Dental Schools around the UK to raise awareness of clefts including the Patient Voice. It appears that clefts are hardly featured in the four year training programme that dental students undertake!

There are 19 Dental Schools in the UK and CLAPA's Adult Voices Council (AVC) are beginning to make presentations to students to make them aware of cleft, supplementing the minimal training they receive. The first one was conducted by AVC member Emma Heesom in May at the Cardiff Dental School where students were given a great presentation and insight into Emma's own cleft story.

REACHING OUT

Emma Heesom
Adult Voices
Council

In May 2016 I went to Cardiff Dental School to talk to students. As a guest of Dr Nikhil Gogna I chatted with the students, from several year groups, about cleft lip and palate. I took them through the medical background to cleft, from how they are formed to the treatment pathway, and I spent some time talking about my own story.

The presentation was the first of what the CLAPA AVC hope will be a calendar of activities at dental and medical schools across the UK. Whilst a little daunting to stand in front of our future dentists and orthodontists, it was a great pleasure to be part of this work.

There are very few opportunities for the students like those I met in Cardiff to learn about clefts in the theoretical sense and even fewer opportunities for them to treat babies and young people, but it is something the AVC is hoping to address.

David's Story


David, Adult Voices Council

I am an adult with a cleft lip and palate; I had operations as a child and have just been through the system again for a series of ops over the past years as an adult. Coping with operations and ongoing treatment, whilst also having a family, maintaining and progressing in a job, continuing with hobbies and community activities etc., has been a challenge and I have a lot to contribute to others in a similar situation.

I joined the Adult Voices Council as a way to come up with strategies to allow us (through CLAPA) to share experiences, give useful hints and tips and most importantly give confidence to others who have been in a similar situation. The council has been in a planning phase since I joined and I am really pleased that that prep work is now seeing positive action. The AVC is a great mix of people passionate about helping others with clefts and we have excellent plans for the year ahead and beyond.

> The AVC is a great mix of people passionate about helping others with Clefts

The adult Facebook group shows that the community is out there and has a lot of questions and concerns that the NHS struggles to cater for but we can help. I am looking forward to seeing us achieve our goals.

JOIN THE ADULT VOICES COUNCIL

The Adult Voices Council is looking for new members! If you are dedicated to improving services and care for adults born with a cleft in the UK, please get in touch with adultvoices@clapa.com to find out more.

DEVELOPING ADULT SERVICES

Over the next year, CLAPA is committed to exploring new ways to support adults born with a cleft, and we need YOUR help to develop our services. Your feedback is so valuable to us, so please get in touch at adultvoices@clapa.com if you have anything to say about how CLAPA could work to improve the support available for adults.

Advice from a Council Member

Cerys (left) at a CLAPA Residential Weekend

Hello, I'm Cerys and I am 14 years old. I'm from Llanelli, Wales and I am about to start my GCSE coursework. I was born with a cleft palate. I found out about CLAPA in 2014 when I was invited to a residential for young people who have a cleft in Wales. I met a load of new friends, it was unbelievable. After the residential, I looked further into CLAPA.

Then I found out about the Children and Young People's Council (CYPC), so, as you do, I applied. Then within a month of applying I had an answer: yes, I was accepted. The first thing I thought of was I can meet more people with clefts and also, me being a girl, SHOPPING in LONDON.
Now I have been a part of the CYPC for one and a half years. During this time I have made many friends and also joined a big loving community. I have had so many great experiences going to London for the meetings, it's unbelievable. The only thing that I would change is finding out about CLAPA sooner. If I had to tell you one thing it would be GET INVOLVED. It could be small or big, get involved and you will not regret it.

BBC CHILDREN IN NEED
has supported CLAPA since 2011. This year, they gave us £41,704 to fund a brand new Children and Young People's Officer post, Family Days, and young people's activity days.

SHORT STORY COMPETITION

CLAPA will soon be announcing a short story competition for children and young people born with a cleft. The winners will be announced during Awareness Week 2017. Look out for more details on our website.

Martha’s Story

I decided to go on the CLAPA Residential Weekend in Cudham because I was having a bit of a hard time at school, feeling like everyone was looking at me and wondering if my friends really liked me. My confidence was very low. I had been on previous CLAPA weekends and had found that sharing experiences and having a laugh with other kids with clefts had really boosted me. I talked to my mum and dad about going on the weekend and they were encouraging.

Because I had been on a weekend before I wasn’t as nervous. The first time I had no idea what to expect, I had never met anyone else with a cleft before. All the girls in my dorm were so kind and amazing that I quickly felt really comfortable. I was looking forward to seeing some of them again at Cudham. It was also nice to see the adults again too as I got a lot of positive feedback from them at the first trip and help from everyone with a presentation at school that I was doing about having a cleft.

Martha (left with the red scarf) at a Residential Weekend in February 2016

Cudham was a beautiful place in the forest and the lady who ran the centre was really welcoming and made delicious food. There were so many brilliant activities, exploring the woods, tag rugby, den building and making campfires and a disco. We also spent lots of time chatting in our dorms. It was really nice that some of the adult helpers were just a bit older than me in their 20s. They seemed really confident and I felt inspired by them.

Every time I leave to go home after a CLAPA trip I burst into tears because I’ve had such an amazing time. When I go back to school I know I feel a little bit proud to have a cleft, I feel much more confident. I wish there were more opportunities to meet other teens with clefts.

I would recommend this trip to all kids with clefts. I have so many amazing memories and I can’t wait to go on another CLAPA camp.

More residential weekends are planned all around the UK. Sign up to our e-newsletter at www.clapa.com to hear when weekends are announced.

A Residential Weekend for 10 people costs around £2,000 - but it’s worth every penny.

My Alveolar Bone Graft

I was born with a unilateral (one sided) cleft lip and palate and a cleft in my alveolus (the part of the upper jaw where my teeth are). I therefore needed some extra bone added here to fill the gap.

Stephy is part of our Children and Young People's Council (CYPC)

I needed this extra bone to be added so my teeth can grow in the right place. I have had two bone grafts; a second was needed because the first graft didn't quite fill the gap completely, although usually one is enough. I am 13 now and have been wearing a brace for just a few months and my teeth are already looking straighter; by the end of my dental work my teeth will look like my friends' teeth.

I had my first bone graft when I was about 10 years old. I came into hospital the week before the operation to check I was well enough for the surgery and to ask any questions. On the day of the operation, I came into hospital early and hungry as I was not allowed to eat for a few hours before the operation and then not allowed any water. The play specialists were really good at distracting me before the operation which made the waiting much easier. I walked down to the operating theatre in my gown to the anaesthetic room where the nurses were lovely. When I had the anaesthetic, it felt as if my eyelids were getting heavy and it was just like falling asleep.

I had to eat only soft foods for a couple of weeks to make sure that the graft healed

During the surgery they took some bone from my hip and put it into my cleft. The scar on my hip is tiny; they also took bone from the same place when I had my second bone graft but the scar really isn't noticeable. Once the bone has been added, the operation is finished by stitching the gum over the bone graft to close it.

When I woke, my mouth felt sore but I didn't really notice my hip hurting at all. The nurses gave me some medicine to reduce the pain, which helped. I was moved back to the ward, where I stayed overnight and went home the following day. I did feel slightly sick after the operation and my hip started to hurt, but the nurses gave me medicine to help with this too. There was a bandage over my hip, and underneath this was a small dressing that was taken off at a follow-up clinic appointment.

I had to eat only soft foods for a couple of weeks to make sure that the graft healed well. It is a really good idea to avoid food with sharp bits (like crisps) for a while too. I had a course of antibiotics to make sure that I didn't get an infection, and some mouthwash too. Some bits of skin did fall away as the graft healed but this is normal. My mouth was a bit sore after the operation but I took paracetamol and this really helped. I also watched plenty of movies to take my mind off it! The stitches in my mouth dissolved and fell out by themselves, often in my lunch! It is really important to keep your mouth clean after the operation, so I brushed my teeth and used mouthwash after every meal for a while.
At first it feels slightly odd and sore brushing around the graft, but you can do it carefully. I was given a really small soft toothbrush which helped with this. I found it easy to eat mashed potato, eggs, yoghurt and jelly, but avoided eating anything too hot or cold for a while. It wasn't long at all before I was eating normal foods and back playing sports.

> **"I now know that I didn't need to worry; you just need to look after yourself while you recover and everything will go back to normal."**

I was really worried about my operation, but with hindsight, I now know that I didn't need to worry; you just need to look after yourself while you recover and everything will go back to normal.

INFORMATION FOR TEENAGERS BORN WITH A CLEFT

**With the help of the Children and Young People's Council (CYPC), we have put together a whole new section of the website with information aimed at teenagers born with a cleft.
Visit www.clapa.com/treatment/teenagers-13-18**

Rachel's Story

It's the 9th March 2015, the day we have been waiting for. I had been induced two days prior due to high blood pressure, but today will be the day we meet our baby. The little baby we have been so desperately trying for the past 3 years.

Harvey with his NG feeding tube

We had our first child in 2010, a healthy (big) baby, Ella-Rose Corbin. She has been desperate to become a big sister for as long as I can remember; blowing out birthday candles wishing for a sibling that she could love, cuddle and feed. Today was going to be that day, except it's going to be a little different to how we had all imagined…

At 22:12, our 8lb 2 baby boy was delivered, placed onto my chest I lent down and kissed his head. I still remember exactly how this felt, my lips touching his cold, wet skin. I looked at him and as much I hate to admit this, my heart sank. I knew instantly something was wrong. He just didn't look right, that tiny little jaw was set so far back. I just knew from that moment. He made no attempt to feed from me, something I had spent hours in my job helping other mums to do, I was determined I was going to breastfeed this time round. I asked my midwife what was wrong with him and was reassured he was just swollen but soon it was obvious she had her concerns too. By this point equipment was coming in, they took Harvey, the baby, to check him over and I saw her face change as she glanced to another member of the team. She can see what I see; she knows there is something wrong with that jaw, I thought to myself. I didn't know at this point she had discovered a cleft palate. The rest is all a blur – doctors came in and told us they were sorry, our baby has a recessed chin and missing palate and he needs to go to special care.

A few hours have passed and we can now go and see our baby. Guilt is all I can feel right now. Why my baby? What have I done wrong? I didn't drink, I didn't smoke, but what if everyone else thought I had, what if it was my fault – I had fallen down the stairs at 29 weeks pregnant and needed surgery on my leg – was this down to me? What does this mean for my baby? My mind filled with questions: my body

I had to eat only soft foods for a couple of weeks to make sure that the graft healed

with guilt but my heart filled with love. Either way, this was my baby and he was perfect to me. I couldn't sleep that night. I googled recessed jaw and cleft palate and that's when I had the diagnosis. Pierre Robin Sequence.

Doctors confirmed this the following morning. He had a feeding tube and was connected to different machines, machines that would alarm every time we cuddled our son. His small chin meant that he would cut his own air supply off as his tongue would fall to the back of his throat, meaning his oxygen levels would instantly drop. We spent 4 weeks in our local hospital before being transferred to Bristol Children's Hospital, we could see specialists here, people who understood our son's condition. He was soon fitted with a nasal pharyngeal airway, a small tube passed down one nostril which would keep his airway clear and prevent the tongue from falling back. We spent the next few weeks learning how to care for him, suctioning and changing the tube.

Expressing milk and feeding him via his nasal gastric tube 3 hourly. This wasn't what we had planned but this was how it was going to be. We tried small amounts of milk in squeezy bottles but he never really got the hang of this. He spent the first 10 months in and out of hospital with repeated chest infections and after a swallow X-Ray was performed, it was decided it was in his best interest to stop oral fluids. As he grew, so did his jaw and by 7 months old he only needed the airway at night. A few weeks later we were able to remove this completely. The NG tube was replaced with a gastrostomy, a small tube directly into his stomach to make feeding easier. He gained weight, got stronger, and in May 2016 he had his soft palate repaired. He has one more operation this year to fix the hard palate but I know he will sail through this, just like everything else.

It's not been easy but it's been more than worth it.

Harvey has come on leaps and bounds since his surgery

Olivia's Story

My name is Olivia Sharon Galbraith and I am 10 years old.
I live in Inchinnan in Renfrewshire which is near Glasgow Airport.
I live with my mum, dad and little sister Lucy. I was born with a cleft lip and palate on 7th February 2006.

My mummy and daddy found out at a scan just a few weeks before I was born. Mummy said when I was born I was the most gorgeous baby she had ever seen. As long as I remember I have known I had a cleft. There are loads of photographs all around the living room. In school everyone in my class knows I had a cleft lip and palate as I have been off a few times recently after my bone graft operation (which was easy peasy!!!!).

I go to Inchinnan Primary and I asked my Head Teacher, Mrs Dalrymple, if I could help raise awareness about CLAPA. She asked if I would like to do a presentation to the whole school. I love to talk so said yes right away! I am also a member of the Scotland Children & Young Persons Committee so at the last meeting I told Gillian (Scotland Senior Regional Coordinator) that I was going to do a talk to the school. Gillian sent me a slide show which had lots of information.

On the day of the presentation I was quite nervous as I decided to show the whole school my collage photo, which shows my CLAPA journey from birth. Although my class has seen this, I wasn't sure how the rest of the school would react. My mum told me that I didn't need to show it, it was up to me. I did the presentation at the School Assembly and everyone was really good and listened to my talk. They asked lots of questions at the end. When I showed them my collage photo some of them said I was sooooo cute, so I was happy. My teachers said I am very brave after all my operations but I don't see that.

The Head Teacher and some parents spoke to my mum and said my presentation was awesome. Some of the parents said their kids came home from school and went straight on to the CLAPA website to show them what CLAPA was all about. I think my talk must have been good. Some of the kids filled out feedback forms which my mum is sending to CLAPA. I am happy that I helped raise awareness of CLAPA and I am hoping that the school will adopt CLAPA as one of their charities next year. I am going into Primary 7 and I have just been awarded House Captain so I am very excited.

Dina’s Story

“At my 20 weeks scan the doctor told us that it looked like our baby boy had a cleft lip. We had never heard of cleft lip and palate before. We were told that we just happened to be unlucky. The doctor explained that we wouldn’t know whether there was a cleft of the palate until after the birth. I didn’t understand anything at that moment, it was a mix of emotions as the future was so unknown.

“We were so fortunate to be in the UK when Tristan was born, as cleft care here is second to none, and we wish with all our hearts that other families of children with clefts will be as happy, support each other and treasure every moment of their time together no matter what happens.”

CLAPA has worked hard over the past 37 years to become respected as the voice of the cleft community in the UK. We are proud of our involvement in many initiatives to improve cleft care, from the centralisation of services in the early 2000s to the launch of the Cleft Collective and other research programmes This year we decided to focus our efforts on running our first public campaign about cleft lip and palate, and we thought it was fitting to start at the beginning of the cleft journey with ‘Diagnosis’.

Why Diagnosis?

No matter what a parent’s feelings are when they’re first told their child will have a cleft, it’s not a moment they soon forget. We know that there can be problems with how the news is delivered or what happens shortly afterwards, and we want to know more. We’re asking our community to contribute by telling us all about their experiences of diagnosis – the good, the bad, and everything in between in a new survey.

What Next?

The results of this survey will inform our next steps. We will consult with a wide range of medical professionals, including midwives and sonographers, to gain a better understanding of the issues around diagnosis and what can be done.

Join In!

Visit www.clapa.com/survey2016 to take part in our survey on diagnosis. Your story matters to us, whether it started last week or last century. Add your voice and help us make a real difference to the 1,000 new families each year in the UK who find out their child has a cleft lip and/or palate.

Fundraising Stories

Schools

QUEEN’S SCHOOL
Students and staff from The Queen’s School in Chester completed an epic 120 mile bike ride from Holyhead to Chester in July to raise almost £2000! The annual HQ bike ride is a Queen’s School tradition. Thanks to a nomination from student Zoe, who was born with a cleft and took part in the challenge, all the money raised will be going to CLAPA!

GREENBANK PREPARATORY SCHOOL in Cheadle raised an incredible £4,271.03 in May during their Charities Week. CLAPA was put forward by Katie, a Nursery Nurse at the school, whose little girl Sophia was born with a cleft.

Who Do You Know?

Here at CLAPA, we want to make sure every single person in the UK who needs CLAPA's support receives it. To do that, we need your help! We rely on our fantastic supporters – people like you – to keep running and growing our services. But that doesn't mean you need to do all the work!

Ask yourself – who do you know who could help you support CLAPA? Think of your child's school or nursery, your place of worship, your workplace, your local pub landlord. Perhaps you're a member of a club or team, or know someone who runs a local business looking to do some good?

Tell them your story and ask if they could support CLAPA through a fundraising event or Charity of the Year award! Whoever you know, we'll find the perfect way to get them involved in our work and help us make a real difference where it's needed the most.

To find out more, contact our friendly fundraising team on 020 7833 4883, email fundraising@clapa.com or visit www.clapa.com.

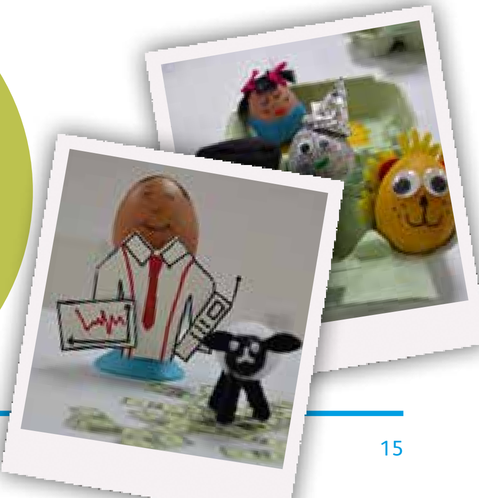
GAP Bridgend have chosen CLAPA as their Branch Charity of The Year thanks to Paul whose baby was born in 2015 with a Cleft Lip, who manages the branch. They've been selling merchandise and displaying collection cans, and have raised over £260 so far.

Trusts & Grants

Ashleigh Trenzinger, who works at Schuh's Head Office, invited us to apply for a grant from The Schuh Trust and wrote a lovely cover letter in support of our application. Ashleigh and her son Finlay, who was born with a cleft lip and palate, have benefited from CLAPA's work and she wanted to give something back. Our application was successful and we were awarded a grant of £9,934 for our work in our Central (Midlands) region!

Business

S E Controls in Lichfield have chosen CLAPA as their Charity of the Year and have already raised over £3,000 in just 6 months with a series of creative fundraisers, including one egg-cellent egg-based idea! Employee Nadine has a daughter born with a cleft and nominated CLAPA.



Get Inspired

Simon was born with a cleft lip and palate, talipes, and Gorlin's syndrome. Despite this, and numerous operations, Simon likes to get out and run. This year he is running an amazing seven running events of between 5 miles and 10K each. Good luck Simon!

CLAPA Heroes

Rosie, Emma, Vicky and Sara took on the ultimate challenge in April by running the London Marathon, raising an incredible £7,400 between them - what a superhuman achievement!

The Mini Clan in Scotland run an annual event called the Thistle Run, where hundreds of minis take to the road, heading from the Falkirk Wheel to Anstruther. This year they broke records, raising £8,000 for their two chosen charities - meaning CLAPA will receive an amazing £4,000! CLAPA was nominated by Kristeen, whose mum who was born with a cleft.

Lewis, now 23, was born with a cleft and despite 18 operations has forged a successful career as a chef and has become an inspiring ambassador for our work. This year he organised a charity dinner at his work place, as taking to the skies, to raise over £2500 for CLAPA! He chose to fundraise big this year to celebrate coming to the end of his treatment pathway, and enjoyed it so much he's already thinking of ideas for 2017!

Kids

Leon and his family raised £100 from saving pennies and selling super cute knitted Easter chicks which his mum kindly made!

Emma and her two daughters, Annabel and Jessica, organised a series of cake sales to raise money and awareness for CLAPA!

CLAPA South Wales Committee at the Cardiff Sponsored Walk

Harrison enjoying his first CLAPA Sponsored Walk in Cardiff

Awareness Week
7th – 15th May 2015

For Awareness Week this year we saw a record-breaking eleven Sponsored Walks – and one incredibly creative Sponsored BOUNCE – take place all around the UK, from Cornwall to Glasgow! Over 700 people signed up for their nearest event to celebrate Awareness Week together and raise vital funds for CLAPA's work. The month of May also saw an array of coffee mornings, gigs and school events.

Our CLAPA Sponsored Events raised over £26,000! Every single penny of this will make such a difference to our work. We can't thank you all enough for making 2016 our biggest Awareness Week yet, and we're already planning ways to make 2017 EVEN BIGGER. So please, stick **6th-13th May 2017** in your diary and join us for Awareness Week 2017 both online and in person to make an even bigger impact!

Edinburgh Sponsored Walk

Maidstone Sponsored Walk

Ruby the dog supporting CLAPA at the Redditch Sponsored Walk

Laura and Frankie from Happy Faces Leicester at the Hyde Park Sponsored Walk

Milton Keynes Sponsored Walk

Newcastle Sponsored Walk

Volunteering

Firstly we would like to say a HUGE THANK YOU to all of our volunteers for the amazing work that you do for CLAPA. The support you give to those affected by cleft is remarkable and your dedication and commitment to the organisation are overwhelming – we couldn't exist without you!

While you've been busy supporting people all over the UK, the Volunteering Team at CLAPA have been busy behind the scenes updating and amending processes to ensure all volunteers receive consistent support. All documentation, handbooks and forms related to volunteering – including new guides for Branches, Happy Faces Groups and the Volunteer Handbook – are now stored on our online Volunteer Resource Centre. Get in touch with your named CLAPA contact to get access.

All in all, these changes reflect our commitment to providing our volunteers with the best possible support and to ensuring their work is as valuable to them as it is to us and the rest of the CLAPA Community. We look forward to seeing what else we can accomplish together in 2016/17!

New Branch: Buckinghamshire & Bedfordshire

"When we received the diagnosis that our daughter would be born with a cleft lip and palate our world fell apart. We had very limited knowledge of what that meant and life felt very uncertain and scary. The thought of anyone feeling how we felt when we received the diagnosis breaks my heart, so when the opportunity arose to become a volunteer for CLAPA I couldn't say no.

"We are now in a positive place about, our daughter, Penelope and everything that goes hand in hand with being born with a cleft. I'm keen to help raise awareness of all things cleft and to support as many people as possible, whether that be as a parent, a wider family member or the individual directly affected by their cleft, from diagnosis to adulthood. I feel excited and honoured to be part of the CLAPA volunteer family and my personal aim (and passion!) is to make sure that nobody feels alone on their cleft journey. Awareness and support is key. Together, we are stronger!"

Lisa Drew joined the newly formed Bucks and Beds Branch in South East England.

Patient Voices

This year CLAPA has set up a number of Patient Voices Groups, made up of parents and patients who meet with health professionals to represent the needs of the local Cleft Community. For Alice Sheppard, Project Assistant at Birmingham Children's Hospital (BCH), "the Patient Voices Group acts as an invaluable opportunity to gather constructive comments. It not only helps us to develop in a particular area but can also highlight issues or grey areas which we may not have considered ourselves."

But it's not just clinicians who benefit, for many people in the groups the opportunity to discuss issues directly with the Cleft Team is rewarding. For Nadine Steele, the Birmingham group is "a great opportunity to meet new people who understand the range of emotions, challenges and appointments which affect patients and families of those born with a cleft. I was able to speak to other parents, teenagers, young adults and medical staff in an informal gathering where we were able to openly share problems and anxieties which we had all encountered, or suggestions for passing on information to patients or the way appointment days are structured." The group is an opportunity to "improve an already great service provided by CLAPA and BCH. Here's to raising cleft awareness nationwide!"

CLAPA hope to see Cleft Teams adopting this idea in the future as the groups are an incredibly valuable resource to improve care.

SHARE YOUR STORY

CLAPA is always looking for new stories from our community to share with the world, whether you're a proud parent or you were born with a cleft yourself, if you can put your experiences into words, we'd love to hear from you!

Visit www.clapa.com/support/your-stories to find out more.

Spotlight On: Happy Faces Leicester

Laura Williams writes: "When Claire (Central England Regional Coordinator) and I first discussed the possibility of a Leicester Happy Faces group, I never knew how many families would be interested. After promoting on Facebook, through the Cleft Team, and any other ways possible, Happy Faces Leicester was launched."

"It wasn't until the families started pouring through the door that I actually realised the impact it would have! The first meet up was a huge success! Twelve families attended with children ranging from 4 weeks to 8 years old, along with members of the Trent Cleft Team and representatives of CLAPA. As everyone had something in common to chat about, families were sharing experiences and supporting each other in many milestones in a cleft child's life. The children played happily together, as children do and enjoyed a cupcake and some fruit; I'm sure you can guess which plate was empty first!

"The responses from all involved were very positive. Some families had never met other families in the same situation before and found it very reassuring to talk to parents and see other children that were further along their cleft journey. It was a fabulous afternoon and I look forward to the next meet-up, where hopefully some new families will come along too!"

Find your local Branch or Happy Faces Group by visiting www.clapa.com/in-your-area.

Scotland Adult Patient Group

Iona was born with a cleft palate and lip pits.

“There has been an increase in the demand for adult cleft services in Scotland as a result of more of a focus on the transition from child to adult services, as well as people returning to the cleft service in adulthood. There is a need for surgical and dental input as well as psychology services. However, there is currently no definitive adult pathway in Scotland. Therefore, to meet the needs of patients, Cleft Care Scotland initiated an Adult Patient Representative Group to gain views on how to address this gap in care.

“As a group, we discussed what we thought an adult pathway would look like and how we might access it. Things that were important to us were general practitioners being aware of how to refer an adult to cleft services as well seeing as many healthcare professionals in one visit to minimise the number of hospital appointments. Once Cleft Care Scotland had made progress with determining what a service would look like, we met again as a group to discuss where adult clinics should take place. Cleft Care Scotland hopes to move forward with the initiation of an adult cleft service after a proposal has been agreed within the group.

“Being involved in the process of an adult cleft service has been a great opportunity. I feel this has been an area of cleft care that has been missing and now many adults will benefit from the new adult service. In this project, the patient voice has been valued by Cleft Care Scotland and I have enjoyed meeting new people and contributing to what I’m sure will be a greatly beneficial adult service.”

Also in Scotland, mum Mandy has been volunteering with CLAPA part time as an intern to help us raise awareness of cleft lip and palate. Between her and other volunteers we have given 10 talks in schools – 2 of which were from children who reached around 500 people between them. We look forward to seeing many more presentations like these over the next year!

Our Funders

CLAPA couldn't carry out our vital services without the generous support of our funders. We receive grants from a number of charitable trusts and foundations to fund the costs of specific projects, such as our Regional Coordinators Project, as well as our core organisational running costs. Grants we've received recently include:

- **The Artemis Charitable Foundation** named CLAPA their Charity of the Year for 2014/15. They gave CLAPA a generous donation, as well as a sizeable Christmas gift! We were nominated for the award by an Artemis employee, who is also a CLAPA supporter.
- **Robert Barr's Charitable Trust** has funded CLAPA since 2007. Most recently, they gave us £10,000 towards our core running costs.
- **BBC Children in Need** has supported CLAPA since 2011. This year, they gave us £41,704 to fund a brand new Children and Young People's Officer post, Family Days, and young people's activity days.
- The **Big Lottery Fund**'s Reaching Communities England programme gave us a grant of £284,881 over four years for our Regional Coordinators Project in CLAPA's Central, East of England, and South East England regions.
- The **Big Lottery Fund**'s Investing in Communities Scotland programme has given us £199,838 under their Investing in Communities Programme for our Scotland Regional Coordinators Project
- Our loyal supporters at **The Childwick Trust** have given a generous grant of £10,000 for our services in South East England.
- The **Patrick & Helena Frost Foundation** has funded CLAPA for nearly a decade. Most recently, they gave us £10,000 towards our core running costs.
- **The Robertson Trust** has given us £30,000 over 3 years towards our Scotland Regional Coordinator Project.
- **The Romeera Foundation**, managed by Kearsley Airways Ltd, has given us £10,000 towards our core running costs. We were nominated for the grant by a Cleft Nurse Specialist, who is also a CLAPA supporter.
- **The Schuh Trust** has given us £9,934 towards CLAPA's services in our Central Region. We were invited to apply for a grant by an employee at Schuh's Head Office, who is also a CLAPA supporter.
- **The Sick Kids Friends Foundation** has given us £24,458 towards our Scotland Regional Coordinator Project.
- **The Scottish Government Health and Social Care Directorate** has given us two grants for our work in Scotland under Section 16b of the National Health Service (Scotland) Act 1978. One of the grants part-funds our Scotland Regional Coordinators Project, and the other funds our work with children and young people in Scotland.
- **Smile Train**, an international children's charity, has funded CLAPA for many years. Most recently, they have helped to support the Regional Coordinators Project.
- **Glasgow Children's Hospital Charity** has given us £24,458 towards our Scotland Regional Coordinators Project.

If you are interested in funding CLAPA, or you have information about a trust or foundation you think CLAPA could apply to, please get in touch with our Senior Trust and Grants Fundraiser, Rowena Knight, at rowena.knight@clapa.com, or call the office on 020 7388 7399.

A number of funders give CLAPA smaller – but nonetheless completely indispensable – grants for our services and core running costs:

Sylvia Aitken's Charitable Trust
The Alchemy Foundation
The Annett Trust
Anson Charitable Trust
The Ian Askew Charitable Trust
Misses Barrie Charitable Trust
Bedfordshire and Luton Community Foundation
The FC Burgess Sunday Appeal Fund
The Calleva Foundation
The Camelia Trust
The D'Oyly Carte Charitable Trust
The CE and MM Campin Trust
The Christadelphian Samaritan Fund
The Clover Trust
Baron Davenport's Charity
The Bernard and Joan Dunn Charitable Trust
The Dyers' Company Charitable Trust
The Earl Fitzwilliam Charitable Trust
The Hugh Fraser Foundation
Frazer Trust
The Gordon Fraser Charitable Trust
HealthEast Healthy Communities Fund
The Charles Littlewood Hill Trust
Ibbett Trust
The Imago Trust
David Laing Foundation
Raymond and Blanche Lawson Charitable Trust
Lewis Ward Trust
Liverpool Charity and Voluntary Services (LCVS)
The Lynn Foundation
The Madeline Mabey Trust
The Orr Mackintosh Foundation Limited
The Maurice Marks Charitable Trust
Mazars Charitable Trust
The Sir John Middlemore Charitable Trust
D C Moncrieff Charitable Trust
G M Morrison Charitable Trust
Margaret Murdoch Trust
Edith Murphy Foundation
Mr and Mrs J A Pye's Charitable Settlement
Mrs F B Laurence's Charitable Trust
The Pennycress Trust
Press Relief – The News Community Fund
Redditch Borough Council
Reuben Foundation
The Royal Bank of Scotland Charitable Trust
The Charles Skey Charitable Trust
The N Smith Charitable Settlement
The Sobell Foundation
The Soham Staploe Rotary Club
Barbara A Shuttleworth Memorial Trust
St James's Place Foundation
St Michael's and All Saints' Charities
The Swire Charitable Trust
Tay Charitable Trust
The Douglas Turner Trust
The Ione Vassiliou Charitable Trust
The Jeannine Vassiliou Charitable Trust
The Nicka Vassiliou Charitable Trust
The Felicity Wilde Charitable Trust
The Worshipful Company of Carmen Benevolent Trust

Thank you to each and every one of our fantastic funders. With your help, we can give parents one-on-one support, bring families together to form connections and share coping mechanisms, and help people affected by cleft face the future with confidence. Together, we are building a vibrant and welcoming cleft community in the UK.

The CLAPA Team

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Cherry LeRoy
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Gillian McCarthy
Senior Regional Coordinator for Scotland

Melanie Skinner
Scotland Support Officer

Rebecca McDonald
Scotland Support Officer (Maternity Cover)

Mandy Temple
Scotland Support Volunteer

Volunteer Trustees

Full administrative and financial details appear in the charity's Annual Report and Accounts, available from CLAPA Head Office or the Charity Commission Website.

CLAPA
Cleft Lip & Palate Association

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