CLAPA NEWS

Issue 28 // 2017/18

Need to Talk?
Page 14

Young Ambassadors
Page 24

World Smile Day
Page 32

CLAPA
Cleft Lip & Palate Association

In this issue:

Features:

Mandy Haberman, creator of one of the first specialist cleft feeding bottles, talks to us about her daughter's experience with Stickler's Syndrome. Page 16

Isaac's Story
"Isaac arrived a week late, but we seemed to have a healthy first child. We left hospital, assuming everything was fine..." Page 18

At the start of 2017, Dr Ed Wright challenged himself to run a mile a day, every day of the year! Find out how far he's come. Page 8

Foreword

The CLAPATHON at the Cleft Lip and Palate Awareness Week celebration in May 2017

Welcome to CLAPA News 2017/18

The past year has seen some major developments for CLAPA, with changes across the charity as we work to better support our wonderful cleft community. Our range of feeding equipment has expanded to include Dr Brown's products. We have new CLAPA boxes for our Welcome Packs which now include a picture book for siblings; and we've renewed our Information Standard accreditation so you can be sure our information is top quality.

On the services front, we have secured three further years of funding from the Big Lottery Fund for our existing England Regional Coordinators, and will have recruited new part-time regional staff to cover every UK region by the end of the year. We have also created a new Scotland Children and Young People's Council to complement our wonderful UK wide group! We have held numerous family events, parties, residentials, and even an adults' mini-conference – all supported by our brilliant volunteers – and we're keen to do even more moving forward!

This work is funded by you, our incredible community and this year you've supported us in so many ways with acts of genuine heroism - from cake sales and nominating us as charity-of-the-year, to extreme triathlons, marathons and trying to break the world pull-up record! The CLAPA community is amazing, we couldn't do what we do without you, and CLAPA News is, as always, dedicated to you all!

With best wishes for 2017/18

Dr. David Stokes
CEO, Cleft Lip and Palate Association

Helpers at an Awareness Week 2017 event in London

CLAPA Helpers

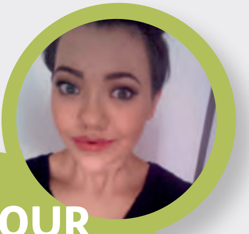
Would you like to help out at CLAPA, but aren't sure how much time you can commit? Sign up to join our bank of CLAPA Helpers, and get alerted about casual opportunities to help out at times that suit YOU! These range from cheering on runners at a local race, to filling in for Santa at a local branch Christmas party, there's a role to suit every schedule and skill-set! It couldn't be simpler – you fill in a short form on our website to tell us what kind of things you're interested in, and we'll add you to our Helpers bank. There's no pressure, no commitment, and you can opt out at any time.

This is an easy, flexible way to help CLAPA make a difference in your area, meet new people and try new things.

Sign up today at www.clapa.com/helpers to see what kind of difference you could make!

Take Control of your Communications

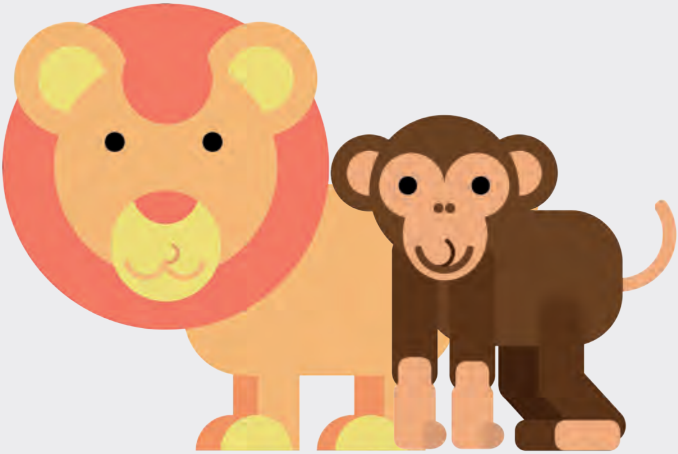
The law is changing: from May 2018, you'll need to opt in to receive different kinds of communications from organisations like CLAPA. This means that if you signed up to the CLAPA Community more than a year ago we may not have legal permission to send you anything once the May deadline has passed. Opt in before then to make sure you get the information you want from us when and how you want it. Visit www.clapa.com/update-your-details/ to find out more and tell us how you'd like to be contacted.



SHARE YOUR PHOTOS TO HELP OTHERS

We're delighted to have received funding from St James's Place Foundation to help us publish a number of new medical information leaflets, including one for teenagers and another for adults born with a cleft. We're now looking for photos of adults and older children (especially before/after treatment photos) to bring this new leaflet to life.

To find out more or to submit your photos get in touch at: info@clapa.com



CLAPA is excited to launch our new Redbubble shop featuring a range of designs on a huge variety of products, from clocks to coffee mugs to babygrows! Our thanks go to illustrator Jack Mellows for allowing us to use his fantastic 'cleft animals' illustrations to help CLAPA raise funds and awareness. Visit www.redbubble.com/people/clapacommunity to see the full collection.

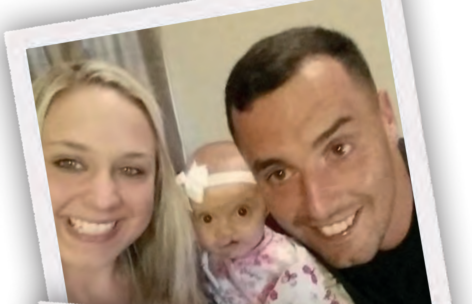
In Your Area

We are thrilled to announce we have now recruited 4 new Regional Engagement Officers based in those regions not covered by our Regional Coordinators! This means everyone in the UK now has a local staff member dedicated to supporting their region, and we're hoping to grow this steadily over the next few years.
Find yours at **www.clapa.com/in-your-area/**

Big Lottery Fund

We have secured a grant of £323,076 over three years from the Big Lottery Fund's Reaching Communities programme to fund the work of our Regional Coordinators in 3 English regions. We are so pleased that the Big Lottery Fund has decided to continue its support of CLAPA and people affected by cleft lip and palate, and we're excited about what we'll be able to accomplish over the next three years.

Fundraising Stories



Mark's Story

This year we had six runners in the London Marathon. Mark Lennon was the runner who took up our silver bond place!

Mark with Amarlia

"CLAPA have been fantastic to us since we found out our little girl Amarlia was going to born with a cleft lip and palate, providing us with help, advice and even free specialised bottles!

I would like to thank everybody at CLAPA for giving me this amazing opportunity. Everyone who has donated and encouraged me, my wife Nicola for being so understanding through all my training and always being my biggest supporter, my family for all their help and support, and my daughter Amarlia, whose bravery through her operations and resilience to bounce back so soon afterwards are so inspiring to me, and I promised to make her proud of me on the day of the marathon, just like I am so proud of her!"

Love Running?

Join Team CLAPA today!

BRIGHTON Brighton Marathon
15th April 2018

LONDON British 10K London Run
8th July 2018

EDINBURGH Scottish Half Marathon
23rd September 2018

Call: 020 7833 4883 Email: fundraising@clapa.com

Best of #FundraisingFriday

This year, we had some incredible people take on a huge variety of challenges for CLAPA. One of our favourites was **Will Lance**, who climbed all of the 5,895 metres of Kilimanjaro in March 2017! Will even sent us this brilliant picture of him with one of our T-shirts at the top.

"I have always wanted to help CLAPA help children who have the same condition [as I have] but don't cope as well as I have, and also show parents that it isn't as bad as it may seem. The planning has taken many years to put into place and…[the climb] is a way that I proved to myself that anything is possible to accomplish if you put your mind to it."

Jenny, pictured below, has been fundraising for us since 2012! She's raised over £1,000 for CLAPA so far, and still counting!

"Being born with a cleft was difficult but I wouldn't know any different. […] CLAPA is obviously a charity very close to my heart and I love trying to raise money for them."

Think you've got what it takes to be featured in **#FundraisingFriday**? Get in touch with our fundraising team at: **fundraising@clapa.com** for information, ideas, and all the help you could need!

Will Lance at the summit of Kilimanjaro

Jenny

'365 Mile Man'

Ed Wright, from Penmaenmawr on the Welsh coast, decided to kick off January 1st 2017 by running a mile. This was the first of the one mile runs he planned for every single day of the year to raise funds for CLAPA. Ed has been blogging about his daily runs and the sights and sounds he encounters along the way. We've picked out a few of our favourites below.

DAY 36

Day 36 mile 36

Sunsets & Zombies

At the risk of sounding like an over optimistic fool, the evenings are starting to be noticeably lighter. There can be few places in the world (other than at the poles!) where this is more noticeable than in Penmaenmawr; where the mountains provide a natural amphitheatre hemming the town in on 3 sides, leaving the only visible horizon over the sea to the north. Whilst this provides a highly defensible stronghold against the zombie apocalypse (especially if you blocked the A55 tunnels) it also ensures that in the winter it is possible to go for days without seeing direct sunshine. As the year wears on and the sun begins to peep above the crags and quarry machines, it can give rise to spectacular sunrises and sets as it slinks and arches beneath the sea's horizon, only to re-emerge on the opposite side a few hours later.

As it was a clear evening and apparently only a few minutes until sunset, I put down my tea cup and got today's mile in, running towards the west as much as I could. While the year is not far enough on for a bells and whistles sunset, it is still spectacularly beautiful and a sign that spring is on the way!

Day 54 mile 54

Dancing with (Hurricane) Doris

Today is nuts! It is not a day for lingering or exploring. I ran 1 mile, down the road and back. While it's not as bad as some elements of the media would suggest, the weather is still pretty vicious when it gusts! The side-winds jostle out of alleyways, the sea makes its own racket and the jackdaws in the trees are in obvious disarray! Upon re-entering the house as breathing and heart rate return to normal and the door closes on the tumult, the silence hit like a wall. Time to put the kettle on. Keep safe all, and keep on the ground if you can't!

Day 100 mile 100

265 to go, but there is cake

Today is my hundredth day of running (at least) a mile every day this year for charity. So to celebrate this small victory of fitness I decided that cake was in order! Today's run went along Penmaenmawr Prom, where I did the first run on day 1, and where I hope to do the last run at the end of the year.

DAY 100

DAY 155

DAY 200

The tide is a long way out today so the sound of the sea is masked by the white noise of the express way; as the tyre and engine noise breaks over the wall which divides the road from prom, sand and sea. There is quite a strong breeze, hence the candles didn't stay lit for the photo, but this does not seem to perturb the sparrows which were springing about the grass at the edge of the dunes, now that the seagulls have taken their 12 hourly commute to the low water mark. While it is not as hot as yesterday, it is still pleasant, but the clouds look as if almost anything could happen later!

It's been a great 100 days, I've got a bit fitter, seen some amazing places, met some great people and done a bit of good along the way. The support and kindness I have encountered have been astounding.

Day 155 Mile 155

Knee Deep in the Irish Sea

As a bit of low impact therapy and to tick one off the bucket list, I ran for a mile in the sea along the beach. Not on the sand or splashing through the surf, proper knee to waist deep fun. I got a dry sack on my back for my shoes, house keys, towel, shopping (comprising butter and mushrooms for later) and GPS run tracker (which I have been trying to record each of these on) and did it. It was great. It felt like seriously hard work, but there is something wonderfully childish about it. It was nice to be in surprisingly good company, with a few other people obviously enjoying the beach and doing their own thing, be that the family dodging waves, the people flying kites of various levels of complexity and beauty through to the people driving a pony and cart who I had great fun keeping pace with along the surf line for a while.

I had a laugh and it was fun; I suspect a few people in the village think that I have completely lost it and the tendon pain in my foot feels a lot freer. The latter is hard to tell at this stage if it is just a result of fun being the best medicine, but time will tell!

Day 200 Mile 200

Yet another milestone reached!

So far over £700 has been raised thanks to the generosity of people out there. At the moment that means that on average every mile I run earns £3.50 for charity. Wow!

Find out more about Ed's challenge, and keep up to date with how he's doing at **1mile365days.wordpress.com**

Feel like challenging yourself? Get in touch with our friendly fundraising team at fundraising@clapa.com!

Awareness Week

6th – 14th May 2017

For the second year running, Cleft Lip & Palate Awareness Week has broken records! You raised over £35,000 with an incredible range of events across the country, money that could be used to run 25 Christmas parties, send out over 1,800 Welcome Packs, or provide over 520 places at family activity days!

From a Milton Keynes Superhero Run, to the ever popular South Wales Branch Cardiff Bay Sponsored Walk, to Scott Harrop's 72-hole golf Challenge, the range and breadth of events this year was fantastic!

Moreover, over 400,000 people saw content from CLAPA across social media and hundreds of you shared your stories, spreading awareness not only in your own communities but throughout the UK.

SAVE THE DATES!

We're hoping to keep our record-breaking streak going for a third year in a row. Awareness Week 2018 will be from **Saturday 5th May to Sunday 13th May** – save the dates!

For the first year ever we marked the end of Awareness Week with an incredible finale in the Queen Elizabeth Olympic Park, where 35 brave souls took to the ArcelorMittal Orbit (the UK's largest sculpture) and lowered themselves the whole 262 feet!

Deputy CEO Claire Cunniffe pictured here suspended over the 114.5m drop!

Nicci

"Steve, Lucy, Holly and I had a wonderful time at the CLAPATHON! It was such a welcoming and friendly setting with a perfect location at the Olympic Park. With excellent views on our sponsored walk, the energy and atmosphere were really exciting and we all thoroughly enjoyed the day.

I thought Awareness Week was more popular this year and seemed to really spread more awareness of CLAPA and the work that they do.

I think raising awareness of cleft lip and palate is crucial for all families as many people do not know what it is. This is valuable information sharing because this could help a parent/carer recognise signs and symptoms of a cleft if it has been missed by professionals. This is what happened in Holly's case. Holly had a late diagnosis of cleft palate and it was missed, despite me saying something was not quite right when feeding Holly as a baby who had nasal regurgitation and inability to latch on to bottle teats. As a parent, I was unaware that these were classic signs of a cleft palate. Holly eventually had her surgery at 14 months old. This resulted in delays in speech and language and hearing delays too.

Holly raised the money for the Sponsored Walk and CLAPATHON as we set up a JustGiving page with Holly's story on there. Holly had a very difficult start to her life and has been such an amazing and brave little girl. She has flourished into a bubbly and happy child. Her determination to learn, thrive and develop has been nothing short of incredible. Holly has attended two sponsored walks now and completed the whole walk unaided. She was leading from the front and excited to do it to help other babies and children. Holly was so, so pleased to get her certificate at the end of the walk and told everyone about what she had achieved.

Having Holly has changed our lives and makes her so special because she has been such a brave little girl in spite of her cleft. It's been a privilege to be able to support CLAPA and raise awareness."

Cleft Lip and Palate Awareness Week is a national campaign to fight the myths and misunderstanding around how cleft lip and palate affects people and their families in the United Kingdom, from diagnosis through to adulthood.

It's a chance for people affected by cleft to share their stories with the people in their lives and shed some light on a condition which is still misunderstood by the general public.

If you've got an idea, big or small, which could help CLAPA raise awareness of cleft, please get in touch with our friendly fundraising team at any time by emailing fundraising@clapa.com, or give us a call on 020 7833 4883.

Awareness Week 2018 will run from 5th-13th May – get involved and help CLAPA raise a smile!

Parent and Peer Supporters

Louise and her son Oliver

My journey began when I gave birth to a bouncing baby boy in November 2002.

From the moment he was born, my husband noticed that Oliver was struggling to breathe and his chin was a very funny shape. He was making very strange noises and was gagging.

Oliver was born with a cleft palate and Pierre Robin Sequence.

I went to see Oliver in the Special Care Baby Unit and I'm not ashamed to admit I was horrified by what I saw when we walked in the door. He was on his front, had all these monitors on him, and he did have a funny shaped chin. I was told that a Cleft Nurse Specialist from Alder Hey would come to see us on the Friday night to tell us about the condition and what would be happening in the future. This is when the fun began.

My Cleft Nurse became our guardian angel over the next 18 months, I really don't know what we would have done without her. Oliver was being feed through an NG tube every 3 hours and we had to bath him prone.

Finally the week of Christmas we took Oliver home. We got through the 1st night with the apnoea monitor going off quite a few times which gave us a heart attack but we were home and it didn't matter as long as Oliver was okay.

Finally in February we were able to remove the NG tube as Oliver was taking enough through the bottle and he started to control his tongue meaning we could see his face a bit more, which was a lovely sight!

Then the day of his operation to repair his cleft palate arrived in September 2003, when he was 10 months old. He came through his operation fine; I think it was more traumatic for us than for Oliver. This is when I decided that I would like to do something for CLAPA as they had always been there for me when I needed advice, answers to a question, or just needed more bottles. **I went on a Parent Supporter Course in May 2005 and it was one of the best courses I have completed for a long time.**

I now feel very lucky to have been through this experience. Having come out of it the other side, I look back and don't know how we did it at times, but we are all here to tell the tale and I thank every single person who was involved in Oliver's care. Would I wish to go through this experience again? Gosh no. But would I change it? Not for anything.

I have met so many wonderful people and can't thank CLAPA enough. I look at the person Oliver has become now and couldn't be prouder of him and the little hurdles he has overcome. If possible it makes him more special.

It costs £300 to train each Parent and Peer Supporter. Help us make sure everyone affected by cleft can talk to someone whenever they need to. Get in touch at: fundraising@clapa.com

How it works

1

Get in Touch

Visit clapa.com/support to tell us a little about yourself.

You can also call 020 7833 4883

2

More Info

We may be in touch if we need more information.

We may also suggest a different service.

3

Make a Match

We'll match you with the volunteer we think can best understand your needs and experiences.

4

Getting Started

We'll tell you and your supporter about each other before the first contact.

5

Contact

Your Parent or Peer Supporter will contact you within 48 hours.

6

Feedback

You'll be asked to fill in a short feedback form to help improve this service.

The Haberman Feeder:
The Mandy Haberman Story

Mandy Haberman is an inventor and entrepreneur whose innovations include the Haberman Feeder, a feeding system designed for babies with serious feeding difficulties, used in hospitals and by families across the world. For Mandy, the Haberman was more than just a good idea; it was a necessity – her daughter, Emily, was born in 1980 with Stickler's Syndrome, a connective tissue disorder that includes a cleft palate.

"Emily couldn't breastfeed or feed successfully from any of the bottles and teats that we tried (and we tried everything that we could find, including lambs' teats from the vet!). Spoon-feeding was a disaster - she would scream and most of the milk ended up on my lap. She would choke on any milk that did make it as far as her mouth. Then she would vomit. Cup-feeding was no better. She was failing to thrive after losing a lot of her birth weight. For 4 months, there was no option but to feed her by nasogastric tube. The whole experience was devastating.

"We didn't know that Emily was going to be born with problems. Like most new parents, we assumed our baby would be perfect in every way. It was a terrible shock when she was not.

"We went through various emotional stages, firstly shock and distress, then thinking why us? It wasn't 'fair'. Then guilt - I must have done something wrong during the pregnancy to cause this. That was followed by a period of feeling something akin to bereavement for the healthy child that we didn't have. I loved Emily desperately but the ongoing and growing burden of anxiety became almost too much to bear."

Gallery EDITED BY JAN SHURE

How Mandy's aid is saving babies

The rare disease which struck her baby Emily, led courageous Mandy Haberman to an invention which is helping babies everywhere. JAY GRENBY heard Mandy's story

Determined mum, Mandy and Emily, now seven

Mandy's invention made waves when it went public

Parents whose babies have had to spend time on NICU or SCBU have significantly higher rates of PTSD than in the general population. Though Mandy was never diagnosed with PTSD, the turning point for her came when she reached out to someone she trusted.

"One day, in tears, I admitted my feelings to my health visitor. Even now, 37 years later, I find this very hard to write: Deep down, a part of me wanted this problem to simply fade away. What sort of a terrible mother was I to have thoughts like this? I felt so guilty, that I hadn't even spoken about it to my husband. My wonderful Health Visitor replied, in a very matter of fact way, "Oh, that's very common. Lots of mums feel like that in this sort of situation". Whether that was true or not, I'll never know but it took all the guilt away and made me feel much better. She also helped us in our decision to move Emily from our local hospital to GOSH, where they had experience of treating her condition. As soon as we became proactive, instead of feeling powerless, we felt much more positive."

The experience made her more determined, not only to create a way to help feed Emily, but to help the many other families suffering from the same issues. Mandy spent five years researching before she developed the Haberman Feeder.

"Whilst Emily suckled on [a] dummy, I syringed milk in through the corner of her mouth. She was relaxed and happy and the action of suckling helped her to swallow. That was the seed of my invention."

"I showed [the Haberman] to medical professionals and asked if they had any babies on which they would like to try it. […] There was a baby with Pierre Robin's Syndrome (PRS). The mum was in tears trying to feed her baby, so the ward sister relented and asked the mother if she would like to try my product. It worked and, for the first time, her baby fed successfully, and was contented and happy. The mum and I both cried - tears of joy."

"Despite her rocky start to life (or maybe because of it) Emily grew up to be a determined and strong minded young woman. She is a consultant anaesthetist and a talented artist, married with two beautiful babies of her own. We are very proud of her!"

Thousands of babies have since benefited from the Haberman

You can find out more about Mandy's work at habermanbaby.com, or visit clapa.com to learn about the range of bottles and teats available for babies with a cleft. Your Cleft Nurse Specialist is always the best person to speak to if you have any questions about feeding your baby.

We send out a free Welcome Pack to every family affected in the UK containing specialist feeding bottles and teats, information, and guidance. These packs cost around £20; help us to make sure every family gets vital feeding equipment as soon as possible please get in touch at fundraising@clapa.com

Isaac’s Story

Isaac 2 Weeks before the operation,

Isaac and his sisters,

Isaac arrived in October 2008, a week late, but we seemed to have a healthy first child. Everything was new to us; breastfeeding, sleeping (or lack of), settling him. We left hospital assuming everything was fine. I wanted to feed him myself, however when we got home the problems started. He wasn’t settling or gaining weight. We were told he was a needy baby and to give him a dummy. We did, but he wouldn’t keep it in his mouth. After a month, he hadn’t put his birth weight back on so the midwife suggested using a bottle. We had a different child overnight and over a weekend he put on two ounces!

With feeding sorted we moved on quite happily until just before his first birthday. We spent most of a three-week period in Alder Hey to treat croup that wouldn’t improve with steroids. Eventually they put a camera down his throat to see what was happening – all appeared healthy and we were told there was nothing medically wrong with him. This started a period of regular monthly A&E trips with croup and then asthma attacks, which he was diagnosed with at two years old.

We knew there was no development delay, but Isaac’s speech wasn’t as advanced as his peers. He had speech therapy but after 6 months of no improvement we saw a consultant speech therapist at Alder Hey just after his fourth birthday. Within five minutes of that appointment we were shown his cleft palate and referred, that afternoon, to see the Cleft Team!

Everything clicked – why I couldn’t breastfeed, why a dummy wouldn’t stay in, why his medication failed, why he couldn’t blow out candles on his birthday cakes! How had we missed it? How could all the doctors have missed it?

A week later Isaac had his operation and


Isaac today

was amazing, even if it was tough watching him eat afterwards. He loved his food but was terrified to eat, thankfully it didn't last long. He recovered quickly and was back at pre-school after a couple of weeks. We moved to Hertfordshire shortly after, and Isaac's care shifted to GOSH. His asthma came under control. His speech had improved so much, something we thought would never happen.

Isaac is now eight. He is happy and contented. He doesn't speak in large groups at school and is quite often nervous about speaking. We can't help but wonder if he would have been like this if his cleft has been spotted at birth? We are so grateful to the amazing staff at Alder Hey and GOSH. We also know that so much of Isaac's story is down to him, the resourceful and hard-working boy we love.

Diagnosis Survey

In last year's CLAPA News we launched a survey into experiences around diagnosis, and were flooded with over 1,200 responses! At the time of publication, we're working with one of our research partners to thoroughly analyse the results and put together a plan of action to improve things for the future. In the meantime, you can take a sneak peek at some of the figures we found most interesting below.

Diagnosis at birth

Only **50%** of parents whose babies were diagnosed at birth agreed that "staff were knowledgeable and sensitive about cleft lip and palate."

Late diagnosis

When a cleft palate isn't noticed until at least **24 hours** after birth, this counts as a 'late diagnosis'. **72%** of parents with a late diagnosis said their child's cleft was "missed by multiple health professionals on many occasions."

72% of parents with a late diagnosis also said they "felt personally responsible for my baby struggling to feed."

Breastfeeding

Before diagnosis, over **50%** of parents wanted to exclusively breastfeed their baby. Only 5% ended up being able to do this.

Activity Days and Residential Weekends

Activity Days and Residential Weekends are some of CLAPA's most popular events. They're a chance for 8-16 year olds with a cleft from across the UK to have fun, make friends, and meet lots of other people like them in a safe and supportive environment.

Here you can read all about Lucy and Mae, who kindly answered our questions about their experiences at two of our recent events.

Lucy, age 13

Woodrow High House Residential

What has growing up with a cleft been like for you?
I didn't really understand what a cleft was properly until the age of 8. I just thought I was different. Moving into Secondary School, I was bullied, not just for having a cleft. That hurt my self-esteem considerably but I didn't tell anyone. I regret not saying anything sooner.

How did you get involved in CLAPA?
In 2013, a few weeks before my bone graft, I wanted to do something for a charity. My mum told me about CLAPA, a charity that had supported me earlier on in life. I agreed and did a table sale. I raised £510, and I've been involved ever since!

What type of cleft were you born with? Have you had any treatments?
I was born with a unilateral cleft lip and palate on my left side. I have had 7 operations.

Has being involved with CLAPA made a difference to you?
I didn't realise how much CLAPA have helped me on the events I've been to. They have made the biggest difference and I don't know what my life would be like without CLAPA.

What do you hope to achieve in the future? How might CLAPA help you?
I want to do more to help raise money for CLAPA for the amazing things they provide. I will definitely be going on more residentials in the future.

Each place on a Residential Weekend costs around £170! Help us support many more young people like Lucy and Mae for years to come by supporting our work.

Mae, age 10 ¾

Young People's Activity Day

What has growing up with a cleft been like for you?

It has been really hard growing up with a cleft. I couldn't speak properly, I had trouble speaking clearly and was bullied. Until I was 5, I did speech and language therapy, 1 or 2 sessions per week, and have had 3 surgeries before I was 3.

How did you get involved in CLAPA?

My mum and I saw a poster about it in the hospital and we filled in a form online and, here I am.

Has being involved with CLAPA made a difference to you?

It has made me braver, as I was so nervous before as I had never met anyone else [with a cleft] before. It has made a real change in my life and how I look at myself.

What do you hope to achieve in the future? How might CLAPA help you?

I hope that I will be able to talk better, and I want to become a helper in the future.

Anything else that you might want to share about yourself

I used to think that I was weird and ugly, whereas now I can look at myself and say I like what I see!

TELL YOUR STORY

Do you have a story to tell? Get in touch at info@clapa.com to share your story with the CLAPA Community!

Focus On: Adults

Adults Mini-Conference

On Saturday 8th July 2017 we held our first Adults Mini-Conference in London, dedicated to exploring issues affecting adults born with a cleft. It was a day of informative talks, personal stories and positive, open discussions.

Special mentions to Andrew Dixon-Smith and Tony Ruel!. Andrew and Tony have been working incredibly hard over the last 3 years as co-chairs of our Adult Voices Council. The time has come for both to step down. Our incoming chair, David Nankivell, is looking forward to expanding the Council's work and building on the discussions from the Adults Mini-Conference.

In incredibly good news we've received some funding from the VTCT Foundation to recruit an Adult Services Coordinator! Whoever takes up this exciting new post will be responsible for working out and setting up a whole new range of services for adults affected by cleft.

We've also received some funding from the St James's Place Foundation to produce some more information aimed at adults. We're now looking for PHOTOS of adults and older children to bring this new leaflet to life.

Any high-quality photos would be appreciated, but we're particularly looking for 'before and

after' surgery photos for procedures adults or older children may go through, such as rhinoplasty, dental surgery, osteotomy, etc. As long as you're happy for us to use these photos online and in the print leaflet (with or without your name attached), we'd love for you to send them in to us at info@clapa.com

At the Adults Mini-Conference, one of our incredible volunteers and aspiring photographer Ryan Trower kindly agreed to take photos. We've reprinted them here. You can find more of Ryan's work on his Facebook page: @ryantrowerphotography

WHAT YOU SAID

'Really good, really informative, and really helpful'

'Very interesting to be in a room with a lot of other cleft people… I've enjoyed meeting other people and hearing their stories'

'It was great!'

'It was lovely meeting new people… it's a really great experience, because there's not so much support for adults'

This was our first mini-conference, and we plan to do more. If there's a topic you think deserves its own conference we'd love to hear from you. Get in touch at: info@clapa.com

Young Ambassadors in Scotland

This year, three of our Scotland Children and Young People's Council (SCYPC) were selected as Young Ambassadors to represent youth across Scotland for the Year of the Young Person. Here, Olivia and Ewan share their stories as they prepare to start their terms as Young Ambassadors.

Olivia

You are about to start your term as a Young Ambassador. How did you become a Young Ambassador and why?

Gillian McCarthy (CLAPA Senior Regional Coordinator for Scotland) sent details to my mum and when she showed me what it was about I was excited. It's all about Year of the Young Person and I will be getting involved in creating things to do for the young people in my area, giving kids lots of things to do out of school.

You're a member of the SCYPC, what is the SCYPC?

We meet every few months and talk about how to raise awareness for CLAPA and what type of events we think other kids would like. We recently had the Scottish Parliament at our meetings to talk to us about children's rights.

When did you join the SCYPC and why?

I like to be involved and make plans so this was right up my street. I also wanted to give up my time as CLAPA have helped me and my family so much.

How did you get involved in CLAPA?

I have always gone to the CLAPA Christmas parties since I was a baby and, as I've got older, I have done many talks at school and written some articles for the local newspaper and CLAPA on growing up with a cleft. I also attend all the family events.

Has being involved with CLAPA made a difference to you?

Yes it's made me more confident on how I look and meeting other kids with clefts helps me talk about my feelings and feel proud of how far I've come.

What do you hope to achieve in the future?

I would like to be a cleft nurse as I think they are amazing, although the surgeons and Toby, my cleft dentist, are amazing too!

What would you say to young people with a cleft who may be struggling in some way?

You are amazing and should be proud of who you are. If people stare, they are not being rude, just curious, so just tell them all about cleft. I tell everyone!

Ewan

What are Young Ambassadors?

Young Ambassadors are a group of children and young people aged 8 to 26 who represent other children and young people across Scotland, supporting them to get their voices heard in 2018.

You are about to start your term as a Young Ambassador. How did you become a Young Ambassador, and why?

I was fortunate that Gillian, who leads the Scottish Young Persons Group, sent me the information on becoming a Young Ambassador. This sounded like a great opportunity to spread the word about the Cleft Lip and Palate Association as it is not a commonly known charity. I am also excited to work with other children across Scotland during the Year of Young People 2018 and become part of something very special.

When did you join the SCYPC and why?

I have been part of SCYPC for over a year now and I decided to join to meet children and young people like me and raise awareness of CLAPA and the challenges we face. We have meetings every three months or so to work on a variety of projects. Our latest involves working with the Scottish Youth Parliament. In our recent meetings we have been working with them to produce a video about cleft lip and palate to raise awareness.

I think I'm the oldest in our group which is fun and enables me to share my experiences with younger members who may not have had certain operations yet or who are unsure of what it might be like being a teenager with a cleft.

What has growing up with a cleft been like for you?

Growing up I feel like I have had a normal childhood. I'm now going into my fifth year at secondary school and I have a good group of friends and I am enjoying school (as hard as that is to believe). However, I know for younger children with cleft this is not the case but I believe as you get older people have far more important things to worry about than what you look like. I've had to make many trips to the dentist, especially when I was younger, and have had multiple surgeries but, now that I am reaching the end of my treatment, I realise that it has all been worth it.

Each place on one of our Children and Young People's Councils costs around £600 per year. We believe giving young people a voice and a chance to make a positive difference to others like them is vital, and as such we hope to create a number of other local CYPCs around the UK.

Alice's Story

It was wonderful news – we were expecting our 3rd baby in June 2013! My husband, David, and I already had two boys, Harry and Jack.

My pregnancy felt different this time. I was extremely sick and something preyed on the back of my mind. The big day arrived and we welcomed Alice Elizabeth, who weighed a very healthy 10lb 11oz. I watched as the nurses gave her some oxygen, and I noticed they were discussing and agreeing on something. They handed back Alice and they said she was fine. Then I asked what they'd been discussing, and was told Alice had a cleft of the soft palate.

David and I had never heard of a cleft palate, this was to be the start of a whole new journey for us.

I remember being in a bubble and not taking very much in. David gave Alice her first bottle and the only way I can describe how she drank was she sounded like Maggie from The Simpsons. She sucked hard and put a lot of effort into it but couldn't suck much milk out of the teats, and it was very tiring. Our first night went by in a blur, I sat up chatting with the midwives whilst they helped me feed. I would keep it together, and then I'd cry once they left.

The next morning a lovely lady called Lynn arrived bright and early from Manchester's Cleft Team. Lynn was so kind and straight-away I felt so much better. Lynn explained in easy terms all about Alice's cleft. She explained that clefts occur in very early pregnancy, and it was no one's fault. This put my mind at ease as being Alice's mummy, I had blamed myself.

Alice would feed for 1 ½ hours and re-feed an hour later. We became very isolated, and only told a few close family and friends. I still ask myself: why did I do this? A mixture of reasons, I think. Would we be gossiped about? What would people think? People might stare. Would I get support?

This is something I totally regret and I would always try to encourage families to be open, be proud, and ask for support. Lynn often mentioned a support group we could join called CLAPA Happy Faces Lancashire, based in Preston. I kept telling Lynn I didn't need to talk, but deep down I think I did. I struggled for 7 months before joining the group, which was run by Maria who had been through the same thing. They organised meet-ups so children could play and parents could chat and get advice. I would chat to other mums, who gave me support, practical advice, and answered all my silly questions. They gave me tips on things to take to hospital, what it would be like and how Alice would be. Most of all I made a lovely friendship with a lady called Samantha, her husband and 2 children.

March finally arrived I felt slightly nervous but Samantha had talked me through everything. During pre-op measurements, Lynn noticed that Alice's head had grown off the scale. We talked it through and decided to get the palate op out the way, and then I'd visit my GP. Once at the hospital the nurses were so welcoming and put us at ease. I made the decision to go with Alice down to theatre, fighting back the tears as I knew she was in safe hands.

Alice was very grumpy, tired, and cried when she came back round from surgery. All she wanted was cuddles and sleep, her mouth was swollen, cut, and she looked pale. Lynn and a cleft ward nurse Katie came to help as she was struggling to feed. Once home Alice was really unsettled and would cry a lot. I felt I had a different baby. Lynn visited, we were still struggling with feeding and I was very scared I'd hurt her mouth, Lynn managed to get Alice to suck from the bottle, the first time she had ever sucked without help.

I visited our GP regarding Alice's head. We were quickly referred to Blackburn Hospital, where an MRI scan showed she had a cyst growing on her brain. Once again we were back in Manchester feeling totally heartbroken, but Lynn and Katie supported us through her operation.

After a difficult few weeks I took to social media to tell all our family and friends about Alice's journey, and was amazed at how much people cared and offered us support. I so wish I'd done this from the beginning. Alice's cleft saved her life and we will always be truly grateful to Lynn for all she did for us. Alice is amazing, so happy and becoming more confident daily. Her speech is fantastic and her palate is working beautifully, we are extremely proud.

Every year in May we support Cleft Lip and Palate Awareness Week with sponsored walks and teddy bear picnics, until last year when Preston held their first sponsored bounce. Seeing my children and family all wearing their CLAPA t-shirts makes me so proud, we are cleft strong!

Many people often ask us how has this affected us. My answer always being we are stronger than ever, we are a team and together we will fight anything and we will stand proud and spread awareness and if Alice's misfortune can help other families then we are happy.

We're currently looking for a new volunteer Happy Faces Coordinator in the Preston area. If you're interested in supporting people affected by cleft in the area, get in touch at: volunteer@clapa.com

Laura's Story

I was told at my 12 week scan that Harrison had a unilateral cleft lip. I found this very difficult to take in and instantly searched the web for pictures. My first thoughts were horrible: what is he going to look like? Why me? How could this happen?

It was, or felt like, a long wait to see the specialist at the hospital - I was anxious to see my little one. I finally went in, and my consultant showed us our baby...a baby boy. All I could do was cry, and cry more. He told us about everything, putting our minds a little at ease. I was in love with my boy. More scans, every few weeks, discovered that Harrison's cleft affected more than just one side, he had a bilateral cleft lip and his palate was affected. I cried even more, as I'd just got my head round the first one.

I felt like I needed to relax and try and enjoy what was left of my pregnancy, but this was very hard. I was nervous about the birth, I didn't want to go over and I didn't want to be induced, but everything I didn't want to happen did, making things seem so much worse.

When Harrison was born…

I couldn't look because I was scared. What if I didn't love him? What if he didn't look like I expected? I just cried and cried, with my husband telling me, 'Laura he is gorgeous! He is just perfect!'

I had bad after-pains so this delayed me holding him, but as soon as I did, all was forgotten. He was beautiful; I was totally in love with him - my little precious baby boy. Harrison adapted to feeding straight away and drank like a little trooper. I couldn't stop looking at him, but I was still scared for when my other kids came, how would they react? Telling them was hard, they didn't really understand. My youngest girl explained in her own words about it to her friends, pushing her lip up was the only way she could explain. This didn't bother me, as she didn't really understand. But when they came to the hospital there wasn't one word about his lip, just 'can I hold him?' They weren't bothered about it. This was a huge weight lifted for me.

Once home, and out and about, I was proud that nothing bothered me. I would rather speak to people about it, rather they ask me questions, but not one person said anything. When one young child at school asked, my kids and their friends explained proudly about their baby brother. The children had educated their school about it, everyone knew - they all loved Harrison and would swamp his pushchair.

We then decided to start fundraising

My son wanted to sell cakes at school, and we did another cake sale at a baby clinic and the nursery I work at, Nest, which also did a pyjama day, all in aid of CLAPA. My nursery was so supportive, I was overwhelmed. We raised a lot of money, but also raised a lot of awareness as many people didn't know anything about cleft.

We then decided to have a party for Harrison. But it wasn't just about him, it was about raising awareness, and if we could raise money then even better! I set out to get lots of raffle prizes and things to make it an extra special night. We had it all sorted, Paw Patrol mascots, face painting, my son Hayden doing a tombola, and a food and candy cart.

I was stressed as it was non-stop and there were some setbacks, but I loved all of it! When the day came I was unsure who would turn up, but I had 200 people attending! I was so overwhelmed with it all, I just sobbed. I couldn't thank Jellylegz the entertainers enough; they stepped up and went above and beyond. They did all this for Harrison, they were more than happy to help us and fell in love with him just like everyone else had. They said their team had done it from the bottom of their hearts and loved doing it all.

The night was fantastic, we raised £1,017! We raised awareness about cleft lip and palate, but also had a fantastic night doing it. We will go again bigger and better next year.

What happens next?

Harrison's surgery is coming up soon. I'm ok with it, but I cry every time I have an appointment about it and I know I'll be an emotional wreck. I get my head round it then people ask me and say oooh he's going to change again and I break down crying, but I know it's going to be like this and I know it's in Harrison's best interests to get it done young, as he won't remember anything.

It has been a scary and emotional journey but I would not change it for the world. Harrison is the most adorable, handsome fella, our precious baby boy, who we, and his brothers and sister, adore so much.

Interested in doing some fundraising of your own? Get in touch with our friendly team at fundraising@clapa.com or give us a call on 020 7833 4883

Cleft Care UK

In 1997, cleft treatment in the UK began to undergo a huge shift. Before then, treatment was provided by 57 centres up and down the UK, but following centralisation, that number has shrunk to 11 hospitals. A shift of this kind often suggests cuts or a reduction in the service, but this was not the case here.

Change was desperately needed. It was spurred on by the results of a survey conducted in the mid-90s which found that outcomes for children with a cleft often fell below those in the rest of Europe. Something had to be done, and the decision was made to concentrate cleft care into more specialised multi-disciplinary teams, working in broad regional networks. No longer could cleft surgeries be carried out by non-specialist surgeons. Now, to qualify, surgeons had to complete at least 40 cleft surgeries per year.

The good news is that, 20 years on, the impact of this change is starting to become clear. A study, carried out by Cleft Care UK (CCUK), looking at 268 5-year-olds born with unilateral cleft lip and palate, found that almost every outcome has seen improvements, some of which are quite dramatic.

However, some important outcomes have remained stagnant; oral health outcomes, for example, have changed very little. In 1997, 45 % of children were tooth decay free in the original survey, a number which has only increased to 48 % in the current survey.

Even those outcomes which have improved are still not as good as they could or should be. A substantial proportion of children still have poor results, for example, 17 % have unintelligible or just intelligible speech at 5-years old.

There is also a huge variation between centres, both in their practice, and their outcomes. For speech intelligibility, the centre a child was treated at can explain up to 13 % of the variation in their outcomes. Ultimately the CCUK report found that care predicts outcome. Where there was good provision of hearing and of speech interventions, there were good speech outcomes. This is a hopeful finding, suggesting that outcomes can be improved further.

There is also evidence to suggest some preventative oral health measures, like fluoride tablets and varnish are used rarely and often ineffectually. The evidence suggests they are often only being applied once decay has already begun to set in, treating the disease rather than preventing its appearance.

Overall, the report does paint a picture of a vastly improved service, but one with some lingering issues that must be firmly addressed if the service is to continue to improve, as it must. As your patient voice, CLAPA will continue to work with our dedicated surgeons, researchers, and other NHS professionals to make sure it does. And, of course, we'll keep you posted on progress!

'CLAPA's Children and Young People's Council enjoys a Residential Weekend in August 2017. Since the Council was formed, they've helped a number of different researchers put together and evaluate projects aimed at young people born with a cleft.'

Matilda's Masterclass for World Smile Day 2017

On Wednesday 4th October, we headed to Carnaby Street to visit Urban Decay Cosmetics for a makeup masterclass with business manager Matilda Lansdown. Matilda, 26, was born with a bilateral cleft lip and palate, and has undergone around 13 surgeries throughout her life.

"I love makeup and I love being able to open the beauty world up to all," Matilda said about her World Smile Day celebration. "It is a chance to support The Cleft Lip and Palate Association, raise awareness and hopefully inspire and educate anyone and everyone on the endless and ever-changing possibilities of makeup.

"I wear makeup same as I wear underwear, it makes me feel ready for the day and can reflect my mood and style that day. Makeup should not be a mask but an extension of your personality."

"Makeup should not be a mask, but an extension of your personality."

The basement room of Urban Decay Carnaby Street

World Smile Day 2018

World Smile Day 2018 will be on Friday 5th October. It's a great excuse to organise a fun celebration and raise awareness at school, college or your workplace. Get in touch with our fundraising team at fundraising@clapa.com for support

"I think the scariest thing when you're younger is when people ask you questions about it and you don't know what to say."

Back in 2013 when she was just 18, Matilda took part in the Channel 4 show **Embarrassing Bodies**, which followed her journey through getting jaw surgery (osteotomy). In this procedure her jaw was moved forward 13mm, which she says drastically improved her speech. You can find a clip of this show on CLAPA's website under Treatment > Teenagers > Jaw Surgery, but please note it does contain graphic images of surgery that some may find disturbing.

A number of young women born with a cleft joined us in a packed-out room in Urban Decay's flagship European store. Matilda answered questions about her life, her cleft, and her love of cosmetics as she had her makeup done by a colleague and showcased her lipstick routine.

"I think the scariest thing when you're younger is when people ask you questions about it and you don't know what to say. I come from a big family, so we always talked about it, […] my mum's a nurse and my grandad is a doctor, so that also helped with knowing how to answer questions."

"I've always been quite vocal, but…that's still scary because you can get some nasty people who have nasty comments to make and even now still, on Instagram, I'll have nasty people, but I just delete them and block them. I don't even respond. I feel if you respond to negativity you're just going to get negativity back, you just block it, that's what I do."

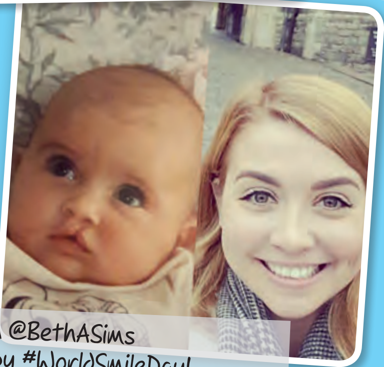
What's Your #ReasonToSmile?

@clapacommunity

@incredible_isla
Today is #worldsmileday so here's my #reasontosmile with both her smiles!

@CarlaDevinel
My #reasontosmile born with a cleft palate & still smiling. #WorldSmileDay

@punc_loopyxxlou
A reason to smile #worldsmileday



Beth @BethASims
Happy #WorldSmileDay! #ReasonToSmile this throwback to when I was a chubby cleft baby

Our Funders

Thanks to the generosity of our new and loyal supporters across the UK (and even the USA!), CLAPA went from strength to strength in 2016-17. Without this generosity, the people who have shared their stories in this edition of CLAPA News wouldn't have received much-needed support from CLAPA. It is due to grants, donations, and in-kind gifts from our incredible supporters that people affected by cleft can get the help they need today.

- **Robert Barr's Charitable Trust** has funded CLAPA for 10 years. Most recently, they gave us £10,000 towards our core running costs.
- **BBC Children in Need** has supported CLAPA since 2011. Most recently, they funded the post of our Children and Young People's Officer, Family Days, young people's activity days, and our Children and Young People's Councils.
- **The Big Lottery Fund in England** recently awarded CLAPA a second grant for our England Regional Coordinators project through their Reaching Communities programme. This time they gave us a generous £323,076 over three years.
- **The Big Lottery Fund in Scotland** continued to fund our Scotland Regional Coordinators Project through their Investing in Communities programme.
- **Crown Worldwide** chose CLAPA as their Charity of the Year. This support has included ongoing funding towards core service costs, advice and support, and significant volunteer time from their generous staff.
- **The Patrick & Helena Frost Foundation** has funded CLAPA for nearly a decade. Most recently, they gave us £10,000 towards our core running costs.
- **Glasgow Children's Hospital Charity** has continued to fund our Scotland Regional Coordinators Project.
- **The Robertson Trust** continued their support of our Scotland Regional Coordinators Project.
- **Edinburgh Children's Hospital Charity** continued to fund our Scotland Regional Coordinators Project.
- **The Scottish Government Health and Social Care Directorate** has continued to contribute to our Scotland Regional Coordinators Project.
- **SE Controls** have generously supported CLAPA with over £8,000 as their Charity of the Year.
- **Smile Train**, an international children's charity, has funded CLAPA for many years. Most recently, they have helped to support the Regional Coordinators Project.

Do you know someone who could support CLAPA?

Whoever you know, we'll find the perfect way to get them involved in our work and help us to make a real difference for people affected by cleft. Our friendly fundraising team is here to help – contact us today on 020 7833 4883 or email fundraising@clapa.com

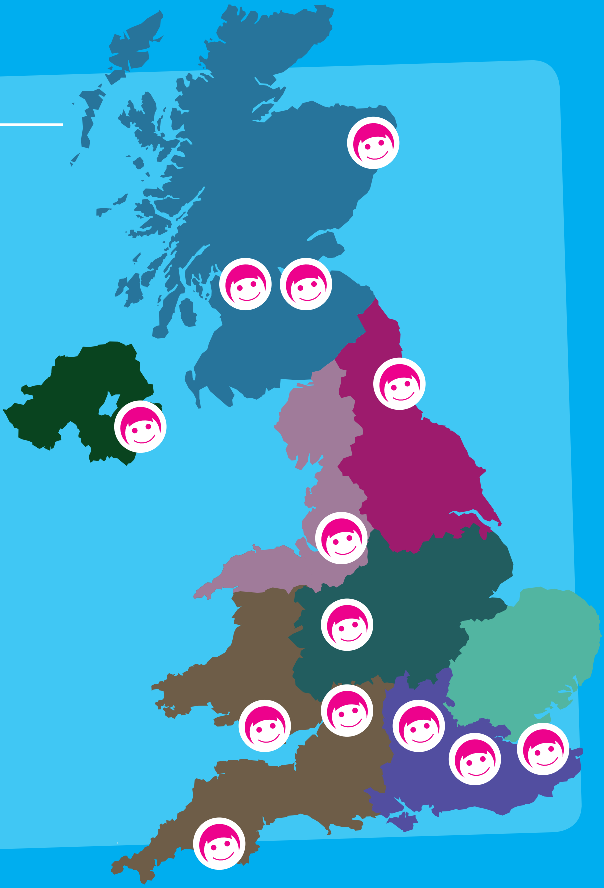
We also received crucial funding for our projects and core running costs from:

The Alchemy Foundation
Anson Charitable Trust
The Ian Askew Charitable Trust
Aspire Housing Association
Misses Barrie Charitable Trust
Michael Brown and the Weald of Kent Golf Club
The Calleva Foundation
The Camelia Trust
Chichester Access Group
The Christadelphian Samaritan Fund
Marilyn Clarke and the Frinton-on-Sea Golf Club
The Clover Trust
The Bernard and Joan Dunn Charitable Trust
The Dyers' Company Charitable Trust
Energy and Technical Services (ETS) Ltd
Frazer Trust
Greenbank Preparatory School
Holmesdale Lodge
The Incorporated Church Institute
The Imago Trust
Mrs F B Laurence's Charitable Trust
Raymond and Blanche Lawson Charitable Trust
The Charles Littlewood Hill Trust
Lewis Ward Trust
Lindfield Bonfire Society Ltd
Liverpool Charity and Voluntary Services (LCVS)
The Lynn Foundation
The Madeline Mabey Trust
Marathon Oil
Millward Brown UK Ltd
The Mini Clan
D C Moncrieff Charitable Trust
G M Morrison Charitable Trust
Edith Murphy Foundation
Oast Quilters
Ommaroo Hotel
The Pennycress Trust
Queen Elizabeth Grammar School
Rathbones Investment Management
Reuben Foundation
Rusdene Services Ltd
The Charles Skey Charitable Trust
St James's Place Foundation
The Swire Charitable Trust
The Ione Vassiliou Charitable Trust
The Jeannine Vassiliou Charitable Trust
The Nicka Vassiliou Charitable Trust
Veolia UK
Waitrose Community Matters
The Worshipful Company of Carmen Benevolent Trust

On behalf of the cleft community, thank you so much to all our amazing supporters. With your help, we have provided one-on-one support through our trained Parent and Peer Supporters [p. 14-15], held confidence-boosting residential weekends for children and young people [p. 20-21], and run Happy Faces family support groups across the UK [p. 26-27]. Together, we can make sure that everyone affected by cleft lip and palate feels supported, connected and empowered.

In Your Area

Visit www.clapa.com/in-your-area for the most up-to-date news and events from the CLAPA Community in your region of the UK. You can also find local groups, or trained volunteers to talk to one-on-one at any time. It's your community – be a part of it!



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

Registered Charity England & Wales
(1108160) and Scotland (SC041034)
Green Man Tower, 332B Goswell Road
London, EC1V 7LQ
T:020 7833 4883
E: info@clapa.com
www.clapa.com

@clapacommunity facebook.com/clapacommunity
clapacommunity flickr.com/clapa vimeo.com/clapa

Design and print by Captiv8. Tel: 01892 611500 Web: www.captiv8uk.co.uk