CLAPA
Cleft Lip & Palate Association

CLAPA NEWS

Issue 26 // 2015/16

CLAPA is Growing! Meet our new staff and trustees

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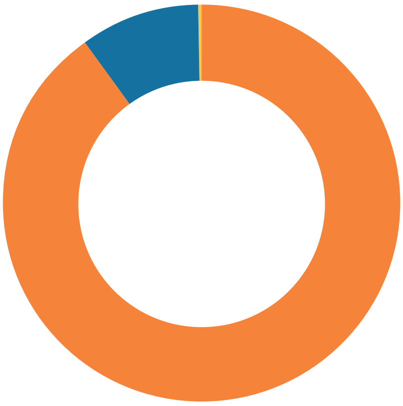
Registered Charity England & Wales (1108160) and Scotland (SC041034)

Welcome to CLAPA News In this issue

Accounts Summary

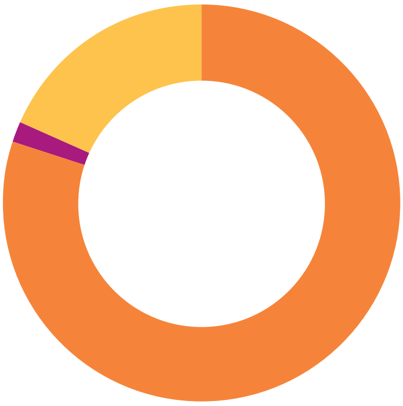
2014/15 Financial Year

Income £638,640



🟧	Donations/Grants	£575,719
🟦	Sale of Goods	£61,673
🟨	Other Income	£1,248

Expenditure £599,841



🟧	Charitable activities	£480,204
🟪	Governance	£10,609
🟨	Generating income	£109,028

Foreword

Mark Russell, Chair of CLAPA's Trustees

A large part of our role as Trustees is defining a direction and strategy for CLAPA that is coherent, relevant and that remains focused on our vision: a society where having a cleft presents no barrier to achieving your desires and ambitions. That means supporting those individuals and families affected by cleft, the health professionals that treat and support them, and the wide range of services, volunteers and CLAPA Community which makes it all tick.

To continue to do this the Board of Trustees needs committed and passionate individuals who want to make a difference, and we are blessed to have had the support of a tremendous group of Trustees over the last 4 years of my tenure as Chair. Some of these Trustees have now stepped down from their roles, meaning we have said goodbye to a number of trustees in the past year who have given a huge amount of their time and experience. A big thank you then to Emma Southby, Peter Leslie, Bernie Nyman and Helen Langford, who have all left the Board in the last year but who all remain firm members of the CLAPA Community!

And there's a big welcome, too, to 6 new Trustees recently recruited to help us continue to meet our objectives. Our new trustees are listed on our website and all bring a unique and valuable perspective to cleft and our strategic and operational priorities, with skills ranging from social media and PR, through to HR, Law, Governance, Volunteering and IT. And everyone has been affected by cleft in some way, so they bring a personal as well as professional opinion to the table.

I'm delighted about this development and the additional energy and perspective it will undoubtedly bring to the team. I would also like to thank all those fabulous candidates who also put themselves forward for the roles but were not chosen this time around.

Finally, a big thank you firstly to the growing CLAPA team who have worked so diligently to meet our objectives and goals. And of course to you, the members of the CLAPA Community who share our vision and support us and those affected by cleft so readily as volunteers, supporters and participants in the activities and initiatives we are all building. Enjoy this edition of CLAPA News and thank you again for your continued support.

News From Clapa National


CLAPA Staff posing for a Happy Holidays photo in 2014

The last year has been huge for CLAPA, and we've been able to reach more people than ever before thanks to a number of exciting projects and the seven new staff members who are helping us make them happen.

Our network of CLAPA Branches and Groups continues to evolve, with new committees continuing the work of the Bristol and Merseyside Branches, and entire new Branches being formed in the West Midlands (page 18), the East of England, the North East and Glasgow. At the moment we're also looking into setting up our first Branch in the North East, as well as establishing a new Branch in Glasgow. Happy Faces Groups around the country continue to welcome new parents, and new groups are being established with the help of Regional Coordinators, such as the new Cambridge Happy Faces Group and the Antenatal Group at Broomfield Hospital.

At the Branch AGMs in 2015, CLAPA unveiled our brand new Branch Manual to support Committee Members through the ups and downs of running their Branch, and this will soon be joined by a Happy Faces Guide to support even more volunteers to start up local groups.

Following our Conference theme in 2014, CLAPA has focused on starting up Patient Voices groups around the UK, and three are currently active in the East of England, Central England, and Scotland (page 15). CLAPA GOSH has also held successful Parent/Professional Forums which have put the patient voice front and centre.

A cake to mark CLAPA's 35th birthday at a South London & Surrey Branch fun day.

The past year has seen 60 new Volunteers and 22 new Parent Contacts being trained, and we've shown our appreciation with a brand new Volunteer Handbook and our first ever Volunteer Awards. On top of this, we celebrated National Volunteers Week in June by sending out thank-you certificates to all the volunteers who help CLAPA continue its work!

Adult Support has taken a huge leap forward with our new Peer Contacts, who are adults with a cleft trained to give one-on-one support to others over the phone or email. A list of Peer Contacts can be found on our website. The Adult Voices Council have a few new initiatives planned for 2015/16, so keep an eye out! Our Children and Young People's Council were treated to an exchange trip to the Azores in Portugal, as well their own Residential Weekend. CLAPA also has run two other confidence-boosting weekends for young people in Wales and the Midlands.

We have some very big plans over the next year, including a full overhaul of all our information materials and a complete redesign of our website! Both of these ambitious projects are in full swing right now, so make sure you sign up to get our newsletter at www.clapa.com to be the first to hear about any updates.

● We are always happy to chat about the work we do at CLAPA. Get in touch by calling 020 7833 4883 or email info@clapa.com. To keep up to date with all the latest news at CLAPA National and beyond, sign up for our e-newsletter at www.clapa.com.

New Staff at CLAPA

GET IN TOUCH
See the back of the magazine for a full list of staff and Trustees. To get in touch, call our office on 020 7833 4883, or see our website, www.clapa.com, for full contact details.

Welcome to…

Chris Williams
Volunteering Officer

I joined CLAPA in May 2015 as National Volunteering Officer to support volunteers in the areas of the UK that don't yet have a Regional Coordinator. It is wonderful to be working with so many inspiring and dedicated people who support cleft lip and palate.

CLAPA has a fantastic relationship with its volunteers, fundraisers and the Cleft Teams, so I've been given a really warm welcome already. I have very strong links with CLAPA being born with a bilateral cleft lip and palate myself. I have been a volunteer and fundraiser for many years and remain Chairman of the Great Ormond Street Hospital (GOSH) Branch. We've already seen some fantastic achievements at CLAPA and I'm very much looking forward to building on these over the coming months.

Cherry LeRoy
Regional Coordinator for South East England

I joined CLAPA in June 2015 and support volunteers and families in the South East of England. I am delighted to be working for an organisation that has such a dedicated team of enthusiastic volunteers and look forward to building on the good work that has already been established to support cleft services at a local level.

My background is working with children and families, and I have been working in the voluntary sector for the past 18 years where the ethos has been to empower families. I hope to bring some of my skills and experience to those roles and to learn from families and volunteers about their experiences.

Claire Evans
Regional Coordinator for Central England

I joined CLAPA in October 2014 and support volunteers and families in the areas of England served by the West Midlands Cleft Service and the Trent Cleft Service.

I've been busy meeting lots of brilliant volunteers and supporters and continuing to build a strong support network by recruiting and training new volunteers across the region. CLAPA already has an excellent, longstanding relationship with both Cleft Teams in the region so I've been given a really warm welcome and we're working on some exciting projects!

Rowena Knight
Trusts and Grants Fundraiser

I joined CLAPA in October 2014. Since then I've been working to bring in grants from charitable trusts and foundations so that CLAPA can continue to help people affected by cleft reach their full potential.

My main priority is to fundraise for our Regional Coordinator Project (page 17) so that CLAPA can provide local support for everyone who needs it. Getting your feedback is incredibly important for my applications, so if you see a CLAPA survey aimed at your region, please fill it in!

Gillian McCarthy
Senior Regional Coordinator for Scotland

I joined CLAPA in October 2014 on a part time basis and have spent time getting to know our volunteers and the issues for those affected by cleft in Scotland. Everyone has made me feel very welcome and I'm thrilled to have taken on this role full-time as of September. I started my career as a Speech and Language Therapist specialising in youth offending but left that to move into service development and latterly worked at the National Autistic Society developing a new project with volunteers and adult clients. I'm also really passionate about baby signing!

Melanie Skinner
Scotland Support Officer

Melanie will be joining the team on 1st September 2015 as our Scotland Support Officer. Melanie has experience of developing branches across Scotland and working with volunteers and is really excited about coming to work for CLAPA.

Preeti Baid
Senior Fundraising Manager

I joined CLAPA in September 2015. My previous experience includes working for a number of leading international charities, predominately in Major Giving roles. I am excited to join CLAPA at a time of such growth and movement in the charity!

After almost five years at CLAPA, our Finance Manager, **Edit Walsh**, has left the organisation. As soon as she joined in July 2010, Edit got to work putting CLAPA's accounts in order, and five years on she leaves us with our finances in tip-top shape! In that time she's also managed our feeding service which delivers specialist bottles and teats to parents, as well as our Christmas cards every year. CLAPA's Volunteers and Branch Committee members will know Edit for her unbeatable efficiency when it came to paying invoices and expenses, and for her patience and care in supporting others to write budgets and manage their finances for all sorts of events and activities.

We will all miss Edit and her distinctive and elegant dress sense, her infectious smile, her love of champagne and chocolate, and of course for all the wonderful experiences we've shared with her as a core part of the CLAPA team.

New Trustees

CLAPA is governed by a Board of Trustees who are all volunteers. There's a mix of parents, adults with a cleft and cleft health professionals, all of whom bring their own unique mix of skills and experiences to the table.

In early 2015, we recruited SIX new Trustees!

Nick Astor - PR and Communication professional and father of a child with a cleft

Cassie Footman - Human Resources professional and mother of a child with a cleft

Yin Jones - Former barrister and mother of a child with a cleft palate and PRS

Judy Kreig - Qualified lawyer and adult with a recent diagnosis of submucous cleft palate

Jemma Morgan - IT professional and mother of a child with a cleft lip and palate

Marie Pinkstone - Lead Speech and Language Therapist, North Thames Cleft Service

"My Cleft, My Voice!"

CLAPA CONFERENCE

21st November 2015 - LONDON

Taking Control

The theme for CLAPA's 2015 Conference is 'Taking Control'. The event will look at what motivates people to become an advocate for their own (or their child's) care, and how this involvement can benefit them in unexpected ways.

CLAPA Branch Reps at our London conference

Our 2014 Conference was all about 'The Patient Voice' and how much CLAPA and the NHS value both patients and parents coming forward to give their feedback at every stage of the care pathway. We also heard from other organisations about how they were involving their community in their work and what a positive impact it can have.

In 2015, we'd like to take a step back and look at the very different reasons why some of our volunteers decided to take control and make their voice heard in what can sometimes feel like an intimidating medical environment. We'll hear from young people making a difference in the NHS, adults at various stages of treatment who have taken control of their care, and parents who have been driven to speak up for their children and others like them.

In particular, we will look at how young people with a cleft transition into adult patients and how they can be best supported to understand and feel in control of the future of their own care after years of going along the treatment pathway.

This Conference will also see the launch of two new resources that have relied on feedback from people like you every step of the way – our redesigned website and our brand new range of information leaflets!

Even if you can't attend in person, we will be streaming the entire conference LIVE online so you can join the debate from the comfort of your own home. Visit www.clapa.com to find out more and to book your place, or call 0207 833 4883.

Adults

With an increasing focus on adults with a cleft, members of Adult Voices (AV) together with Regional Coordinators have been busy getting information out there that will encourage more adults to be aware of what is available, whether these be clinical services, emotional support, or even volunteering opportunities. A number of projects are currently in progress.

Updates from the Adult Voices Council

Peer Contact Training: Eight adults with a cleft attended a two-day training weekend in November 2014 to become Peer Contacts, volunteers providing confidential one-to-one support to other adults. The training was delivered by CLAPA staff as well as a Clinical Psychologist from a Cleft Team. These Peer Contacts are now listed on the CLAPA website, and more promotional materials are in the works to raise the profile of the service. Already there are new volunteers eager to attend another training weekend, so we are excited to see this service expand over the next year!

- AV members have been presenting to their local Cleft Teams to keep them up to date on CLAPA's services for adults, and they have also been active within our Patient Voices groups (page 15) to ensure the needs of adult patients are considered.
- AV have been working to ensure each CLAPA Branch Committee has at least one adult with a cleft.
- CLAPA's website is being redesigned in consultation with AV members to make sure the content for adults with a cleft is both appropriate and comprehensive.
- AV members have been heavily involved in the evaluation and production of CLAPA's first information leaflet aimed exclusively at adults with a cleft.

Do you want to find out more about what services CLAPA has for adults with a cleft? Make sure you sign up for our regular e-newsletters at www.clapa.com, including a quarterly mailing for adults with a cleft.


Chris just after his 10,000 ft tandem skydive in aid of CLAPA

Cover Star Chris

On the cover of this year's CLAPA News is Chris Williams, long-time volunteer, first-time skydiver, and, as of May 2015, CLAPA's new Volunteering Officer. Chris was born with a bilateral cleft lip and palate and has represented adults with a cleft at some prestigious venues, including Harvard University and the Houses of Parliament!

From Cleft Clinic to Catwalk: Jennifer's Story.

Jennifer Mitchell was born with a bilateral cleft lip and partial cleft palate at Falkirk Royal Infirmary 18 years ago.

Like her older brother Donald, now 21, who had an incomplete unilateral cleft lip, it wasn't discovered during scans, and the family experienced the usual busy rounds of appointments and surgeries twofold throughout their childhood.

She and Donald appeared together on a CLAPA poster approximately 12 years ago which was placed in hospital waiting rooms all around the UK.

In April 2015, Jennifer enjoyed publicity of a different kind, starring in a fashion photo shoot for the Daily Record, Scotland's biggest selling daily newspaper. Under the heading "Does my bum look big in this?" Jennifer and two others modelled designer Jasper Conran jeans.

Jennifer said: "I cannot imagine not having a cleft lip now, it's part of me. I do get very frustrated by being a cleft patient though, and am thoroughly bored of appointments and procedures.

"I am happy with how I look and have no plans to change anything with more surgery."

Jennifer had her lip repair at four months, a minor surgery at five years old and a bone graft at 10. She had braces from ages 8-10 to widen out her palate arch, then train track braces for two and a half years. She wore a dental plate with false teeth for a while, and as her bone graft was not strong enough to support implants, she has recently opted for false teeth on a bridge as a long-term solution.

Jennifer added: "I don't see the point in more 'cosmetic' surgery at all, I ruled that out after my last bone graft. To me that will just be altering my scars to make them, perhaps, slightly less noticeable scars. But I am comfortable with how I look, so whose benefit would that be for? Not mine; for now I am happy as I am."

> "I cannot imagine not having a cleft lip now, it's part of me"

PHOTO CREDIT DAILY RECORD NEWSPAPER.

Jennifer in her photo shoot. Jennifer and Donald as children Jennifer and Donald in 2015

New Leaflet For Adults

At the moment, CLAPA is working on a range of new information leaflets covering the stages of treatment for people with a cleft, from diagnosis and infancy right through to adulthood. We're hoping to launch hard copies by the end of 2015, but before then we're looking to host digital copies on our brand new website which will launch during our 2015 Conference (page 4).

This means that for the first time we'll have information products aimed exclusively at adults with a cleft! We've worked hard to make sure this new leaflet addresses the most common questions and concerns for adults with a cleft, but we need your help to make sure that our information continues to be relevant and comprehensive.

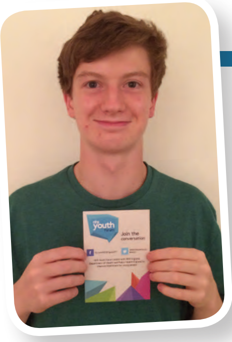
With this in mind, please give us feedback on both the leaflets and the new website when they are launched! Your voices are the most useful tool to help us improve going forward, so please lend yours to the discussion by letting us know how we can better support you.

FIND SUPPORT

Visit www.clapa.com to find a list of trained adults with a cleft who can provide one-to-one support. Alternatively, you can email info@clapa.com or call 020 7833 4883 and ask for CLAPA to put you in touch with a suitable Peer Contact.

Facebook.com/groups/CLAPAadults
Twitter@adultvoices

Children and Young People



Meet Ben

I'm Ben, 17 from Sheffield. I was born with a cleft of my hard and soft palate. I've been part of the Children and Young People's Council at CLAPA for around 9 months now and am thoroughly enjoying it – I just wish I'd found out about it sooner! I'm mad keen on most sports and love music – particularly playing bass guitar with my band around Sheffield!

Why I got involved?
I originally set out to join CLAPA in a volunteering role before being directed to the CYPC. I've been really enjoying my individual role and of the Council itself as well as the experience of meeting loads of likeminded people and the chance to work with them. When the opportunity came up to apply for the NHS Youth Forum for the coming year I saw it as another chance to express my voice, both on issues raised by the council and on larger, national topics of debate. Particularly at my age, the issues affecting young people are ones the NHS are taking into serious consideration and I wanted to have my say in shaping our future NHS. The chance to meet loads of people, like the CYPC, from a variety of contexts and backgrounds also had its appeal!

What I'm hoping to get out of it?
Initially I plan, where appropriate, to input the issues and indeed some of the solutions the CYPC at CLAPA has raised. Hopefully I can use some of those transferable skills I've learnt working with the CYPC in the Youth Forum and equally provide some feedback to the council as to the main topics of debate for young people. In the longer term I hope my experience over the next year with the Youth Forum and the knowledge I gain can be of use to both the CYPC and any other area of CLAPA I may get involved in later on.

> **"I wanted to have my say in shaping our future NHS"**

Coping with Braces

CYPC Member Will explains how he manages to cope with new braces.

"The first week with braces is normally the worst, as your mouth has to adjust to it. In my case I had to keep the brace on 24/7 because it was glued on in place.

If it rubs against your gums or lips, the best method I found was putting a bit of soft, clear wax next to where the brace is attached to, the hospital might give you some when your brace is fitted but if not you can just ask them for some, you could also use cotton wool instead. If it keeps hurting after a few days, you might have to go back to your orthodontist.

You can also buy a separate soft baby toothbrush just for brushing your braces, this will not hurt as much as adult brushes and you will be able to fit it into tight corners of your mouth. You can also get special toothbrushes just for braces.

Remember to drink lots of water and try to not eat junk food, chocolate, snacks or anything with lots of sugar in. Your braces can be a 'plaque trap' and if you are wearing your braces for a long amount of time plaque can build up in the bits under your braces and erode your teeth. It is ok to have a few treats a week but remember to brush your braces to try and get the plaque out.

Wash your mouth out with mouthwash or salt water. Do this about three or four times a day or after eating. This will be better than brushing your teeth at first because your gums will be sensitive.

One last tip is to get some rest. This will take your mind off your braces, which will help ease the pain."

RESIDENTIAL WEEKENDS

CLAPA's Residential Weekends are for children and young people with a cleft aged 9 to 15 in the UK. They're all about having fun outdoors, building confidence, trying new things, and making new friends in a safe and supportive environment. We run these weekends all around the UK, so there'll be one near you soon!

Upcoming Residential Weekends

16th-18th October 2015
Staffordshire

26th-28th February 2016
Kent

How can I be the first to find out about these?

Sign up at www.clapa.com to get our newsletter for young people, as well as announcements about events like these weekends!

> **"I can't believe how much stuff we did in a weekend- but we certainly packed in a lot- we had toasted marshmallows around a camp fire on the Friday night, a disco on the Saturday night and tag rugby, t-shirt painting, walks during the day as well as free time to have adventures and build dens in the grounds.**
> **I enjoyed all my activities - especially the disco!!"**
> **Jenny, 11**

Q&A

Becoming an Adult Patient

In the NHS, the process of going from being a child to an adult patient is called 'transitioning'. It usually happens between the ages of 16-20, depending on your Cleft Team and what kind of treatment you need.

Transitioning into an adult patient can be an exciting time, as it means you'll now be able to get more involved in your own care and have more control over what happens to you, but you may also be feeling uncertain about what the future holds. Depending on where you are in the UK, your care may move to a different hospital with a different team, and this can be tricky to adjust to. It could also be that, for now, you're all done with surgery and other cleft treatment so you've been 'discharged' from the service.

Some Cleft Teams run 'Transition Days' which are intended to help young people like you understand what's going to happen and explain to you how you can navigate cleft services as an adult. If you can, do go along to these, as not only will you be better informed moving forward, you'll also get to meet other young people like you!

Just remember, under the NHS you can return to cleft treatment at any time in the future, even if you'd just like to talk about your options.

GET IN TOUCH

facebook.com/groups/CLAPAYoungPeople

Your Stories

Dealing with Diagnosis
Joanne's Story

Joanne Graham wrote a six-part column for Prima Baby Magazine which documented the diagnosis, birth and homecoming of her second baby, Isaac, who was born with a cleft lip. Excerpts from these columns are printed here with the kind permission of Prima Baby Magazine.

When she first received the diagnosis, Joanne and her family were thrown and didn't know what to expect. Luckily, a visit from their Cleft Nurse Specialist reassured them.

"Knowing there were other families who had been in our shoes and had enjoyed a happy ending really eased my sense of isolation, that feeling of "Why us?". And when [Cleft Nurse Specialist] Dorothy bid us farewell, she left us with a bundle of leaflets, a promise to stay in touch and a more optimistic outlook. A week later, when my husband Alex and I attended a 4D scan (with Dorothy in tow) to try to find out more about our baby's defect, our main feeling was excitement at properly seeing our unborn son rather than horror at what he might look like. And when that precious little face appeared on the screen, offering us just the tiniest glimpse of the cleft that would make him so special, I squeezed Alex's hand and knew we couldn't wait to meet him."

The Graham family shortly after Isaac was born

The time came to tell the rest of her family – and the world! "After speaking to CLAPA, I printed off some photos of cleft babies and tried to explain things to [2-year-old] Noah in simple terms. "You're going to have a little brother and he might look a bit like this," I said, trying to sound upbeat. He studied the images curiously and didn't look distressed at all. But I knew the test would come once the baby had arrived. Aside from Noah, we knew we had to prepare our loved ones too, so it wasn't a shock when he was born. "I want them to celebrate his arrival, not pity us," I said. So Alex and I agreed it was best to share the news sooner rather than later.

When we'd been expecting Noah and were told he might have Down's syndrome, we'd kept it to ourselves as we didn't want to worry everyone. But as the pregnancy progressed, I'd found it tough and could have done with support. I started by calling round our nearest and dearest. Some took the diagnosis better than others. There were lots of questions and I tried to answer as best I could, although I still didn't understand it myself, really. "He's perfectly healthy, apart from this," I explained. "And so am I." After that I decided to post the 4D scan of our baby on Facebook, as an easy way to spread the news. The response was amazing – calls, emails, comments – and all overwhelmingly positive. People just wanted to know how they could help.

There was a huge sense of relief knowing everyone was behind us, and it got Alex and I thinking. There was so much ignorance about the condition – perhaps we had a real opportunity to educate the wider community? "Why don't we set up a fundraising night for CLAPA?" Alex said. "They've supported us so much already." Everyone thought it was a great idea. Soon we had a venue, businesses were donating raffle prizes, while others gave decorations, refreshments and offers to perform. The only difficulty was finding a glam maternity dress for my bump! The night was such a success that we quickly followed up with a second one, raising more than £1,100. It was wonderful to think something so good had come from the situation – and it made me feel so hopeful for my baby's future."

Baby Isaac was born 1st July 2014, and the midwife quickly confirmed that his cleft didn't extend into his palate.

"With the checks out of the way, at midday my mum brought Noah to meet his little brother. We wanted him to see 'his baby' before anyone else. When Noah arrived, he was a little shy, but this soon gave way to a fascination and he went in for a closer look. Seeing our two sons together for the first time was so emotional, especially when Noah gently touched Isaac's face and ran his fingers over his mouth. "Hasn't he got lovely lips?" I said, relieved at his lack of surprise or horror. I just hoped everyone else would be so welcoming of our beautiful new child."

Sue's Story

Sue was born with a cleft lip and palate in 1938, ten years before the NHS and over sixty years before any Cleft Teams as we know them today were established. Recently, Sue decided to write down her story from start to finish and share it with CLAPA and our community.

Her story includes anecdotes about how the local hospital was bombed during her palate repair procedure, her father leaving to go to war with a photo of his two children that cropped her out, and memories of growing up in a small village in Dorset where others like her were few and far between. She also remembers the particular struggles she had with her speech due to her cleft palate, and how it continues to affect her to this day.

As Sue says: "Looking back over the years I realise that I depended a lot on my friends and family to help me with speaking, letting them do it for me. I have come to accept how I am, and know my limitations, for instance I could never go on television or give a speech, but I think that in this life you have to make the best of what you have got. I know that there are people who are a million times worse off than me."


Sue at 21 years old

You can read her story in full by visiting www.clapa.com.

> "Looking back over the years I realise that I depended a lot on my friends and family to help me with speaking, letting them do it for me"

#SHAREYOURSMILE

In the run-up to Awareness Week 2015 we asked our community to share their favourite photos of smiles with us on social media and through our website. Here are some of our favourites!


Zachary was born during Awareness Week 2013 with a bilateral cleft lip and palate. Here he is on his first day of preschool.


Alice was born with a unilateral cleft lip and palate, while mum Rachel was born with a cleft lip.


"**Lily** aged 5 weeks showing us her first big wide smile – which is going to be very missed! She has a unilateral cleft lip and palate."


Oscar at 10 months old, 3 months after his lip repair surgery


Steph and her daughter Lola were both born with a cleft palate

Fundraising Heroes

Our patron Carol Vorderman did her bit to raise vital cash for CLAPA by auctioning off some of her designer outfits on HardlyEverWornIt.com. Amongst the items up for grabs was the dress she wore on her last ever episode of Countdown, as well as gowns from the likes of Michael Kors and Vivienne Westwood. So far, she's raised over £5.5k for CLAPA, and the total is still going up! Carol, whose big brother Anton was born with a cleft, was thrilled with the amount, saying "it will go to a very good cause."

Lauren

Lauren started fundraising for CLAPA back in 2012 when she saved up her pocket money to make a donation. Since then, she's raised over £2.5k! This year she organised a 'dress-in-blue' day at her old school during Awareness Week, where they also had a lot of fun with CLAPA's smiley face stickers. Well done, Lauren!

The Bartons

Their youngest, Oscar, was born with a cleft lip and palate, and so the Barton family organised a fundraiser at their local Vintage Nostalgia Fair. Everyone joined in, including their godson Riley who performed on stage for the first time playing some acoustic tracks and encouraging the audience to donate. All in all, they raised a fantastic £1,850!

Superstar Cyclists

Orla raised a brilliant £253 with a trip down Hadrian's Cycleway over four days in April, as well as a cake sale at her school where she and her friends sold over 100 pieces of cake!

Regan may only be 7 years old, but that didn't stop him from cycling for SIX HOURS through Milton Keynes, completing an incredible 26 mile route to raise over £1.5k for CLAPA! Regan's parents (including mum Cassie who is one of our new CLAPA Trustees) ended up taking on the challenge with him, and his little sister Keira organised a cake sale to boost his fundraising total. Regan's school was so impressed with his efforts that they decided to support CLAPA as their Charity of the Year.

Becky, Craig, Steve and Cheryl made the most of their 21 mile sponsored walk through London by educating passers-by about CLAPA and cleft. The walk, which took them from Kingston Bridge to Westminster Bridge, raised over £1,000!

The British 10K London Run

Every year, CLAPA gets around 30 places for runners in the British 10k London Run, and to make sure every one of them knows just how much we appreciate their hard work, we show up in force to cheer at the top of our lungs! To get your place for the 2016 race, contact our fundraising team at fundraising@clapa.com

CLAPA Founder Continues to Give Support

When Anne Pitchforth's son Alex was born with a cleft lip and palate in 1969, there was very little support for parents and families. A support group was set up between Queen Victoria Hospital and Great Ormond Street Hospital, and years later this grew into CLAPA. Anne's grandson Ryan was also born with a cleft lip and palate! Anne very kindly put CLAPA forward to be part of the East Sussex Section of the Caravan Club's fundraising for a year, raising a fantastic £1,750 in all!

Charity of the Year

From village pubs to multi-national corporations, many companies have 'charity of the year' schemes that help organisations like CLAPA by raising funds all year round. Some even match the amount raised for double the donations!

One such organisation is the Artemis Charitable Foundation, which awarded CLAPA an incredible £25,000! It all started when Neil Ramsey, who works in the Edinburgh office of Artemis Investment Management, nominated CLAPA after the support he and his family received following the diagnosis of his son Alexander with a cleft lip and palate.

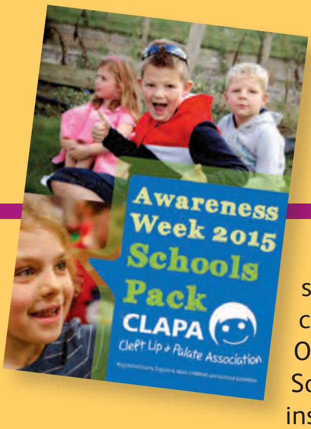
"We've been blown away by the care we have received and I'm glad that I could indirectly do a little bit myself to help those in the same situation that we find ourselves in... [Alexander] is doing very well, 5 weeks on from his first op and we are delighted with how he is progressing and developing." - **Neil**

"It is great to be supporting CLAPA via our charitable foundation. Our staff overwhelmingly chose CLAPA to be their Charity of the Year and we are delighted to support them in the excellent work they do and the profoundly positive impact they have on so many families."
- **Lindsay Whitelaw**, Chairman of The Artemis Charitable Foundation

A huge thank you to Neil and the staff at Artemis for voting for CLAPA! Ask your employer or child's school if they have a Charity of the Year scheme, and get in touch with CLAPA at fundraising@clapa.com if you need help submitting a nomination.

Find out how you could run for CLAPA in the 2016 London 10k by emailing fundraising@clapa.com.

Awareness Week



This year's Awareness Week saw a new record of eight sponsored walks being held around the UK, including a Treasure Hunt and many walkers in fancy dress!. We're still trying to get that number up to ten, so if you've got a great spot in mind for a fun and family-friendly walk during Awareness Week (or any time!) in 2016, get in touch at fundraising@clapa.com or call 020 7833 4883.

As well as the walks, many of you took this week as a chance to do something special for CLAPA. Our brand new Schools Packs inspired students, teachers and parents around the country to put on non-uniform days, cake sales, and presentations to educate the whole class about cleft. May also saw a number of skydives (including our very own cover star, Chris Williams), several runs, a team of Tough Mudders, and a 15-person trek up Ben Nevis!

Sponsored Toddle

During Awareness week this May, we approached Lily's nursery to see if they would like to raise funds for CLAPA. They thought this would be a great idea and suggested a fancy dress sponsored toddle in the local park. So, on Wednesday 13th May, the day after Lily's birthday, and after Chris Evans wished her luck on Radio 2, they toddled around the local park. They managed to raise an amazing £446.50!"

Maria Blackhurst, LCL Branch

Sponsored Walks

Manchester

Cardif

London

Norwich

Brighton

Redditch

“Spirits were high despite the high winds pushing against us on our way over to Fife and the wind and rain on the way back, ” wrote Allison Wardlaw of the Edinburgh Branch about their first sponsored walk, “We were still able to enjoy the beautiful views from the bridge and I think most of us got our picture taken at the ‘love locks’.”
Forth Road Bridge, Edinburgh

“In the fifteen months we’ve been part of the cleft community we’ve been consistently stunned and inspired by the drive, courage and sheer determination of both children and parents,” said mum Carly, “[We organised ‘Hyde and Seek’] to help CLAPA continue to support them, and all the children and parents yet to come.”
Carly has since gone on to become Chair of the South London & Surrey Branch!

Speak Out!

This year’s theme for Awareness Week was ‘Speech and Communication’. We were getting a number of calls from parents concerned that their child couldn’t access speech and language therapy (SLT), and a short survey we conducted revealed that only 55 % of people around the UK got all the specialist SLT treatment they needed. A large part of our awareness-raising activities is to do with showing how a cleft can affect different aspects of people’s lives, and so in 2015 we took Awareness Week as an opportunity to do three things:

1. **Educate the cleft community and raise awareness of how a cleft palate can affect speech**
2. **Praise the fantastic work done by Speech and Language Therapists around the UK, including the specialists in the Cleft Teams**
3. **Empower and equip parents and carers of children with a cleft to participate in their child’s care.**

We spent the week posting up information and advice which you can now access from our website, as well as encouraging people to share their own stories around how cleft and speech has affected them and their family.

Around half of all children born with a cleft palate will need some form of speech therapy, and there are many adults with a cleft who still have speech issues. We shared a number of tips around aiding a child’s speech development, including giving them chances to practice sounds and build confidence by reading out loud. This is what inspired the book character dress-up theme for our Sponsored Walks and produced some fantastic photos!

AWARENESS WEEK IN NUMBERS

196 Schools Packs sent out around the UK

142 Collection tins distributed to fundraisers

29,200 CLAPA stickers covered the UK with smiling faces

597 supporters joined our Sponsored Walks

130,000 people saw our posts on social media

7,288 likes, shares and comments on our posts during the week

Do you have a place in mind that would be perfect for a CLAPA sponsored walk? Make sure you get in touch in 2016 to have your walk end up in CLAPA News!

Volunteering

Our volunteers help us organise events for families around the country to enjoy.

At CLAPA, there are as many different kinds of volunteering as there are volunteers! We always need new people to help us set up Happy Faces groups, join Branch Committees and be outspoken ambassadors for the work we do, but there are many other roles that can include talking to people one-on-one, using your professional skills to help CLAPA, or even using your unique experiences as someone affected by cleft to improve services in your area.

This year, following our 2014 Conference, we've been looking more at Patient Voices and how we can use our growing community to push for real change in cleft services. Read on to find out how you can take an active role in shaping the future of cleft care…

Patient Voices

Providing a voice for young people, adults and parents across the UK affected by cleft

'Patient Voices' projects bring together a range of people with experience of cleft services to represent the views of the cleft community. This way, Cleft Teams get a group of people to consult with on things like information leaflets and changes to services, and the local cleft community has a point of contact for any issues or suggestions they have, about how the service is run. This means the voices of patients and parents can be front and centre in the discussions that affect them the most.

CLAPA's 2014 Volunteer Awards were held after our 35th Anniversary Conference

A Patient Voices group in the East of England was established in October 2014 and has developed strong links with the Cleft Net East team at Addenbrooke's Hospital in Cambridge. The first task of the group was to review literature provided by the service for families. The Cleft Team said that "it was a hugely positive step forward in working together," and they are now looking at transition activities for teenagers as well as ways to improve services for patients from ethnic minorities and other cultures.

Another great example of how patient representation can be really successful is from CLAPA Great Ormond Street Hospital (GOSH) Branch in London. Committee Member Claire Brown explains:

"The idea of developing a Pre-op leaflet was to produce a list

Spotlight on: Tony Ruel

"This year the spotlight is on Tony Ruel, an active CLAPA volunteer for over three years, who is super committed and supportive of CLAPA's work. His volunteering work includes sitting on the Regional Coordinators' Advisory Board, being a Peer Contact, Co-Chairing the Adult Voices Council, and being a Committee Member of the West Midlands Branch. Tony is also often found presenting at events and holding information stands for us locally in the West Midlands. He is set to get involved in new pieces of work in the Central region including the new Patient Voices Group and support for adults at the Cleft Clinic in Birmingham…he never stops!

"Tony deserves lots of recognition and appreciation of his work, he makes a massive contribution to CLAPA's work in the West Midlands and beyond, and increases our effectiveness in supporting families in the region. A huge thank you to you Tony and to all our other fabulous volunteers in the Central Region!"

Claire Evans,
Regional Coordinator for
Central England

of questions that might arise when preparing to stay in hospital for the lip or palate repair operations. These questions were simple ones that parents might feel are inappropriate or too silly to ask in their clinic or pre-op appointments. For example, what are the beds like? Can we bring in our own food? Are there showers?

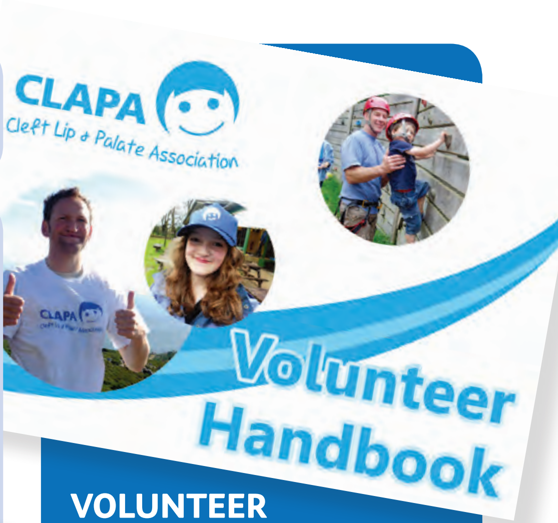
"The committee discussed how to put the questions together and using social media seemed like the best way. I agreed to ask my Happy Faces Group through our Facebook page. We had a great response and came up with a list of 20 questions for the leaflet, which was then passed to the branch to approve and now we have a leaflet which is given out at the pre- op appointments."

CLAPA GOSH has also been doing a great job with involving local parents in their very successful Parent/Professional Forums. The most recent Forum in June 2015 gave 60 parents the unique opportunity to interact with the Cleft Team at GOSH and tackle any concerns – from the seemingly trivial to the most serious. This Forum focused on the topic of Speech and Language Therapy following on from our 2015 Awareness Week, but CLAPA GOSH are planning more in the future around various other topics, so keep an eye out!

In Scotland, Cleft Care Scotland have been consulting with an adult patient representation group about pathways of care for adults. Further groups for parents and children and young people are also being developed, and we hope to grow these over the next year.

We are working hard to establish projects across the country and aim to have a Patient Voices group attached to each Cleft Service by 2017.

We are currently recruiting members for the West Midlands Patient Voices Group which will be based at Birmingham Children's Hospital, as well as the various groups in Scotland. Get in touch with your regional contact (page 18) for more information.



VOLUNTEER HANDBOOK

New in 2014/15 – a new handbook for inducted Volunteers to help them every step of the way.

Whatever your skills, however much time you can spare, we've got the perfect Volunteer Role for you. Email volunteering@clapa.com or call 020 7833 4883 to find

Surgeon David Drake received the 'Extra Mile Award' in 2014 for his work with the Cleft Team in Morriston Hospital, South Wales.

VOLUNTEER AWARDS

We were so thrilled to be able to celebrate our Volunteers in 2014 with our very first Volunteer Awards that we're running them again this year – and we've added two new awards! Visit www.clapa.com to find out more about how you can nominate a volunteer, Branch, group or even a Cleft Team that's gone the extra mile.

Regional News

A big part of our regional work is giving people affected by cleft opportunities to meet one another. Here are two little boys with a cleft meeting at the Hyde & Seek Sponsored Walk in 2015!

> “I get lots of advice and support in our activities from my Regional Coordinator and it’s good to have someone with local knowledge, contacts and experience so I don’t feel alone when planning things. They are a valuable member of the team, I’d be lost without them.” **A CLAPA Volunteer**

Regional Coordinators Project

The Regional Coordinator (RC) Project aims to engage and support people affected by cleft at a local and regional level by creating new posts for Regional Coordinators to cover the nine regions of the UK.

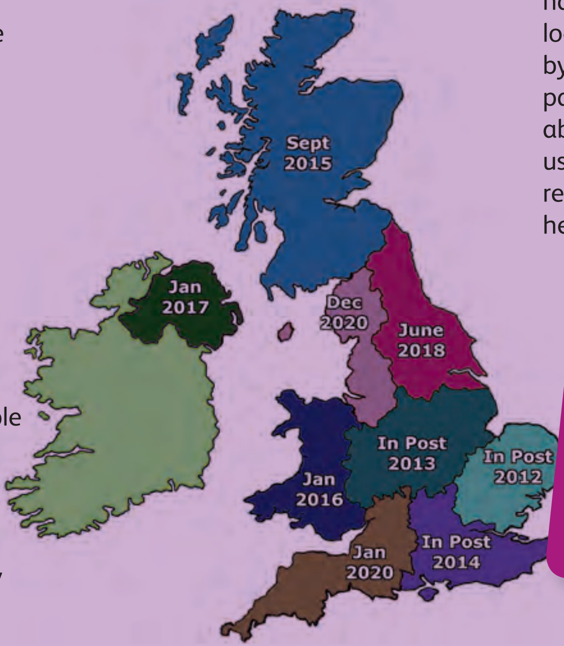
Regional Coordinators have several key responsibilities:

- Involving our community of families, patients and health professionals in local activities and events, as well as gathering feedback and data.
- Supporting local people affected by cleft through assisting local Branches, Happy Faces Groups and Cleft Teams with their activities.
- Promoting opportunities for volunteering and fundraising as well as training and supporting volunteers to develop a nationwide volunteering network.
- Raising awareness of CLAPA and cleft lip and palate
- Improving services for people affected by cleft by working closely with local Cleft Teams and promoting opportunities for user representation

The project started after our 2010 survey indicated there was a lack of local and face-to-face support available for people affected by cleft. By 2020, CLAPA aims to have all nine Regional Coordinators in place across the UK.

This project is externally evaluated by the Centre for Appearance Research (CAR), a world-leading research centre based at the University of West England. Over the years this project has been active, CAR have been hugely helpful in finding ways for us to improve the way we deliver services, as well as the services themselves.

This map shows the current recruitment schedule for Regional Coordinators.



This schedule is entirely dependent on both funding and resources, and we are working extremely hard to make it a reality.

What helps us the most is feedback from our community. We need your stories and your voices to help us complete this project and ensure everyone affected by cleft in the UK has access to an active and supportive local cleft community all held together by a CLAPA Regional Coordinator. On page 20 you’ll find more information about our 2015 Survey which will help us prove to funders that this project really can make a difference – please help us by taking part!

> “Many positives steps have been taken throughout the second year of the Regional Coordinators Project and CLAPA continues to grow in strength and numbers, delivering a local service which many families and individuals value highly.” – CAR’s End of Year Report on the Regional Coordinators Project, 2014

Spotlight on: Scotland

Gillian McCarthy started working 2 days a week as our Scotland Engagement Officer in October 2014, and in September 2015 she starts as our full time Senior Regional Coordinator for Scotland. In the nine months she was with us part time she managed to accomplish a huge amount, including gathering evidence for a successful Big Lottery Investing in Communities funding application of almost £200,000 to provide local services!

In April 2015 we had our first adult patient rep group meeting with Cleft Care Scotland to discuss the pathways for adults during the transition stage and also for those entering into the health care pathway at a later stage. Further groups are also planned for the parents of children with a cleft. We will also be launching the Scotland Children and Young Persons Council and older children's activity groups in September.

Our Edinburgh and Aberdeen Branches continue to go from strength to strength and we will be launching our Glasgow Branch in September 2015.

We hope to start many more Branches across Scotland so if you are interested in joining or forming a Branch in your area please get in touch!

At the beginning of July 2015 we invited our members to a Family Day, funded by Children in Need and taking place at Crieff Hydro in September 2015. All 30 children's places were booked within just over 24 hours! It is clear we need to run more of these events and we endeavour to seek funding to run these regularly across Scotland.

We have lots planned for CLAPA's future in Scotland with two local staff members in post in September 2015, we aim to run more Branches, Happy Faces Groups, older children's activities, awareness sessions, patient representation groups and much more. Our launch event will be held on 1st November, venue TBC, so please come along to find out more and if you have some time to spare please get involved.

A family at our first ever Sponsored Walk in Edinburgh, May 2015

Welcome to the West Midlands Branch

West Midlands Branch Committee

"Having been a very active volunteer in the West Midlands for over 2 years I was very eager to hear about the possibility of setting up a branch here. After attending an initial meeting of those interested I was extremely happy we had enough interest to start one and I was elected co-chair. I am really excited to be part of a unique wonderful bunch of people as passionate as I am to help families and adults affected by cleft in the area, as being a very large region there hasn't been much. I am very much looking forward to our launch party event to meet our local families and adults and arranging many more fantastic events in the future!"
Selena Foster, CLAPA Volunteer and Parent Contact

YOUR REGIONAL CONTACT:

CENTRAL ENGLAND
Claire Evans, 07792 772362,
claire.evans@clapa.com

EAST OF ENGLAND
Tansy Miller, 07772 684398,
tansy.miller@clapa.com

SCOTLAND
Gillian McCarthy, 07586 045402, gillian.mccarthy@clapa.com

SOUTH EAST ENGLAND
Cherry LeRoy, 07985 538982,
cherry.leroy@clapa.com

ALL OTHER REGIONS
Chris Williams, 020 7833 4883,
chris.williams@clapa.com

You can also visit www.clapa.com or call our office on 020 7833 4883

Five Years On: The Survey

CLAPA Branches put on fun and family-friendly events, all run by volunteers

Our 2010 survey was, at the time, the biggest investigation into our community we'd ever attempted. At this crucial tipping point in CLAPA's history, we wanted to know what our members wanted, what they were happy about, what we could do better, and most of all we wanted to know where to focus our efforts next.

While there were countless positive and encouraging comments throughout the answers, a few things became very clear. First of all, even though 89 % of people thought it was important for CLAPA to have a local presence, many lamented that there were so few local events and activities, and that so much of what we did revolved around our office in London instead of actively supporting local volunteers. There was also a dire lack of support for adults with a cleft, with over half of the adults surveyed saying it wouldn't affect them at all if CLAPA ceased to exist. Our membership scheme also wasn't having the intended effect, as while everyone we circulated the survey to was a member, less than half considered themselves to be part of CLAPA. Many other issues were raised – our information materials and website were quickly becoming outdated, our communication methods were ineffective, and we weren't working hard enough to hold the NHS to account.

So, in the past five years, what have we done to change things for the better?
The most obvious change has been starting our Regional Coordinator Programme (page 17), which has put CLAPA staff on the ground where they're needed the most, ensuring there's always a local point of contact for parents, patients and Cleft Teams. This is our most ambitious project to date, and we're thrilled at the support we've received.

Another improvement has been focusing our efforts on better supporting adults with a cleft (page 6), including setting up our Adult Voices Council, training Peer Contacts, and producing brand new information products aimed specifically at patients over 18. We scrapped our outdated Forum and moved the discussions to social media, where our presence continues to expand, and rebranded CLAPA's membership to the 'CLAPA Community', where everyone who wants to be a part of it, is! On top of that, a quick look at page 2 will show you just how dedicated we are to ensuring our website, information materials and communications are the best they can be.

But we know we can do better!
Maybe you've been collecting copies of CLAPA News since the very first magazine-style edition in 1989, or perhaps you've just joined our community? Either way, if you have an opinion about how we can improve, we want to hear it. Visit www.clapa.com to take part in our short survey online, or call 020 7833 4883 to request a hard copy.

Ten Years of Progress
We set ourselves some ambitious goals in 2010. Working with very limited resources and a handful of staff, we know that everything CLAPA have achieved so far (and will achieve in the future) is thanks to the hard work of our dedicated volunteers and fundraisers. We've still got a long way to go, but we couldn't have got this far without you!

As part of our Regional Coordinator Project, CLAPA runs activity days for different age groups across the UK

Top 5 Goals by 2020

1 We will increase our annual income from £396k to £1 million

2 We will have Regional Coordinators in all 9 Regions of the UK

3 We will have appropriate, up-to-date information that reflects the needs of our users

4 We will have an engaged, diverse, representative membership

5 We will be a driving force in improving cleft care in the UK, with a focus on patient involvement

Do you have any ideas on how we can do better? Take the survey and let us know

Five Years On

1 Our income for the year 2014/15 is £638k

2 Four Regions have full-time Regional Coordinators and we have a schedule in place to recruit the other five. Their work is supported by other CLAPA staff members like our new Volunteering Officer.

3 Our information review is currently in its final stages and we hope to launch our new up-to-date range of leaflets shortly. We will also be launching our brand new website in November 2015 which will make finding the right information easier than ever.

4 CLAPA's membership has grown from 7,041 in 2010 to over 23,000! Thanks to a greater focus on communications, our community is more engaged than ever and remains a driving force behind all of what we do.

5 CLAPA is represented on a wide range of boards and committees concerned with cleft care and research in the UK, including the Cleft Development Group, the Cleft and Craniofacial Studies Group, and the NHS Cleft Lip and Palate Clinical Reference Group.

How Will We Reach Our Targets?

1 Our fundraising team has grown from one to four full-time staff members all working hard to bring in the funding we need to support our work.

2 The schedule on page 17 shows how we aim get all 9 Regional Coordinators in post by 2020

3 Once our information review and website redevelopment is complete, we will continue to gather feedback to ensure they are comprehensive and relevant to the needs of our community.

4 The next five years will see us working to diversify our membership, and in particular engaging hard-to-reach groups such as adults with a cleft, BME people, and low-income families.

5 Our Patient Voices projects (page 15) are going from strength to strength, and CLAPA is being increasingly recognised in the medical world as an organisation that represents the voice of people affected by cleft.

CLAPA sends out hundreds of free Welcome Packs with special bottles and teats to new families every year

Medical and research news

The Cleft Collective

An initiative of the UK-based charity The Healing Foundation, and supported entirely by voluntary donations, The Cleft Collective is the largest cleft lip and palate research programme in the world, consisting of a team based in Bristol and a team in Manchester. In this article, they tell us all about their activities and what is planned for the future.

What is it?

An initiative of the UK-based charity the Healing Foundation, and supported entirely by voluntary donations, The Cleft Collective is the largest cleft lip and palate research programme in the world. The Cleft Collective consists of two teams; one based in Bristol and one based in Manchester.

The aim of The Cleft Collective is to make substantial progress toward answering three key questions which parents often ask:

- What caused my child's cleft?
- What are the best treatments for my child?
- Will my child be OK as he/she grows up?

The Cleft Collective Cohort Studies

A cohort study involves recruiting families to participate in the research from an early stage and then keeping in touch with them as their child grows up. Cleft teams around the UK will invite eligible families to take part either before or after the birth of their child, or when their child attends their five-year review clinic. Families will be asked to provide biological samples (such as saliva) and to complete questionnaires at key points during their child's development. We are also asking permission to access the families' medical and educational records, and are running a number of additional studies, including a Speech and Language study and a 3D Facial Imaging study.

We hope the information we collect from families will help us to identify some of the biological and environmental causes of cleft. We also hope that keeping track of the families' wellbeing and the child's development will help us to improve support for families and individuals who have been affected.

16 out of 17 UK Cleft Teams are currently involved in the Cohort Studies, with 12 teams already actively recruiting families. So far we have recruited more than 1,700 individuals (mum, dad, child, siblings) from over 600 families, and more Cleft Teams will be up and running soon!

The Cleft and Craniofacial Clinical Research Centre

The aim of our research centre based at the University of Manchester is to help to improve care for people with cleft lip and/or palate by creating a team who will design and run a wide range of research projects. We currently have two feasibility studies taking place:

ACORN

Children with a cleft lip and/or palate often have unhealthy gums and teeth because they struggle with mouth care. This can affect the success of their treatment, including bone grafts and braces. This study is in two parts.

> "Every cleft is unique and individual to the family, and research such as this is paramount in helping to provide long-term answers into the care and treatment of clefts. To be part of this research is giving a voice to our children as well as ourselves – the outcomes will be invaluable to the future of cleft care"
>
> **Ana and John Hobbs, parents to Abi who was born with a cleft of the soft palate.**

> “Without our help there may never be an answer to the question of ‘why?’ That is the reason I value the opportunity to participate in the research. I can’t change the fact that my baby has a cleft, but I can help to provide answers for future generations”
>
> **Rachel McDermott, mum to Emily who was born with a unilateral cleft lip and gum.**

Stage 1 involves interviews with both children and their parents, to explore their views of oral health. Information from this part of the study will be used to develop ‘if-then’ plans which will be used in Stage 2 on a group of 60 children aged 5-9 years. Children will have some basic dental checks done by a dental nurse in their home to see if there’s an improvement in oral health.

Stage 1 is currently in progress and Stage 2 should be ready to start in January 2016. For more information contact acornstudy@manchester.ac.uk.

SLUMBRS

This study aims to identify the best way to answer the question, “Which is the best sleeping position for a baby with cleft palate?” UK cleft centres differ in their advice about sleep position – some advise sleeping on the back, whilst others advise positioning the baby on their side. There is no clear evidence about which is best for children with a cleft. We have chosen four hospitals to be involved in the study; two that currently advise that babies sleep on their back and two that advise babies sleep on their side.

This study should be starting in July 2015. For more information contact slumbrs@manchester.ac.uk

Taking part in the research

If you or your child are not eligible for the studies we are currently conducting, there are still many ways you can take part in The Cleft Collective research programme:

Sub-studies – we often run smaller studies to find out more about a particular group of people or a specific topic. Some of our recent projects include: fathers of children with cleft, adults with cleft and siblings of children with cleft.

Patient and Public Involvement (PPI) – you can become involved in the research process itself. For example, you can help us to choose the most important research questions, help to shape our research protocols and help to design our materials. This ensures that the research we are carrying out is relevant to people affected by cleft and will make a real difference in practice. To find out more about PPI, please visit www.invo.org.uk.

Cleft Image Bank – the Bristol team collect photographs of families, young people and adults who have been affected by cleft, to give a real-life feel to our work. We use these photographs in our conference presentations, on our website and in all of our materials. Thank you to everyone who has already sent their photographs to us and spotted their children in the media!

Mailing list – both centres send out newsletters twice a year to everyone on our mailing list. These include updates on the research progress, reports on our research findings and opportunities to take part in studies and activities.

Collaboration - If you are a health professional, please contact us about opportunities for collaboration.

Find out more:

To find out more about any of our studies or PPI activities, or to express an interest in taking part, please contact us:

BRISTOL
Email: cleft-collective@bristol.ac.uk
Tel: +44 (0)117 331 0025
MANCHESTER
Email: cleftcollective@manchester.ac.uk
Tel: +44 (0)161 275 6686
Follow The Cleft Collective:
Website: www.cleftcollective.org.uk
Facebook: www.facebook.com/cleftcollective

CLAPA advertises a number of research programmes to our online community. We also publish reports and results from studies around cleft lip and palate which we think might interest our members. Check out the research section of our website to find out more.

About CLAPA

Since 1979, The Cleft Lip and Palate Association (CLAPA) has been the only national charity dedicated to all those with and affected by cleft lip and/or palate in the UK.

We reach out to families from the moment of diagnosis and help them through any difficulties they have before and after the birth of their child by providing a specialist feeding service as well as targeted information and a national network of trained volunteers providing one-to-one emotional support. This first contact is the start of what we see as lifelong support of children born with a cleft and their families, from infancy through to adulthood.

CLAPA is a small charity based in London. We exist to provide support and information for new parents, specialized bottles and teats for babies, activities for children and young people, advice and support on accessing treatment for adults, and volunteering opportunities including our intensively trained Parent and Peer Contacts who provide one-to-one emotional support in their area.

We work closely with the nine specialist cleft teams in the UK as well as generic health professionals to ensure that everyone with a cleft receives the best possible care.

CLAPA's aim

To improve the quality of life for all those born with clefts and their families by providing the most appropriate care, and to make ourselves accessible to all sectors of the community

CLAPA's vision

A society where having a cleft lip and/or palate is no barrier to achieving your desires and ambitions

Staff

Rebekah Ahmed	Community Fundraising Officer
Chris Allen	Post Room Assistant
Preeti Baid	Senior Fundraising Manager
Claire Cunniffe	Director of Development
Claire Evans	Regional Coordinator for Central England
Rowena Knight	Trusts and Grants Fundraiser
Cherry LeRoy	Regional Coordinator for SE England
Anna Martindale	Communications and Information Management
Gillian McCarthy	Senior Scotland Regional Coordinator
Tansy Miller	Regional Coordinator for E of England
Rosanna Preston	Chief Executive
Melanie Skinner	Scotland Support Officer
Claudette Watson	Finance and Admin Manager
Chris Williams	National Volunteering Officer
Louise Wheeler	Community Fundraising Manager

Trustees

Contact: info@clapa.com with the subject: 'FAO 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.

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