CLAPA
Cleft Lip & Palate Association

CLAPA NEWS

Issue 25 // 2014/15

Spotlight On… Adults
Page 5

Spring Survey Results
Page 19-20

The Cleft Collective needs YOU!
Page 21

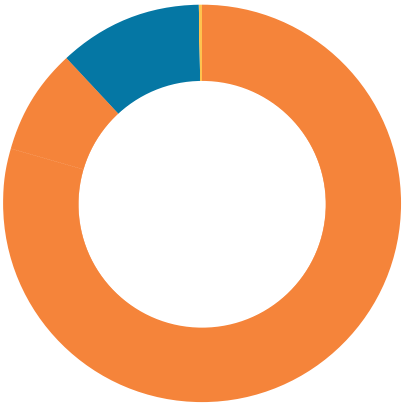
Registered Charity England & Wales (1108160) and Scotland (SC041034)

Welcome to CLAPA News

In this issue

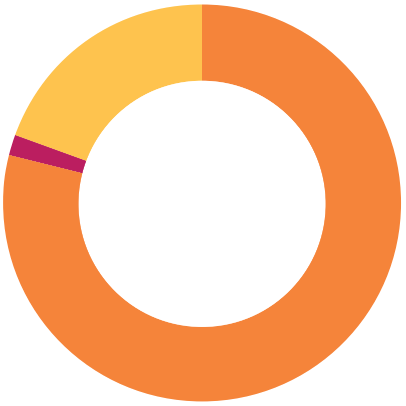
Accounts Summary

Income £524,661



🟧	Donations/Grants	£463,278
🟦	Sale of Feeding Equip.	£60,632
🟨	Other Income	£751

Expenditure £533,262



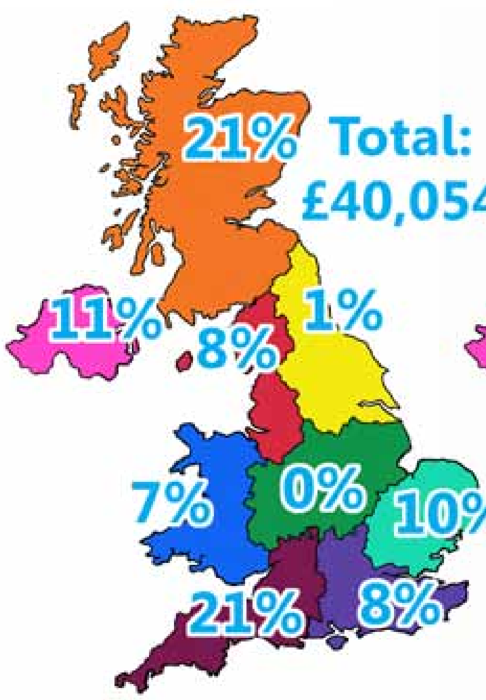
🟧	Charitable Expenditure	£421,596
🟥	Governance costs	£8,444
🟨	Fundraising	£103,222

The Regional Fund

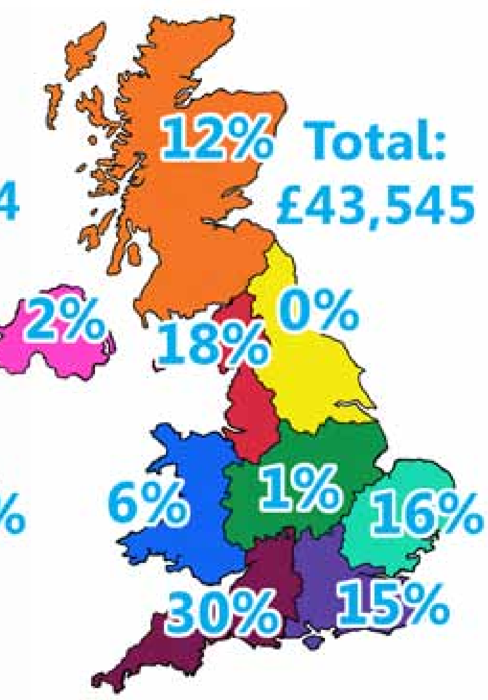
CLAPA's Regional Fund provides local support and activities to all areas of the country, and funds everything from summer and Christmas parties for families to breast pumps and other equipment for cleft teams, as well as local information events and leaflets. Official Volunteers, Parent Contacts and even Cleft Team members are all eligible to apply for funding from our Committee made up of CLAPA staff, Branch Members and other volunteers. The idea of this fund is to use money raised locally to provide local support, encourage collaboration between Branches and to fund activities in areas that don't have a Branch.

2013/14 was the Fund's first year, and we've been delighted to see how many local groups have been taking full advantage of this opportunity. For more information on how you can apply for funding, visit www.clapa.com/get_involved.

Income 2013 – 14



Expenditure 2013 – 14



The Patient Voice – speak up and make a difference

Rosanna Preston, CLAPA Chief Executive

It’s been 35 years since CLAPA was set up by patients and clinicians. At the start it was entirely run by volunteers so it’s appropriate that this year’s issue of CLAPA News is full of examples of people like you taking the opportunity to speak up and use their voices to make a real difference in the cleft world.

In the last year, CLAPA has represented people affected by cleft in the design of cleft services, the way cleft treatment outcomes are reported, research (page 21-22) and at National and International Conferences. We have also been part of a Europe-wide group writing guidelines for cleft care across the continent. A particularly exciting project we have been part of is aimed at improving the diagnosis of cleft palate to reduce the number of late diagnoses. Around 30 % of cleft palates are diagnosed after the first 24 hours and sometimes it is weeks, months or even years before they are detected. This is unacceptable and distressing for families and we are doing everything we can to get these numbers down by educating health professionals.

We love to represent patient views but we really want to see more patients having the chance to speak for themselves and this is the theme of our conference in 2014. The first step in getting more patients involved is to make sure we are in touch with people affected by cleft. If you want to get all the latest news and information about CLAPA’s events and activities then make sure we have your email address so that you can get our regular e-newsletters and notifications of events. If you know anyone else affected by cleft then why not get them to sign up too by visiting our website.

We have plenty of examples already of patients getting their voice heard: Over 650 of you responded to our survey to tell us what you think about cleft services and CLAPA’s activities and there’s more information on pages 19-20; Chris Williams spoke to MPs about the importance of specialised services at a parliamentary lobby (pictured); Eleanor Pedrick and her father featured on the Children in Need Rickshaw Challenge (page 8); at Maria Blackhurst’s suggestion research is now being done into the impact of late diagnosis of cleft palate on parents and the joint Chairs of Adult Voices, Tony Ruel and Andrew Dixson-Smith spoke at the International Appearance Matters Conference in Bristol. Finally this year we launched our Patient Voices project at a workshop at the Craniofacial Society conference in Oxford. The aim of the project is to help all the cleft teams recruit and support patient representatives – if you’d like to become a patient representative email info@clapa.com for more information.

Nick Hurd MP (left) meets Chris Williams and backs campaign for better services for rare and complex conditions like cleft

Finally we have the sad news that after 12 years Sue Carroll, Deputy Chief Executive, decided it was time to move on and left CLAPA at the end of 2013. Sue had been at the heart of CLAPA for a long time, and had seen the charity through many changes. We wish her all the best for what will no doubt be a wonderful future ahead.

● 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.

Updates from CLAPA National

● If you would like to find out more information about any of CLAPA's services for children and young people, please contact Claire Cunniffe, Director of Regional Development at claire.cunniffe@clapa.com or on 07854 298304. You can also contact Claire via Facebook.


Tansy Miller

Welcome to...

Tansy Miller
Regional Coordinator,
East of England
I joined CLAPA in October 2013 and support volunteers and families in the areas of England served by CleftNetEast (Addenbrookes) and North Thames Cleft Service (Great Ormond Street Hospital). It's a real joy to be working with so many dedicated and inspiring people, and I'm looking forward to building up a strong support network of volunteers across the region. CLAPA already has an excellent, longstanding relationship with both cleft teams so I've been given a really warm welcome and we're working on some exciting developments together to help continue to support local cleft services.

My background is in project management and volunteering/community development in the not-for-profit sector so I really hope to bring some of those skills to this role. We've already seen some fantastic new developments at CLAPA recently and I'm very much looking forward to building on these further, but I'm especially looking forward to getting to know you and working with you all closely over the coming months.

Regional Coordinator Project

Our Regional Coordinator (RC) project is all about engaging and supporting people affected by cleft in their local area. The project came about following our 2010 Annual Survey where one of the key findings was that people wanted to see more local and face-to-face support.

At the moment, Tansy Miller is our East of England Regional Coordinator, and in October we will be recruiting two more in the Central and South East of England Regions. These first three posts have been funded by the BIG Lottery Fund and we are in the process of applying to other external funders for the other areas of the UK. By 2017, we aim to have all nine RCs in post, providing local and regional support to the CLAPA community across the UK.

Our RCs work very closely with the local Cleft Teams and other health professionals. They also support local Branches and Happy Faces groups with social events and activities.

There are lots of ways for you to get involved with the project through volunteering and regular Induction and Development Days are organised by the RCs in their region (page 17).

Another key aspect of the project is raising awareness of CLAPA through social media networks by establishing RC Twitter accounts and regional Facebook groups.

The project is being externally evaluated by the Centre for Appearance Research (CAR), a world leading research centre, based at the University of West England.

Welcome to...


Rebekah Ahmed

Rebekah Ahmed
Fundraising and Volunteering Assistant
My name's Rebekah and I joined CLAPA as the new fundraising and volunteering assistant a couple of months ago. I've really enjoyed my time so far – even though it's been hectic – mostly because the people that choose to volunteer and fundraise for CLAPA are so generous with their time and so enthusiastic about what they do! My role mainly involves letting people know about the volunteering and fundraising opportunities we have and helping them to do them. I also help out with the volunteer induction days and the Children and Young People's Council as well as helping to organise the Volunteer and Children and Young People's E-newsletters.

CLAPA Conference

“What Does ‘Good’ Look Like?” 5th October 2013, Glasgow

Last year’s conference was all about the results or ‘outcomes’ of cleft treatment. These days, there is a well-defined 20 year treatment pathway for babies born with a cleft, and further treatment can be sought well into adulthood if necessary, but how do we know this treatment is working? How do we know if it has been successful? It may seem like a simple question, but it certainly kept us busy during our conference in Glasgow last year.

For one thing, patients, parents and health professionals might all disagree about what makes a ‘good’ result or what the priorities should be during treatment. Is it all about appearance, or is functionality more important? What about the effect of so many surgeries and appointments on a patient’s wellbeing? Who should get to decide what comes first? CLAPA is the representative organisation for everyone in the UK affected by cleft, and we see our conference as a way to bridge the gap between parents, patients and health professionals to discuss these kinds of important issues.

For our 2013 Conference the CLAPA team travelled up to Glasgow to bring this event to our Scottish members

During our 2013 conference we heard from researchers on topics like the best way to measure facial appearance and we were even given a preview of some cutting edge 3D imaging technology. We discussed the difficulties in collecting evidence for making decisions about what ‘good’ does and should look like, and several different speakers gave their opinions on why patient and parent involvement in research was so important.

2013 also saw our most diverse group of delegates yet, and a fantastic variety of talks that ranged from brave personal accounts to upbeat presentations on new studies.

This conference was all about what matters to YOU, the people that we work to represent, and our 2014 conference will be no different. We’re moving on from the topic of measuring outcomes to discussing how to make sure patients and parents have a voice in their treatment and the way services are provided. In 2014 we will be looking at the best ways to empower the whole cleft community to get involved in their care at every level, not just to improve the treatment and support they receive, but to lift the standards for generations to come.
We hope you can join us on Saturday 18th October in London either in person or online. Just visit our website www.clapa.com to book your place or to watch the live streaming. If you miss the conference you can watch the videos after the conference is over on vimeo.com/clapa.

CONFERENCE 2014
"The Patient Voice -
speak up and make a difference!"
VISIT WWW.CLAPA.COM FOR
MORE INFORMATION & TO BOOK
CAMDEN TOWN, LONDON -+- 18TH OCTOBER 2014

Conference 2014
18th October, London

The Patient Voice
It’s our 35th Anniversary, and we’re celebrating with our most ambitious conference yet! Join us in the heart of London for a series of talks, presentations and workshops about the benefits of empowering patients and parents to get involved with their own care and what kind of difference this can make in the short and long term. We will hear about the importance of getting your voice heard in treatment and research and how to contribute your voice and opinions to CLAPA itself.

Our conference will be followed by a Tea Party to celebrate 35 years of CLAPA, during which we will announce the winners of the first annual Volunteer Awards (page 18)!

Adult Voices

Awareness Week

'Adults with a cleft' was the theme for Awareness Week 2014. Turn to page 15 for more information or visit cleftaware2014.com

The Adult Voices Council was started in 2010 to help CLAPA better support adults with a cleft in the UK. Since then it has gone from strength to strength, culminating in a group effort to promote 2014's Awareness Week theme of 'adults'. While Adult Voices has not been around quite as long as CLAPA, we'd still like to use our 35th anniversary year to look back on its origins and look forward to the future, starting with a piece from former Chair, Jon Clarke.

It was four years ago and yet it seems like no time since we, a group of adults with clefts, met at the inaugural meeting of CLAPA Adult Voices, to bat around ideas about how we might represent our peers and support CLAPA's work - the term "thought-shower" always makes me chuckle, but I guess it was one of those. I had rarely talked to another person with a cleft, so meeting a whole group was a learning experience that helped me to realise an obvious thing - despite having this one trait in common, we are all very different individuals with different views and different experiences. Hence with this diverse bank of experience, I felt we had great potential to start building a support network - and that is what we have set out to do.

We calculated at the outset that with something like 1 in 700 adults born with a cleft lip and / or palate, there must be over 80,000 adults in the UK with clefts - and hence it is little surprise that our Facebook page grows daily, as does the adult membership of CLAPA. Even if only a small proportion of those people seek peer contact, there is plenty of work to do, and we take one step at a time. As we have spread our network, our experience has been that peer support is the most important thing we can give - whether to share experience, to meet up, to ask advice or to navigate a path back into treatment.

Each moment of contact has been important. Being part of a group of such dedicated and inspirational individuals has been a privilege, and they have made the job of chairing Adult Voices a lot of fun. Andrew and Tony have brought a particular focus to the group over the past couple of years - so I'm certain they will take Adult Voices into new territory so that it can serve the CLAPA community for the coming years.

> "Meeting a whole group [of people with cleft] was a learning experience that helped me to realise an obvious thing – despite having this one trait in common, we are all very different individuals"

Jon Clarke Former Chair, Adult Voices Council.

Spring Survey 2014

In January 2014 we conducted a survey of our community that took an in-depth look at what really matters to adults with a cleft. See page 20 for more.

Find Support Online

Visit www.facebook.com/groups/CLAPAadults to join our Adults support group or follow the Adult Voices Council on Twitter at @adultvoices.


Tony and Andy, Co-Chairs of Adult Voices

Adult Voices Council Welcomes New Co-Chairs

Since January 2014 Andrew Dixson-Smith and Tony Ruel have been co-chairs of the Adult Voices Council. We see this as an exciting and pivotal time for the future of Adult Voices Council.

Our vision is to form a group of members whose aim is to be the voice of adults born with a cleft and to inform CLAPA of issues we should be addressing. Further, our desire is to have a group of adults – both young and old – who reflect the diversity of the adult community living with a cleft and who are proactively generating ideas and forming action plans for Adult Voices – ideas which relate to the region in which they are based. These adults can then support other adults with a cleft in the region they represent. The ideas thus created can also feed into and influence the adult community living with a cleft on a national basis. This group can then promote awareness of services available to adults with a cleft and can provide a regional presence to deliver CLAPA's services effectively. Each member is unique and has gifts and talents which can complement those of the other members within the group. Taken together, these gifts can serve the needs of the adult cleft community within the whole of the United Kingdom.

Why is this important? Research shows that the needs of the adult cleft community are now pressing as never before. Teenagers can sometimes find themselves on a cliff edge staring into the abyss on turning eighteen. The transition from adolescence to adulthood can be traumatic. Adult Voices Council is there to support these young people to overcome their anxieties and apprehensions and to face adult life in all its aspects.

Older people who have a cleft also deserve our support to signpost them to the correct medical advice so that they can make informed choices as well as receive emotional support.

CLAPA needs more and more adults with a cleft to help raise awareness of the support available to every adult with a cleft. We believe we are moving into an exciting era – one in which adults of whatever age can fulfil their potential and achieve full parity. We are very optimistic for what the future holds for us. Watch this space!

PEER CONTACTS COMING SOON

In November, we will be training our first ever Peer Contacts. For many years, parents and other family members have benefitted from the support provided by CLAPA's Parent Contacts, all of whom are parents of a child with a cleft, trained to provide emotional support and a listening ear.

Recently, CLAPA has seen a growing demand for peer support for adults born with a cleft, sometimes looking for information about how to access treatment, seeking emotional support or just the opportunity to talk to someone else who was born with the condition. This is why we are introducing a new kind of volunteer position open to adults with a cleft: Peer Contacts.

Peer Contacts will be on hand to provide support to young people and adults born with a cleft. We intend to train at least one Peer Contact for every region of the UK so that everyone affected by cleft feels they have someone within their region who they can contact.

Peer Contacts will be able to answer questions, offer support and guidance and signpost people to other organisations, where applicable. They will form a support network that has been present for some time for children and parents through Branches and Parent Contacts, but less so for young people and adults. At the time of writing, we are busy planning a training weekend for the first batch of Peer Contacts on 22nd/23rd November. Check our website for more details.

GET IN TOUCH

facebook.com/groups/clapaadults
@adultvoices

Children and Young People

The Children & Young People's Council, Danielle is pictured top left

My story: An Exiled CYCP Member!

Hi everyone! My name is Danielle Keohane and I recently turned 18; an amazing time in my life in terms of independence and parties, but also one which meant I had to leave the CLAPA Children and Young People's Council! My first meeting was on Saturday 4th October 2008 and my last was on Saturday 8th February 2014 – that's one thousand, nine hundred and fifty-four days! Wow…that's a lot!

At first, I was very nervous and didn't really know where to put myself, so was quite content playing 'new girl' for a couple of months, but by the third meeting, after lots of emails and friendly messages, I was well and truly one of the group. During my time in the Council, we designed and helped set up the CLAPA Kidz and CLAPA Edge websites for other children and young people with clefts, we designed newsletters and factsheets for young patients going through treatment, we have met with several researchers and helped with their projects and even been trained as mentors ourselves so we can help younger members of our cleft community. In the past couple of years, the Council has been completely revived and regenerated by Claire Cunniffe – CLAPA's very own superwoman! As one of the older members of the Council, it has been really lovely to be able to get to know Claire better – I'll miss our ginger-jokes and walks back to the station after meetings!

Personally, being part of the CYPC has helped me immensely over the years. I'm not alone in that I spent a long time thinking I must be the only person in the world with a cleft lip and palate because everyone else seemed so 'normal.' As a result of this, my confidence took knock after knock, especially as other children around me became more aware that I was different too. At the time when I joined, I hardly said a word to anyone for fear of them not understanding, or worse, mocking me, but very quickly I learned that if there was one place I could be myself, it was a CLAPA meeting! From there, with the support of the other members, staff and the cleft team I was able to grow to believe in myself, and realise what I was missing out on! Coming forward to now, I'd say I'm the quiet end of sociable, but I love meeting new people, am more than happy to talk about my cleft and have just got into Cambridge University! I'm hoping that it's becoming obvious that the CYPC really did kick-start the changes I needed to make in order to be as happy as I am now.

All in all, I'm so upset to be leaving the CYPC, and will miss everyone so much, but ultimately I know that it's not like I'm actually leaving CLAPA (sorry Claire, you're stuck with me!) – I have just finished my own research project investigating the effects of cleft lip and palate which will hopefully form the basis of a larger-scale study when I go to university. As a cleft patient myself, I obviously have that personal connection to my work which makes me all the more passionate about how I can help CLAPA and raise more awareness!

I can't wait to start my life at university, but I will always be trying to get more and more involved with CLAPA as the CYPC really has made it an integral part of my life and changed me for the better…

…Thank You CLAPA!

Eleanor with Pudsey, Alex Jones and Matt Baker

Taking the Lead

CYPC Member Eleanor was just sixteen years old when she was chosen to be one of five young people to take part in The One Show's Rickshaw Challenge; a seven hundred mile journey across the UK to raise money for BBC Children in Need. It is only through a generous grant from BBC Children in Need that CLAPA's services for children and young people are funded, so for Eleanor this was a great way to give back and to tell her story at the same time.

Eleanor was born with a bilateral cleft lip and palate, and during the course of the programme she and her family opened up about the effect this had on them. "Being born with a cleft lip really knocked my confidence," she said, "as I felt like no-one really understood. I'm much more confident now, but it's been a long journey. I'm doing the challenge with my dad and am so excited. I'm ecstatic, I genuinely can't wait!"

The final appeal aired on Friday 15th November 2013, and all in all the campaign raised an incredible £49.6 MILLION!

We were so proud to see Eleanor on screen representing other young people like her! To watch the short film that aired on The One Show, visit the BBC's website.

Q&A

The Alveolar Bone Graft (ABG) Operation

What is it?
The ABG is a surgery to repair a cleft in your gum. A small piece of bone is taken (normally from the hip) and placed into the space in your gum to fill the gap. This means your adult teeth can grow properly. It won't change how you look.

When does this happen?
When you've lost all your baby teeth and your adult teeth are coming through. Your orthodontist will decide when. It's usually at 8-10 years old.

Can I eat after?
You're advised to stick to a soft food diet until you're all healed up to avoid irritating the bone graft – this isn't as bad as it sounds, because ice cream is especially good for soothing your mouth!

Does it hurt?
In the first few days following surgery, you'll probably be quite sore but regular painkillers help a lot. The stitches in your mouth will also feel a little strange, but these will dissolve. Make sure you get lots of rest after your surgery so you can heal up quickly. Chances are you'll be completely back to your old self within a few weeks.

What happens next?
You might go back for some follow-up appointments, but other than that you'll probably be done with surgery for a while – what a relief!

GET IN TOUCH

facebook.com/groups/CLAPAYoungPeople

Your Stories

"If I could go back in time and get rid of my cleft: I wouldn't. Not for a second. It's made me the man I am today. It's part of my identity. It makes me different and for that I am happy."

Dan's Story

It's 2005 and I'm 18 years old. Currently, I'm in an elevator with my family, leaving the hospital after surgery. I've had little-to-no sleep and my jaws are wired shut. Almost spontaneously, I burst out crying. This is going to be too hard, I think to myself. My Nan comforts me as we make our way back to my Dad's car. Though I think I'm getting ahead of myself.

Quick introduction: my name is Dan, I'm 27 years old and I hail from Bolton. I was born with a unilateral cleft-lip and palate and developed a somewhat pronounced underbite as I grew. Growing up with a cleft was both difficult and strengthening. Difficult in that – like many children with or without a cleft – I was bullied by other kids. Strengthening in that I genuinely believe that my cleft made me a better person.

The first major surgery I can distinctly remember was my Alveolar Bone Graft when I was ten years old, and it was particularly difficult. At that age, you want to be out playing football or inside with video games – instead, for a few days, I was in hospital.

And so we arrive back in the elevator. When I was 18, the surgery was far more obstructive then anything I could remember. The procedure (dentofacial oseteotomy) would remove both my upper and lower jaws. These would then be set in new positions to rid me of my under bite. Finally, the jaws would be held in place with titanium screws whilst tight bands joining my braces would hold them in place until the bone had healed. This would take a month.

The knowledge that I would have to live a month without solid food utterly terrified me. Fortunately, I had good close friends who lightly made fun of it and a supporting family who walked me through it and I owe so much to them all. When the wires on my braces were finally removed (one of the happiest days of my life), my Dad and I raced home and he asked me the question I'd waited 30 long days to hear: "What would you like to eat?" And I answered, of course: "one bacon butty, please". It was the strangest sensation, different teeth were now touching different teeth as I chewed. I had to teach myself how to chew again! Naturally, bits of bacon and bread went everywhere all over the table as I 'ate', but if I'm being honest it was probably the best meal I've ever had.

Growing up with a cleft

Growing up with a cleft was a strange experience. I never felt any apprehension or nervousness when asked about it. In fact, I relish it. I typically try to go into as much detail as possible – the surgeries, the feelings and the fascinating world of cleft palates.

Of course, it was not always so fulfilling. Children will probably bully other children until the end of time, but it's difficult not to feel unfairly singled out. In both Primary and Secondary school, I was the only child with a cleft. I was called the usual (ugly) to the unusual (volcano-face).

However, it wasn't until I started Secondary school that it became really difficult. I got into slanging matches (and a few fights), perhaps as teenage boys do, but I treated it as background noise. I've never blamed the teachers – as I see it, outside of monitoring bullies 24 hours a day, there's not much that can be done to stop it. That's why I think there should be a concerted effort in schools to talk about differences. If we can educate young people about how differences make us what we are, rather than let them define us in a negative way, we could go a long way to making it easier for young children.

As I reached my late teens and early twenties, it was much easier. Though I am sure that there are people who may have muttered something under their breath or stared, I am fortunate that I have surrounded myself with a close group of friends who see me for the funny, kind (and clearly modest!) man that I am today. I am also supremely grateful to my large extended family who care for me in ways that I will never be able to repay.

It's exciting that there is a community for people with cleft or with children who have it. I didn't really have such a thing growing up and it was easy to feel isolated. If CLAPA can help parents, kids and adults with cleft feel a part of something larger, that there's people there to help and to listen, then that can only be the very best of things.

DO YOU HAVE A CLEFT?

Do you have a child with a cleft? Would you like to share your story with our community? Email info@clapa.com with the subject line 'Case Study' to find out more.

Maz's Story

My cleft journey started 37 years ago when I was born with cleft lip and palate. I grew up like any other child with the added hospital appointments and operations thrown in, but I got through it.

My cleft journey started 37 years ago when I was born with a cleft lip and palate. I grew up like any other child with the added hospital appointments and operations thrown in, but I got through it.

Back then, CLAPA didn't exist and they couldn't diagnose at the scans so my mum was just handed me after giving birth and basically got on with it - and for that I'm truly grateful. My dad also was born with a cleft lip and palate and I have an older sister who has gone on to have two children but both of them were unaffected. I didn't let having a cleft stop me and fulfilled my dream of working with children and was a nanny in California which I loved. Sometimes I feel that what I went through as a child has made me a more determined person and has made me who I am today.

My love for looking after children continued and a couple of years after marrying my husband Richard we found out we were expecting our first child. We went to our 20 week scan excited to be finding out the sex of our new baby – little did we realise that our cleft journey was about to start! Even though I was born with a cleft, it was still very hard to take it in when my daughter was diagnosed. However, having the Cleft Nurse phone me shortly after and being supported by my husband and family, we started thinking more positively and wondering what she would look like. When she was born, we totally forgot about the cleft - she had these gorgeous eyes and beautiful wide smile. In fact when it was time for her operation at 3 months I was really sad for her to be changing as I felt I was being given a different baby. She had two operations at 3 months and 6 months, and is now a happy 6 year old who also seems determined (some might say headstrong!).

Four years later, it was like history was repeating itself. We were expecting baby number 2 and at the 20 week scan we were told we were having a boy and that they could see a cleft. After a few wobbly days, which I'm sure everyone has, I decided the best thing was to think positive and look forward - after all there was nothing I could change. The following April, Austin arrived. His cleft was more severe than both mine and Charlotte's and he's had 3 operations. His operations were done later so whereas Charlotte's face had changed at 3 months, he was almost a year old as his lip was done in 2 stages. I'm not a fan of hospitals, but when my children are in I put my "mummy" hat on - it's amazing the strength we find for our babies when we have to. Austin's now 2 and an amazing boy. I feel blessed to have 2 children with cleft and wouldn't change them for the world.

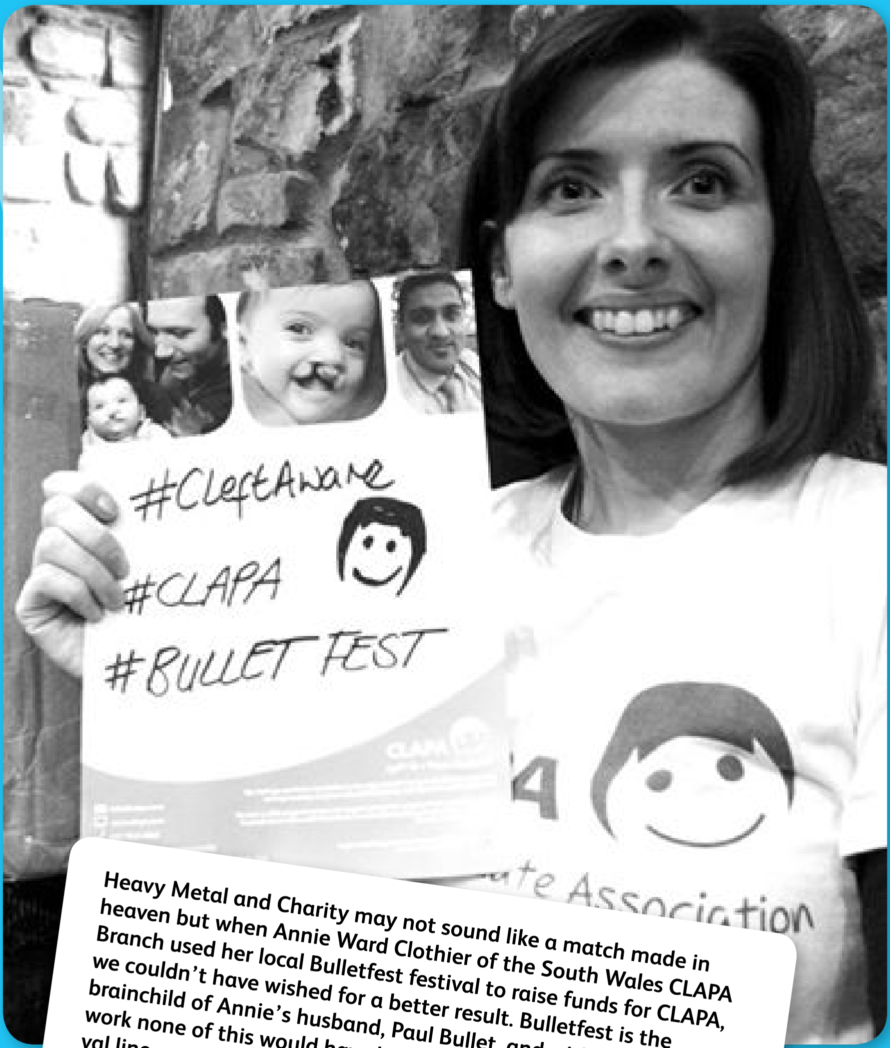
I wanted to be able to help other parents of cleft children and I've now gone on and done the Parent Contact and the volunteer training. CLAPA hold these all around the country and if you're thinking of doing them I'd say do it, I highly recommend them! I personally got a lot out of them. I'm also the Happy Faces coordinator for Norfolk/Suffolk and I arrange meet-ups for those affected by cleft. Our numbers are small at present but I'm hopeful that over time the word will spread and more people will come along. I've met some lovely people on both my children's cleft journeys, and I thank the Cleft Team, CLAPA and my wonderful family for their amazing support!

Sophia

Sophia was born with Pierre Robin Sequence and a complete cleft palate. After struggling to gain weight in early life, she is now thriving and making her family very proud. Here she is with big sister Emily.

Fundraising Heroes

This last year has to be our busiest ever! Luckily Rebekah joined us in March so we now have permanent support in the fundraising department. We've both spent much of the last few months sending out fundraising packs and T Shirts to all our wonderful fundraisers. We would like to take this opportunity to thank everyone who kindly gave up their time and on occasion sanity to support CLAPA! Here are just a few examples of the CLAPA Community at work.

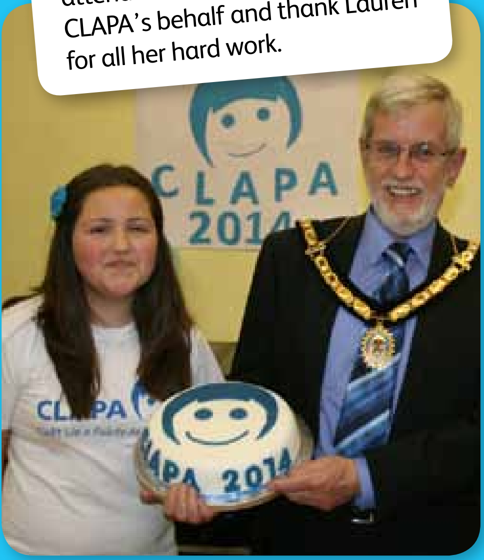


Heavy Metal and Charity may not sound like a match made in heaven but when Annie Ward Clothier of the South Wales CLAPA Branch used her local Bulletfest festival to raise funds for CLAPA, we couldn't have wished for a better result. Bulletfest is the brainchild of Annie's husband, Paul Bullet, and without his hard work none of this would have been possible. The amazing festival line up drew in crowds of people who alongside headbanging and enjoying the music of bands such as Deathbullet, Grifter and Desalvo, also found the time to dig deep and donate to CLAPA. A fantastic amount of over £700 was raised and a great time was had by everyone that came along. A massive thanks goes to Annie and Paul for all the publicity and organisation that went into this hugely successful event!

Little Kishan was born with a unilateral cleft lip and palate, and dad Deep raised over £2,000 for CLAPA by completing a gruelling 60 mile bike ride. "A massive thanks to the team on the day who kept me going and an almighty thanks to my amazing wife who did everything possible to make sure I got to the start line!"

Samantha ran the Hastings Half Marathon and raised £680.

Lauren organised a charity concert in April to raise further funds for CLAPA. Lauren was really hoping to beat last year's fundraising amount of over £600 and managed to double it to £1228! Lorayne and Sarah from the South Wales Branch also attended her event to speak on CLAPA's behalf and thank Lauren for all her hard work.



Joanne wrote a column in Prima Baby and Pregnancy Magazine to talk about her cleft journey to raise awareness. She also managed to raise £1,100 from a Charity Dinner Night and a children's disco party!

Dawn deserves a mention just for looking the happiest we've ever seen someone after completing a marathon! She ran the Edinburgh Marathon in late May and raised £360.

Tom ran the Leeds Half Marathon and raised £700.

Josh was one of our London 10k runners in 2014, and completed the distance in a very respectable 47 minutes. Money is still being counted, but he expects to raise around £1,300 which surpassed all of his expectations. Well done, Josh!

Find out how you could run for CLAPA in the 2015 London 10k by emailing fundraising@clapa.com.

Regional Fundraising Heroes

As many of you will know, CLAPA's income is split into two funds. One of them, the National Fund, is used for all our core services around the UK, including our feeding programme, volunteer training, information and literature and the website. The other is the Regional Fund which is used to support all our wonderful volunteers and branches to put on activities locally and provide medical equipment like breast pumps for new mums.

You may well have been to a CLAPA Christmas party or Summer picnic or even been involved yourself with organising activities in your local area, so you'll understand the importance of supporting these events. In the last year, volunteers put on 10 Christmas Parties, 6 Summer picnics and at least 20 activity days!

Without support for our Regional Fund, none of these activities would be possible so we're asking anyone out there who would like to help to get in touch. There are so many different ways to support CLAPA, as you can see here!

Castle Bromwich Singers

On Tuesday 13th May 2014, Castle Bromwich Singers were pleased to announce that an amazing £2,650 has been raised by delivering various shows during the last 12 months and carol singing through November and December at local venues. The Singers adopt a charity each year and as Rebecca, the grandniece of one of the singers, was born with a cleft lip and palate three years ago, they decided to adopt CLAPA as their charity for 2013-14.

The fundraising year ended as it began with a small talk from CLAPA representatives at Castle Bromwich Baptist Church, where singers rehearse every Tuesday. Last night Tony Ruel, CLAPA Volunteer and Becky Gowers, previously the Central England Regional Coordinator, spoke about how CLAPA was developing in the West Midlands, the activities they are undertaking and how they hope to develop more groups and events in the area. The cheque was handed to Tony by Castle Bromwich Singers' chairman, David Kemp.

Pin Badges

We are looking for people to help us raise money with our NEW pin badges, all we need you to do is ask for a suggested donation of £1. These enamel badges are perfect for wedding favours, to give to people taking part in an event or even as a thank you for supporting your own fundraising. Just contact us and let us know how many you would like.

Rugby Fun Day

Alison Dunster's daughter Esmae was born with a unilateral cleft lip and palate, so she decided to raise money for the South West Cleft Unit and CLAPA's Regional Fund. The Old Redcliffians Rugby Club hosted the rugby fun day and Alison did a sterling job promoting the event through the local newspaper, radio and CLAPA's website, leading to a great turn out on the day. Ann Roberts, Tina Owen and Louise Wheeler, respective members of the cleft team, Bristol Branch and CLAPA's fundraiser attended the event where they were presented with a cheque. Overall Alison raised an amazing total of £3,500. Esmae revelled in all the attention and said she thought the day was brilliant with the climbing wall being the best bit!

Alison organised a great day, Tina said: " I have never folded so many raffle ticket stubs in my life before! The cleft team are very grateful to Alison and all her friends and family who made the day such a success and raised money for the unit and the families we support." Alison is already planning next year's event and we wish her all the best!

GET IN TOUCH

Please download a fundraising pack from www.clapa.com/get_involved for ideas and information on how to get started, or ring our fundraising team on 020 7833 4883

Aberdeen Branch go the extra mile for Team CLAPA

Team CLAPA Aberdeen & North East Scotland are raising money throughout 2014 by completing up to 5 different events. The team consists of Tina Sanderson, Louise Murray, Robin Mant, Geraldine Murray, June Fair, Rebecca Bryce, Steven Crook, Mhairi Stewart, Kelly Duncan, Christine Lamb, Julie Lindeman, Alison MacKay and Kyllie Mitchell.

THE CHALLENGES:

- The Baker Hughes 10k 18/05/2014
- Stonehaven half marathon 06/07/2014
- The Glack Attack 5k Mud Run 23/08/2014
- The Beast Race 10k Obstacle Course - 27/09/2014
- The Glack Attack Halloween 5k Mud Run in the dark 01/11/2014

They have a target of £1000 and are ¾ of the way already. We wish them all the best!

Cleft Lip and Palate Awareness Week

10th - 17th May 2014

Do you have a place in mind that would be perfect for a CLAPA sponsored walk? Make sure you get in touch in 2015 to have your walk end up in CLAPA News!

Sponsored walks

Awareness Week was busier than ever with so many of you doing different events, putting up posters and generally raising awareness of cleft lip & palate. We had everything from sponsored slims to wearing a onesie for a whole week!

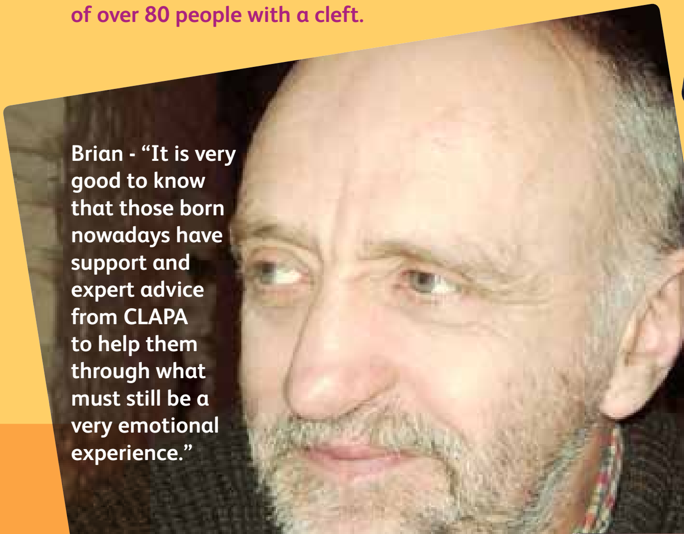
We were thrilled to increase our CLAPA Sponsored walks to 7 this year, these were organsied by supporters and branch members and were open to all the CLAPA Community. We also had another 7 private sponsored walks organised by people who just wanted to invite family, friends and work colleagues. If you are interested in organising a CLAPA walk or just something for your loved ones then give us a call on 020 7833 4883 or email fundraising@clapa.com and we'll email you a Sponsored Walk Organisers' Pack.

Onesie Week

Jenny was very brave and wore her CLAPA onesie all week long for Awareness Week. Raising £534.50, it was 'Beyond all my expectations!' Jenny has also been looking after a collection tin at her workplace Homebasics which has now collected a total of £209.25. We would like to thank Jenny for everything she does for CLAPA!

Wall of Smiles

This year, our Wall of Smiles celebrated the diversity of the cleft community in the UK and told the stories of over 80 people with a cleft.



Brian - "It is very good to know that those born nowadays have support and expert advice from CLAPA to help them through what must still be a very emotional experience."

Kim - "Now I'm glad I was born with a cleft because going through what I have has made me the person who I am today."

Elizabeth - "CLAPA has helped me come out of my shell and embrace my cleft."

Haider - "I believe that scars are not something that should be hidden, they are the evidence that we had fought against something and survived."

Oscar - "It means you're different, but in a good way, and I think you're less likely to judge a book by its cover."

Adults with a cleft

Over 1,000 babies are born with a cleft every year, and while a large proportion of our membership is made up of parents with young children, those children don't stay young forever, and we are seeing more and more adults who were born with a cleft joining our ranks. This year, we decided to focus on the issues that most affected adults who have grown up with a cleft lip and/or palate in order to raise awareness within CLAPA and the wider community of how this condition can affect people into their adult lives.

We used our Spring Survey (page 19) to see what the most common issues were for adults with a cleft, then made sure we had answers for your biggest questions. We'll soon be putting those answers into factsheets and making them available on the Adults section of our website to help you stay informed all year round. We also put the stories of adults with a cleft front and centre with our Wall of Smiles and numerous case studies.

This in turn encouraged other adults to come forward to share their own experiences, ask questions and seek advice from our growing community. Many parents of young children also mentioned that they found it very helpful to hear from people who had grown up with a cleft so they could better understand the issues that their own children might face in later life.

Visit cleftaware2014.com to check out our Awareness Week microsite.

AWARENESS WEEK IN NUMBERS

20,000+ visitors to our Awareness Week microsite

1,500 posters distributed by awareness-raisers

7 runners for CLAPA in the London Marathon

80 people sent in their stories to our Wall of Smiles

80,000 people saw the posts on our Facebook Page thanks to your shares and likes

470 supporters joined our Sponsored Walks

Dates for your diary

Awareness Week 2015 will be from 9th- 16th May

Volunteering

CLAPA is a small charity, and while we are dedicated to our work, there's only so much we can do with our limited resources. That's why we rely on our volunteers and fundraisers to do what we can't.

From sky-divers to Parent Contacts, local organisers to Council members, our volunteers and fundraisers are at the centre of our support network for people affected by cleft. All around the UK, friends, family and people with cleft are using their spare time to give talks, to organise support groups, put up posters, sit in clinics, mentor young people, represent CLAPA on a national scale, even act as a listening ear for others in need. Sometimes we're not even sure how they fit it all in!

We welcome volunteers no matter what their age, background or connection to cleft, and following on from our Awareness Week theme this year, we'd especially like more adults to get in touch and join us in supporting others like them.

You won't be alone in this – CLAPA provides full training and refresher sessions to keep you up to date and confident in your role, and maybe we're a little biased but we think our community of volunteers is the friendliest around!

Even if you don't think you could commit too much time, it's still worth checking out what's on offer to see if there's something you could fit into your schedule. If you're interested in research and campaigning for better treatment, how about getting involved with our Patient Voice programme and representing the needs of others on a national scale? What about acting as a CLAPA Ambassador and attending celebration events to pick up cheques or give a talk? There are so many different ways to help us continue our work – you're bound to find something that suits you down to the ground!

> **"You know what they have been through, you know how much it can hurt, and I really think loss of the feeling that you are alone is the first step towards feeling better about yourself."**

Danielle, 18, on why she wants to see more volunteers who have a cleft themselves

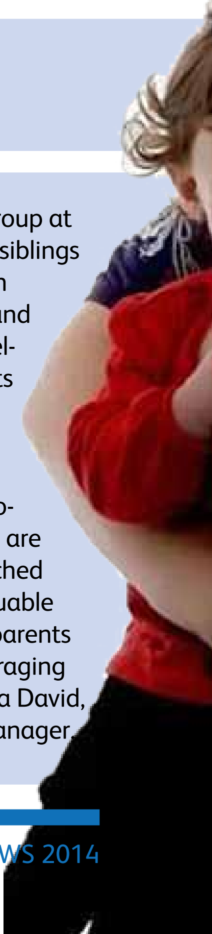
Spotlight On: Redditch Happy Faces

Selena Foster was inspired to set up a Happy Faces group after her daughter Lorena was born with a bilateral cleft lip and palate in 2012. She said, "When Lorena was born we had so many questions and I really wanted to meet with other parents in a similar situation". Selena had been supporting CLAPA through fundraising for a while and became an official CLAPA volunteer in January 2014. In April 2014, she trained as a CLAPA Parent Contact in order to gain the skills she needed to support other parents.

Selena worked with CLAPA's Central England Regional Coordinator and the West Midlands Cleft service to set up Redditch Happy Faces. She found a venue – a local Children's Centre with lots of toys (and some comfy chairs!) and set a regular date - the first Friday of every month. The launch date was set for 2nd May 2014 and work began to promote the group through social media, at the Birmingham Children's Hospital Cleft Clinic and via the local Cleft Nurse, who encouraged her patients to attend.

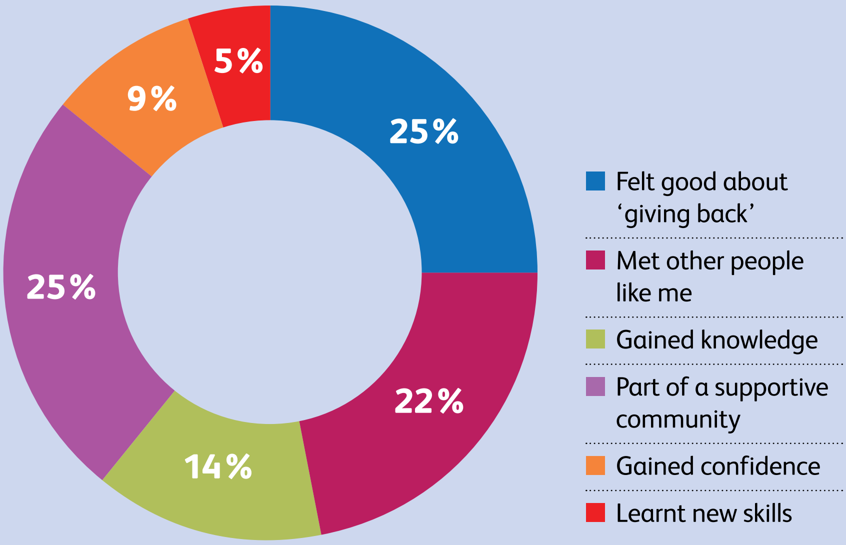
The first meeting was a great success, with 6 families getting together to share their experiences and support each other and since then more new families have joined the group at subsequent meetings. Parents, siblings and grandparents have all been welcomed along to the group and Selena also looks forward to welcoming some expectant parents in the near future.

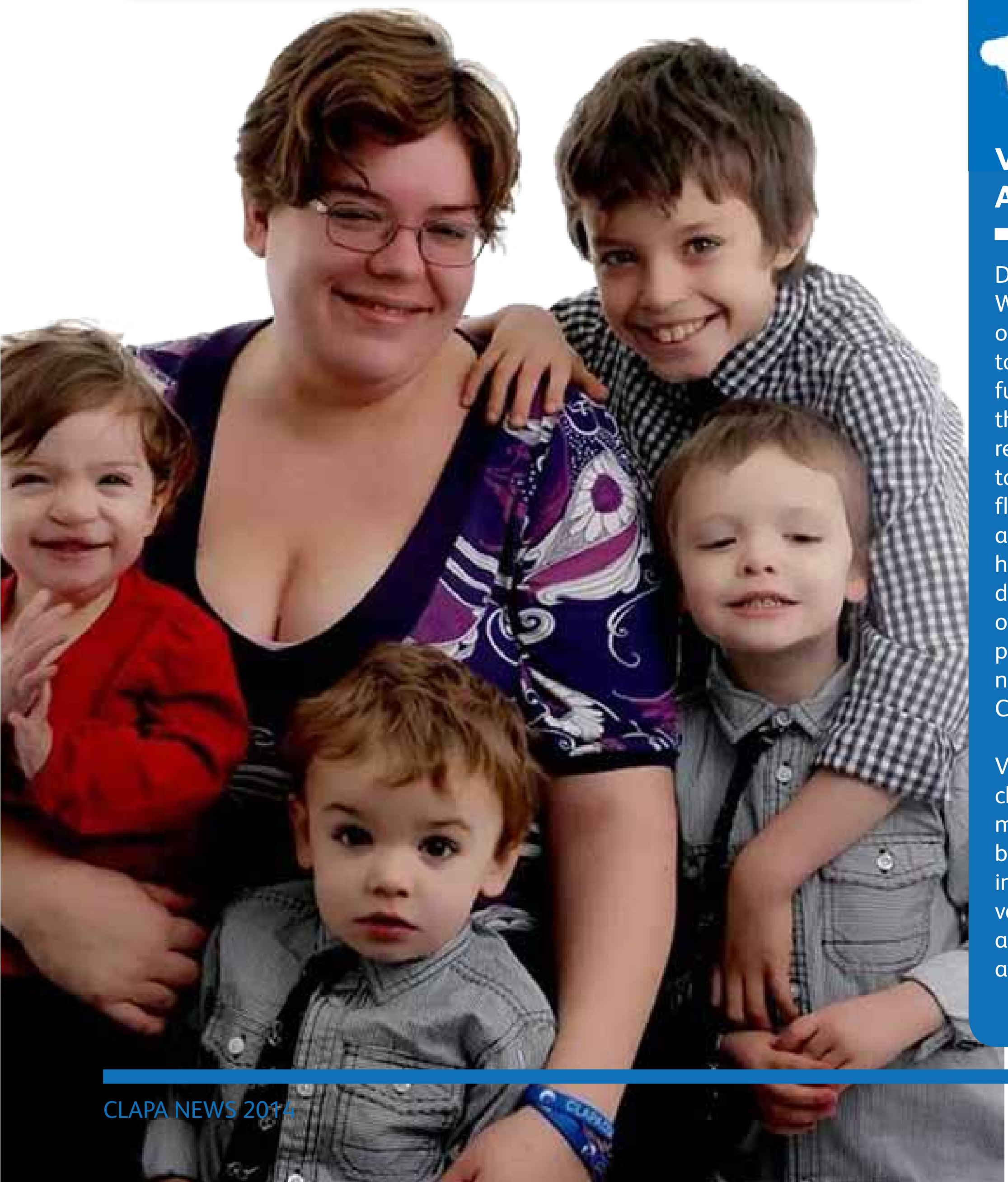
The West Midlands Cleft Service have been very supportive of the group and have been promoting it to their patients: "We are so pleased this group has launched in Redditch – we know how valuable it is for families to meet other parents and children and we are encouraging our patients to attend". – Senga David, West Midlands Cleft Service Manager.



Why Volunteer?

We asked some of our volunteers what they thought the main thing they got out of it was in our Spring Survey.





IS THERE A VOLUNTEER ROLE FOR YOU?

- **Parent or Peer Contact**
- **Clinic Volunteers**
- **Fundraisers**
- **Happy Faces Group Organisers**
- **Branch Committee Members**
- **CLAPA Ambassadors**
- **Awareness Raisers**
- **Residential Weekend Volunteers**

Check out www.clapa.com/get_involved or email volunteer@clapa.com for more information about any of these roles.

VOLUNTEER AWARDS

During National Volunteers' Week in June 2014, we launched our first annual Volunteer Awards to show all our volunteers and fundraisers just how special we think they are and to formally recognise their vital contributions to our work. Nominations are flooding in from our community, and soon our panel of judges will have their work cut out for them deciding who should receive each of our 5 awards which will be presented during our 35th anniversary Tea Party after CLAPA Conference 2014.

Visit our Conference microsite at clapaconference.wordpress.com for more information. We hope you'll be able to join us on 18th October in London to see the winners revealed, and that you'll look out for an announcement about our 2015 awards in the summer.

Spring Survey 2014

In early 2014 we launched the largest survey of our community in 6 years, hoping to get a snapshot of just how much things had changed and what our priorities should be both now and in the future. As a representative organisation, it's important for us to know what really matters to people affected by cleft in the UK so we can make sure our information and campaigns are evidence-based, and this survey was our chance to find out where you stand on everything from scars to speech therapy. This is a small snapshot of some of our results.

PARENTS AND CARERS

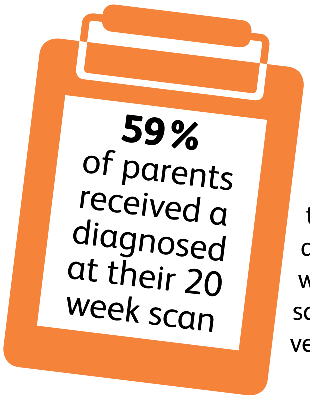
444 parents and carers of at least one child with a cleft were surveyed, and out of these people 85 % had a child under 14 years old.

DIAGNOSIS

59% of parents received a diagnosis at their 20 week scan, but only half agreed that their diagnosis was handled 'sensitively and professionally'. Waiting several days for a second scan to confirm a diagnosis was something that many parents and carers found difficult, especially when it came to reporting the uncertain news to friends and other family members.

2/5 parents received a diagnosis after the birth of their child. In general these were dealt with better than antenatal diagnoses, with 80 % saying all or parts of it were handled well. Nearly half of postnatal diagnoses were of **isolated cleft palates** which typically cannot be picked up on antenatal scans. In these cases, only **60%** of our sample were diagnosed within the national standard of 24 hours after birth, with 14 % not diagnosed until more than a week after their child's birth. A third said they did not get enough support at this time.

We were pleased to see that whenever the local Cleft Teams were mentioned, it was with glowing praise, and many parents said they felt instantly reassured and well taken care of once they were referred, but that this referral process felt far too lengthy. When asked about their last experience with their cleft team, 9/10 said they were happy or very happy.



POSTNATAL SUPPORT AND CARE

Only 18 % accessed a local CLAPA group such as Happy Faces, with a third saying there were none nearby and over 40 % saying they did not know about these. One of our top priorities over the next few years is dramatically improving local peer support, including making groups like this widely accessible.

When it came to choices about feeding their baby, 67 % said they received enough specialist support and advice to make an informed decision, and half said that once they had made a decision they felt well-supported by other parents and health professionals.

HOSPITAL APPOINTMENTS

84% of parents with school/ nursery-aged children said they had to remove their child to attend appointment, and only 59 % said these were marked down as 'authorised'. Only 28 % said they felt there was enough support available at their child's school for children who will have frequent absences for things like surgery.

3/5 parents said they believed it cost more to have a child with a cleft. Of these, 43 % named travelling to and from hospital as the biggest expense.

For factsheets on issues like this related to having a child with a cleft, visit www.clapa.com/parents

ADULTS

108 of the respondents to our survey were adults who had been born with a cleft. Of these, 65 % had a cleft lip and palate, 18 % had a cleft palate only, and 17 % had a cleft lip only.

VISIBLE DIFFERENCES

97%

of people with a cleft lip considered themselves to have a ‘visible difference’, by which we mean something about their appearance such as a scar which is different to the norm. Only 7 % said this didn’t affect them at all, with 72 % saying it negatively affected their personal lives.

Adults had a lot of concerns about getting further treatment which might change their appearance, the most common worries being that more surgery might just ‘make things worse’ or that they would just end up being disappointed with any results. Many did not know that further treatment was even an option after turning 18, much less that this could include non-surgical interventions such as seeing the Clinical Psychologist at their local Cleft Team to talk through their options.

> **“Within my job as a makeup artist I try to encourage people to be happy and positive about their appearance. It’s what’s inside a person that matters.”**

55%

of adults with a cleft said they considered themselves to have some kind of speech disorder or difficulty caused in whole or part by their cleft.

SPEECH

70% said it still negatively affected their personal lives.

7% **said there was enough support for this at their place of work or education.**

59% said there was not. A third said they would like further treatment.

65% **of these did not know how to go about this.**

Public speaking and talking on the phone were particular problems for adults with these issues, and many said they often felt frustrated or flustered when it took a while for others to understand them, even spouses and close friends.

> **“I found I was so much happier when I finally accepted myself. I no longer look in the mirror and just see my cleft. I see me!”**

GETTING FURTHER TREATMENT

2/5 adults said in their experience non-cleft health professionals didn’t fully understand how to treat patients with a cleft, and most of the issues reported were with GPs/Doctors and Dentists. Adults particularly disliked having to explain themselves and their condition over and over again, and often said that their concerns were ignored or that they got conflicting advice from health professionals who weren’t familiar with cleft lip and palate.

Many of the adults completing our survey won’t have benefited from the Cleft Teams that were formed around 12-14 years ago to provide specialist treatment, but those that did were clear that the new system has helped, as younger patients were far more likely to have a positive view of themselves and their cleft. Half of our sample returned to treatment for cleft-related issues as adults, and of those 91 % said their experiences had been good or very good.

Unfortunately, there is little awareness about what is available for adult patients. Half our respondents didn’t know what their treatment options were or how to access these on the NHS, and 2/3 said they didn’t know how to approach their GP or dentist about issues they were having, nor were they confident that the problems could be solved.

Visit www.clapa.com/adults for more information on treatment options as an adult.

Have your say and find out about future surveys by signing up for our e-newsletter at www.clapa.com/members.

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?

Although a cleft in the lip and/or the palate is relatively common, little is known about what causes it to happen. For parents whose child has received a diagnosis of cleft lip and/or palate, feelings of guilt and grief are common, and parents often worry about their child's future. While care for children born with a cleft has improved considerably over recent decades, the burden of ongoing cleft treatment can still have a significant impact.

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

1. What **caused** my child's cleft?
2. What are the **best treatments** for my child?
3. **Will my child be OK** as he/she grows up?

The Manchester Team

The Cleft Collective team in Manchester have been busy completing and getting funding for projects. The ***MOMENT*** study on hearing loss in children with a cleft palate has finished and final results will be published on our website in the autumn. Two more studies are currently being planned. The first, ***SLUMBRS***, will focus on the healthiest sleeping position for children with a cleft palate, as at the moment doctors and nurses have no clear evidence when advising parents about this. The second study, ***ACORN***, is about keeping teeth healthy in children with a cleft lip and/or palate. Another project which is currently underway involves members of CLAPA and is **about late diagnosis of cleft palate**, and focuses on exploring parents' experiences in particular through open-ended interviews.

Finally, we are currently seeking funding for two further studies, the first will be about the **best time for speech and language therapy**, and the second will try to develop a '**Core Outcome Set**' for orthodontics, which is a list of the key things that should be measured in any study in a specific field. A Core Outcome Set makes it much easier to compare the results of different studies because the same things have been measured. In all of our studies, feedback from parents and patients is essential.

> “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.

The Bristol Team

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. Over 3,000 families are being invited to participate in the **Cleft Collective Cohort Studies** over the next 3.5 years. We hope the information we collect from families will help us to identify some of the biological and environmental causes for 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.

Although the research team is based in Bristol, families from across the UK will be invited to participate in the studies.

> “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.

If your child is born, or turns five within the recruitment period, you should be eligible to participate in the main Cohort Studies. Over 500 individuals from more than 150 families have been enrolled in the Cohort Studies so far, and more cleft teams will be up and running soon!

There are also many other 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.

Cleft Image Bank – we collect photographs of families, young people and adults who have been affected by cleft, to give a real-life feel to our work.

Mailing list – we 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.

The Cleft Collective
Closing the Gap in Cleft Research
A Healing Foundation Initiative

Telephone:
+44 (0)117 342 4412
Email:
cleft-collective@bristol.ac.uk

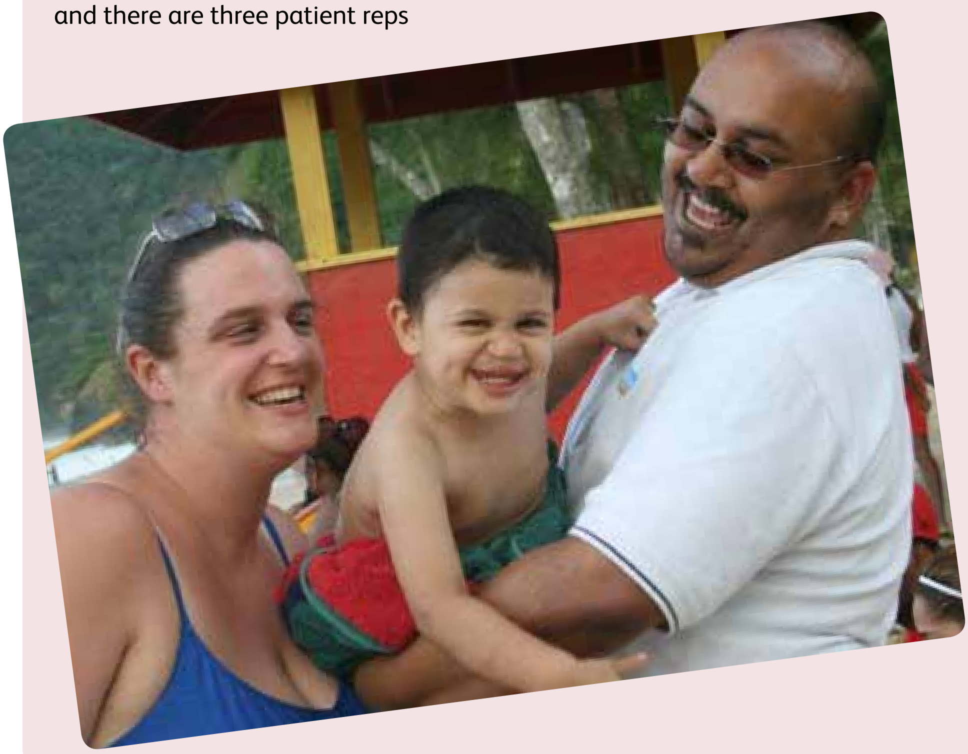
Follow The Cleft Collective

Website:
www.cleftcollective.org.uk
Facebook:
www.facebook.com/cleftcollective
Twitter:
@CleftCollective

The Clinical Studies Group

A key part of NHS medicine is that it should be evidence-based so that clinicians know they are giving the most effective treatment. This is why it’s vital to do research into cleft lip and palate care and this year the Clinical Studies Group (CSG) was set up with funding from the Healing Foundation and the Craniofacial Society.

The CSG helps researchers develop their proposals, which increases the chance of their getting funding, and there are three patient reps on the group plus Rosanna Preston representing CLAPA. Researchers are also supported by the Cleft Collective Clinical Trials Unit in Manchester and if you have a question about treatment that you’d like to see researched then you can contact them both for help to turn it into a fully-fledged proposal. Alternatively you can give your suggestions to Rosanna at CLAPA to raise at the CSG by emailing her at rosanna.preston@clapa.com.



About CLAPA

CLAPA is:

- The only national charity in the UK devoted to supporting all those affected by cleft lip and/or palate
- Well-established, with 35 years' experience of providing dedicated services
- The voice of both the patient and those involved with their care
- All stakeholders are involved in the running of the charity:
- People born with a cleft
- Parents of children born with a cleft
- Health professionals involved in the treatment of clefts

CLAPA's work

- Parent support: UK-wide network of trained CLAPA Parent Contacts, extensive range of literature on all aspects of clefts, telephone advice, online support groups
- Promotion of an active cleft community for all ages which is open to everyone affected
- Feeding support: unique specialist bottle and teat distribution to families and hospitals and free Welcome Packs with a 24-hour turnaround target
- Improving care: safeguarding best practice and lobbying for best possible standards in UK and Europe
- Raising awareness of cleft lip and palate amongst the general public through our information leaflets, appeals, events and publicity drives

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

CLAPA
Cleft Lip & Palate Association

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You can also find us on Twitter (@clapacommunity) or on Facebook (facebook.com/clapacommunity)
Registered Charity England & Wales (1108160) and Scotland (SC041034)

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Tansy Miller	Regional Coordinator for East of England
Rosanna Preston	Chief Executive
Edit Walsh	Finance Manager
Louise Wheeler	Community Fundraising Manager

Trustees

Trustees can be contacted by email: trustees@clapa.com

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

Parent Contacts

If you have any general questions about cleft lip or palate that you wouldn't think of bringing up with your cleft team, or if you would just like to talk to someone informally, get in touch with one of our parent contacts.

We have many parents across the country who have personal experience of cleft lip and palate and are able to offer one-to-one support. For more information and contact details please visit our website.