



Selena's Story

Selena Foster is mum to 3 year old Lorena, who was born with a cleft lip and palate. Selena was given a diagnosis at her 20 week antenatal scan, and worried that the daughter she had so looked forward to wouldn't turn out to be 'perfect'.

Soon after receiving her diagnosis, Selena and her family moved to Birmingham. Knowing few people in her new city, and no-one affected by cleft, she became increasingly isolated.

Selena's life was transformed when she was visited by a Cleft Nurse Specialist, who told her all about CLAPA. Selena read the CLAPA leaflets her nurse gave her and joined our online support group, where she received responses to all her questions. She also called one of CLAPA's Parent Contacts, and found it hugely comforting to speak to someone who had gone through the same experiences.

In October 2012 Lorena was born, and she was every bit as perfect as Selena had hoped. Just a few months later, Selena held a family fun day to raise money for CLAPA and give something back for the support she'd received. With support from her CLAPA Regional Coordinator, she then trained as a CLAPA volunteer and became a Parent

"I probably would have struggled if it weren't for CLAPA. I didn't know anyone affected by cleft – I would have been lost! I love giving something back for the tremendous support I received in Lorena's first few months."



Contact. Selena also started a Happy Faces family support group in her local area which continues to thrive. When CLAPA's West Midlands Branch of volunteers was set up in the summer of 2015, Selena joined immediately, and is now busy organising local social opportunities for families affected by cleft.

USING FEEDBACK

At CLAPA, we value transparency, and we hope our first annual Impact Report will be another way for us to show others in the UK who we are and what we're all about. If you have any comments or questions about this report, please get in touch using the contact details on the back of this report.

About CLAPA

The Cleft Lip and Palate Association (CLAPA) is the only national charity supporting people and families affected by cleft lip and/or palate in the UK.

One in 700 babies are born with a cleft every year. Cleft lip and palate are lifelong health conditions which can cause severe speech, hearing, and dental problems. People with a cleft often have issues with facial growth and appearance, and as a result can suffer from low self-esteem and feelings of isolation. As well as providing specialist feeding equipment

and information, CLAPA brings together families and individuals affected by cleft so that they can share experiences, form strong support networks, feel less isolated, and ultimately learn to cope. CLAPA is also dedicated to involving patients and parents in their treatment, and works closely with specialist NHS Cleft Teams and researchers to improve standards of care.

Year in Finance

INCOME		EXPENDITURE	
Fundraising	£332,086	Unrestricted Funds	£530,254
Events	£137,488	<small>Including core services (e.g. CLAPA Conference, CLAPA News), staff costs, cost of our specialist feeding service, administration, running costs.</small>	
Branches	£40,800	Regional Support Services	£223,598
Donations	£134,548	Restricted Project Funds	£173,143
Legacies	£19,250	Regional Coordinator Fund	£5,606
Donations from Charitable Trusts and Foundations	£70,314	Regional Fund	£44,849
Grant Funding for Services	£306,089		
Sale of Goods & Feeding Equipment	£49,715		
Other	£4,998		
TOTAL:	£763,204	TOTAL:	£753,852

Please Note: These are provisional, un-audited figures from CLAPA's own internal accounting system. A full breakdown will be available in our Annual Accounts, usually published in September after external auditing.

We would like to say a huge THANK YOU to all our volunteers, fundraisers, partners, funders, and staff for all their hard work and support in making 2015/16 a success.

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CLAPA

Cleft Lip & Palate Association



Impact Report 2015/16

"A Year of Growth"

Dr David Stokes, CEO



Joining CLAPA this year has been an absolute privilege for me. I have been awed by all of the amazing things that the CLAPA community does to support not only those born with a cleft, but also the families who are so central to helping those with the condition as they progress through the treatment journey.

But the landscape that we exist in is not without its challenges. Ensuring that medical services remain world-class requires constant vigilance. In some areas, long waiting lists continue to be an issue for patients, there are still issues around diagnosis, and the tough economic conditions have made fundraising even more of a challenge for the charity. Yet, despite these challenges, CLAPA continues to have a massive impact even as we work to make the most out of every penny.

These challenging conditions provide an opportunity for the organisation to develop, and this will be done in consultation with the whole CLAPA family. 2016/17 will be a time for us to take a careful look at how we deliver our services, how we can make our fundraising more sustainable and diverse, and how we can work more effectively as a single organisation to deliver the best outcomes for our community wherever they are in the UK.

As a charity, we are working towards a world where those born with a cleft

are fully supported and receive the best possible care at every stage, from diagnosis onwards, where awareness and education have replaced stigma and where the cleft community has a strong, diverse and representative voice. What heartens me most about joining CLAPA is that everyone shares this vision; from our trustees and volunteers to our paid staff. This vision permeates everything that we do, and I believe that this vision is strongly reflected in all of our outcomes. It is with real pride that I am able to share our impact for the past year in this report.



Local Branch Christmas Party 2015

Bockett's Farm Family Fun Day 2016

Our Impact

April 2015 -
March 2016

CLAPA's vision is a UK where being born with a cleft is no barrier to achieving your desires and ambitions. Our work is all about helping people overcome cleft-related challenges so that they can live their lives to the full.

Members of the cleft community tell us that one of the main barriers they face is the sense of isolation. As a result, many of our services bring people – often families – together to share experiences and ways of coping with cleft-related challenges. Being able to engage with other people born with a cleft is crucial, particularly for younger age groups, so CLAPA delivers special services for children and young people.

Another key element of our work is training volunteers, usually affected by cleft themselves, to support others like them. Our Parent Contacts, Peer Contacts, and Clinic Volunteers provide a listening ear and crucial non-medical guidance to those in need.

We also raise awareness of the impact of having a cleft, so that those affected can lead happy lives.



Local Branch Christmas Party 2015

REGIONAL COORDINATORS PROJECT

We employ full-time Regional Coordinators to support volunteers and activities in their regions. The project is currently running in 4 regions (the East, South East, and Central parts of England, and across Scotland), but we aim to expand across the UK.

In our three England regions:

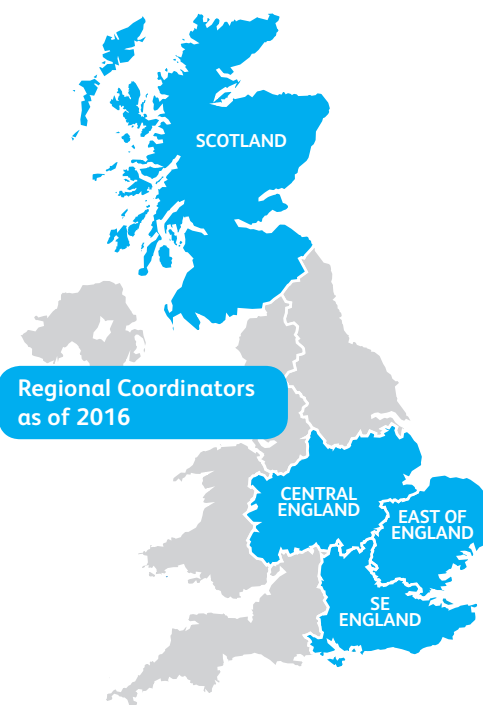
- 1,332 people attended CLAPA events, including local volunteer-run Happy Faces support groups.
- 236 people shared their stories at our events, in publications or online – a vital part of learning to cope and gaining confidence around cleft.
- Our Parent Contact volunteers supported 486 parents and carers of children with a cleft.
- We trained 64 new volunteers. 250 of our volunteers said they had gained enhanced skills and/or knowledge through their volunteering.
- We established 4 new Branches and 5 new Happy Faces family support groups to help our services reach even more people locally.

In our new Scotland region:

- We recruited and trained 15 new volunteers including Branch Committee members, Parent Contacts, and Happy Faces group co-ordinators.
- We launched a new Branch in Glasgow.

- We launched a new Happy Faces group in Glasgow, with 3 more on the way in Edinburgh, Fife, and Aberdeen.
- Our Branches held 5 events for the local cleft community, including Christmas parties, a summer BBQ, and a trip to the panto.
- We ran 5 awareness-raising events and gave 7 talks in hospitals, schools and universities.

Other regions, including Wales, Northern Ireland and parts of England, are supported by the CLAPA National Office, but we hope to raise enough funds to give each of them their own Regional Coordinator as soon as possible.



Regional Coordinators as of 2016



A 2016 Residential Weekend for children & young people born with a cleft

UK-WIDE SUPPORT

For Under 18s Born With a Cleft

Our Children and Young People's Council (CYPC) had a year of fun and productive meetings which culminated in a promotional film being made to showcase their involvement with research. This film was shown at the Appearance Matters 7 Conference to encourage researchers and health professionals alike to involve young people at every stage of their work, and can also be found on our website.

“Helping develop research made me feel better about myself, in a way, because I’ve made a difference to me and other people who have it, so I feel more proud of having a cleft than I was before.” CYPC Member

CLAPA's first ever information leaflet specifically for teenagers with a cleft was also developed with the help of the CYPC this year. In addition, 23 9-15 year olds born with a cleft attended 2 confidence-building Residential Weekends in Central and South East England this year, with more planned for the future.

“It made a real difference to how I think. Meeting other people, even grown-ups, showed me how I’m not the only one like the way I am, there are others and that’s the most important thing to remember. No one is alone.”

Residential Weekend Attendee

For Adults Born With a Cleft

CLAPA's Adult Voices Council has been active over the past year in raising awareness of cleft, particularly in dental schools where in many cases barely an hour of the curriculum is devoted to cleft. The Council was also instrumental in developing a new information leaflet for adults this year which will fill a long-standing need in this area. The size of our online adult support group has increased by 22 % over the past year, and in 2016/17 we will build on this growing engagement to better support this part of our community.



Patient Voices

CLAPA's Patient Voices groups are made up of patients and parents who work with their local Cleft Teams to make a big difference to practice. We started Patient Voices groups in two Cleft Teams, with more planned in 2016/17 Our 2015 Conference theme of ‘Taking Control’ focused on empowering patients and parents to take an active role in the health service. Feedback from this conference fed directly into our strategy for 2016/17.

For Families

CLAPA's family support services are embedded in our Regional Coordinators Project which works to run support groups and train volunteers throughout the UK. This year, 476 new families joined our community. Based on feedback, in 2016/17 we will overhaul our free baby “Welcome Packs” to make them more appealing to new parents and update our range of bottles and teats to keep up with the latest technology.

CORE SERVICES IN NUMBERS

9,231

people received our annual CLAPA News magazine in September 2015

8,344

orthodontic teats sent to families of babies with specialist feeding needs

250

people joined the live-stream of our 2015 CLAPA Conference

100k

visitors to our website’s photo gallery and information sections

735

people took part in our last survey to help us plan for the future

385

free Welcome Packs of special bottles and teats sent to new families



Family Fun Day in Scotland, 2015

MOVING FORWARD

3 things we’re proud of this year:

- The launch of our new website which was based on years of feedback from our community.
- The launch of the Scotland Cleft Community and Family Support Programme, part of our Regional Coordinators Project.
- The publication of new information materials on our website based on a thorough review of what was available as well as feedback from our community.

3 things we’ve learnt this year

- Our original plan to have Regional Coordinators in place across all 9 Regions of the UK by 2017 would have put too great a strain on our resources. We’re busy working on a new strategy so that we can expand the project in line with organisational growth.
- After consulting with volunteers, we have streamlined our application and induction processes, developed new volunteering roles, and introduced a number of new online resources to help people engage with us in a way that better suits them.

- Our children and young people’s services had fantastic outcomes, but we simply didn’t have the resources to deliver more. That’s why we’ve appointed a Children and Young People’s Officer to take things forward.

3 big plans for next year

- CLAPA wants to move into public-facing campaigns to represent the needs of the UK cleft community. 2016/17 will see the start of our first campaign which starts at the very beginning of the cleft journey - diagnosis.
- We will publish new hard-copy leaflets with the most up to date information which will replace the dated look of our existing materials.
- With our new Children and Young People’s Officer in post, we’ll be able to deliver more Family Days and awareness-raising talks in schools. We’ll also introduce new services for older children and young people.

Donating to CLAPA

couldn’t be easier – just head to our website (www.clapa.com) or give us a call on 020 7833 4883. If you fancy giving fundraising a go, contact our friendly fundraising team at fundraising@clapa.com.

We want to make sure that every single person in the UK who needs CLAPA’s support receives it so that no one has to go through their cleft journey alone. To do that, we need to raise £888,000 in 2016/17 – and we need your help!