



# CLAPA Regional Coordinators Project

## Evaluation Interim Report

End of Year Two

November 2014

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## **Acknowledgements**

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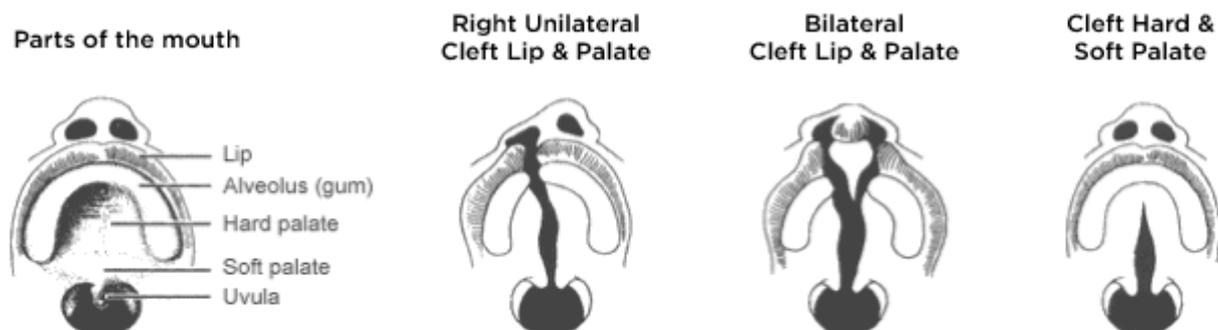
All those who contributed to the Regional Coordinators Project evaluation, including focus group participants, survey respondents, case study providers and so on.

## Report Contents

<b>Glossary of terms</b> .....	<b>4</b>
<b>Lay summary (end of Year Two)</b> .....	<b>6</b>
<b>Introduction</b> .....	<b>8</b>
Background and project rationale.....	8
Project outcomes.....	8
This report.....	9
<b>East of England region</b> .....	<b>10</b>
<b>Outcome 1 (Volunteers)</b> .....	<b>10</b>
Overview.....	10
Feedback from new volunteers.....	10
Feedback from existing volunteers.....	11
Additional activities.....	12
Outcome 1: Summary.....	13
Outcome 1: Key recommendations.....	13
<b>Outcome 2 (Children, Young People and Adults)</b> .....	<b>14</b>
Overview.....	14
Feedback from children and young people with CL/P.....	14
Feedback from adults with CL/P.....	15
Outcome 2: Summary.....	16
Outcome 2: Key recommendations.....	17
<b>Outcome 3 (Parents/Guardians)</b> .....	<b>17</b>
Overview.....	17
Feedback from parents/guardians.....	17
Additional activities.....	18
Outcome 3: Summary.....	19
Outcome 3: Key recommendations.....	19
<b>Follow-up from Year One</b> .....	<b>19</b>
<b>Central region</b> .....	<b>21</b>
<b>Outcome 1 (Volunteers)</b> .....	<b>21</b>
Overview.....	21
Feedback from new volunteers.....	21
Feedback from existing volunteers.....	22
Additional activities.....	22
Outcome 1: Summary.....	23
Outcome 1: Key recommendations.....	23
<b>Outcome 2 (Children, Young People and Adults)</b> .....	<b>24</b>
Overview.....	24
Feedback from children and young people with CL/P.....	24
Feedback from adults with CL/P.....	26
Additional activities.....	27
Outcome 2: Summary.....	28
Outcome 2: Key recommendations.....	28
<b>Outcome 3 (Parents/Guardians)</b> .....	<b>28</b>
Overview.....	28
Feedback from parents/guardians.....	29
Additional activities.....	30
Outcome 3: Summary.....	30
Outcome 3: Key recommendations.....	31
<b>Follow-up from Central region focus groups</b> .....	<b>31</b>
<b>Additional activities (East and Central regions)</b> .....	<b>32</b>
<b>Final summary (East and Central regions)</b> .....	<b>34</b>
<b>Appendices</b> .....	<b>36</b>

## Glossary of terms

Cleft lip and/or palate (CL/P) – 'cleft' means 'split' or 'separation'. During early pregnancy separate areas of the face develop individually, and then join together. If some parts do not join properly this may result in a cleft, the type and severity of which can vary (see diagram below).



**The Cleft Lip and Palate Association (CLAPA)** - the only national charity in the UK dedicated to supporting all those affected by cleft lip and/or palate.

**The Centre for Appearance Research** – a centre of excellence for psychological and interdisciplinary research in appearance, disfigurement, body image and related studies.

**Vocational Training Charitable Trust (VTCT)** – VTCT is a charitable organisation and awarding body. VTCT also supports the health and beauty sector and under its charitable remit aims, which includes research and support for those affected by physical disfigurement.

**Regional Coordinator** – a member of CLAPA staff who is based in a particular region and is responsible for increasing the diversity and frequency of local activity within that region.

**Healthcare Professionals (HPs)** – general and specialist medical practitioners, nurses, dentists, allied health professionals and any other skilled workers providing a form of healthcare service.

**Cleft.Net.East** - a network based at Addenbrooke's Hospital providing a centre for excellence for the region's cleft lip and palate patients, offering care and support from birth right through to adulthood. It is a 'hub and spoke' service, where patients can be seen at Addenbrooke's (the 'hub') for surgery and special clinics, receiving part of their regular care, for example speech and language therapy, at more local centres ('spokes'). The core team travels to nine local hospitals for joint clinics with local specialists. The team is multidisciplinary, and is made up of plastic surgeons, speech and language therapists, orthodontists, ear nose and throat/audiology specialists, paediatricians, a psychologist and nurse specialists.

**West Midlands Cleft Service** – this service covers the west of the Central Region and is based in Birmingham.

**Trent Cleft Service** – this service covers the east of the Central region and is based in Nottingham.

**CLAPA Branch** – CLAPA has branches across the UK, primarily run by volunteers, offering local support to parents, patients and HCPs.

**CLAPA Parent Contacts** – trained volunteers who can offer personal knowledge of the difficulties that can be faced by new parents of babies born with CL/P. Contact details for Parent Contacts are provided on the

CLAPA website. Parents can get in touch directly, or can ask CLAPA to approach a Parent Contact on their behalf.

**CLAPA Peer Contacts** – Peer Contacts are trained volunteers who were born with a cleft themselves. This is a new initiative by CLAPA but will follow similar protocols as Parent Contacts.

**CLAPA Clinic Volunteer** – trained volunteer CLAPA representatives attending cleft clinics in local hospitals to provide face-to-face support and information for parents and patients.

**CLAPA Happy Faces groups** – based around the region, these informal groups are run by trained Parent Contacts. Members meet on a regular basis for the opportunity to gain “a sense of community, understanding, talk about problems, and help each other.”

**CLAPA Adult Voices** – a group of adults who were born with CL/P with the aim of taking an active part in shaping the future of cleft services.

**CLAPA Children and Young People’s Council** – as above; aimed at children and young people aged 9-17.

**Patient and Public Involvement (PPI)** - research and/or service provision that is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE). Patient representatives play an active role in shaping the services the benefit from.

**Patient Voice Project** – a project aimed at increasing PPI within research and cleft service delivery.

## CLAPA Regional Coordinators Project - Evaluation Interim Report (end of Year Two, Nov 2014)

### Lay summary

Cleft lip and/or palate (CL/P) is the most common congenital craniofacial condition, affecting approximately 1 in 700 live births per year in the UK. The cleft and its treatment pose a number of challenges for those affected and their families throughout the lifespan, and having access to appropriate support when it is needed is a vital factor in psychosocial adjustment. The implementation of localised support is a frequently requested and highly valued service, with proven potential to have a positive impact. Following the success of the 2010 pilot project, the Cleft Lip and Palate Association (CLAPA) obtained funding from the Big Lottery Fund to employ three Regional Coordinators (East of England, East and West Midlands (known as Central), South East) over four years, with the aim of improving local service provision for families, young people and adults affected by CL/P.

The three core outcomes for this project are as follows:

**Outcome 1:** Volunteers demonstrate useful and transferable new skills, feel more confident and better able to support others affected by cleft.

**Outcome 2:** Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental wellbeing, enabling to live fuller lives in which having a cleft is not an issue.

**Outcome 3:** Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.

The Centre for Appearance Research, based at the University of the West of England in Bristol, was commissioned to conduct an independent evaluation of the project, allowing service users to provide feedback and to supply evidence to current and future funders to support the continuation of existing services and the development of new services and activities.

The key findings of the evaluation at the end of Year Two (Dec 2013-Nov 2014) are summarised below:

In the East of England, several new volunteers have been trained and continue to rate the training sessions highly. Feedback from existing volunteers was also largely positive, indicating that they feel supported in achieving their aims. The local CLAPA Branch has been restructured in recognition of the increasing scope of its activities and membership. Significant progress has been made in the region in relation to the three key outcomes of the project since Year One.

Prior to the appointment of the RC for the Central region, few CLAPA services existed and volunteers in the region were fairly isolated. A large part of the RC's role this year has been to set up a structure upon which regional activity can be based. As a result, data collection in the Central region has been limited. Nonetheless, the RC has made significant progress in establishing services and networks in the region, as evidenced by the increased level of activity.

Across both regions, events for families and young people have been run successfully and raised local awareness of CL/P. Support for adults with CL/P has been a key focus of the year and Peer Contacts Training has now been implemented. The Parent Contacts service and Happy Faces groups continue to grow. The audience for the regional newsletters and Facebook pages has also grown considerably.

Aims for Year Three of the CLAPA Regional Coordinators Project include:

- Continue to host training days and events as frequently and locally as possible, establish links between attendees prior to the event and advertise more widely in order to increase attendance.
- Continue to support the Children and Young People's Council and host more events and activities for young people of all ages across the regions.
- Continue to support the Adult Voices Council, events and awareness raising for adults with CL/P and the development of Peer Contacts Training.
- Continue to support the Parent Contacts service and the establishment of Happy Faces groups.
- Continue to work collaboratively with cleft teams, non-specialists HPs, other organisations and researchers.
- Expand the current knowledge and progress into the South East region.
- Continue to collect and incorporate feedback from volunteers, parents, young people and adults.

**Thank you** to everyone who contributed to the evaluation report. For more information about this project, please contact [Nicola2.Stock@uwe.ac.uk](mailto:Nicola2.Stock@uwe.ac.uk) or [Claire.Cunniffe@clapa.com](mailto:Claire.Cunniffe@clapa.com).

## **Introduction**

### **Background and project rationale**

A cleft in the lip and/or palate (CL/P) is the most common congenital craniofacial condition, affecting approximately one in 700 live births per year in the UK. For most parents, the 'diagnostic event' is an emotionally demanding experience, and families often express a number of concerns. Complex multidisciplinary care continues throughout the child's lifespan, forming an underlying and unremitting stressor in the family's lives. The cleft and its treatment can also pose challenges for the affected individual in many domains of life, including several areas of psychological and social functioning. Although for most individuals the treatment pathway ends when they reach the age of 18 years, CL/P is considered to be a lifelong condition. Some individuals may continue to experience difficulties into adulthood, and different life stages are likely to bring new challenges. Unfortunately, little is known about what happens to adults once they leave the service. Access to appropriate support is vital to encourage psychosocial adjustment and ultimately improve outcomes for parents, children, young people and adults with CL/P.

The Cleft Lip and Palate Association (CLAPA) is the only national charity dedicated to supporting all people with and affected by CL/P in the UK. They represent the voice of patients, parents and a multitude of Health Professionals (HPs) working in the field of cleft. CLAPA's overall aim is to further improve the quality of life of all those affected by CL/P by providing effective services in all sectors of the community.

CLAPA is already well-established throughout the UK, providing a number of highly-valued National services. As part of their strategic review, CLAPA conducted a National survey open to anyone with an interest in CL/P ('CLAPA 2010 Survey'). A key finding of this survey was the clear need for more support at a local level. Although local support is already provided by CLAPA's network of local branches, significant gaps and limitations in this service has been observed. In addition, the amount of branches across the UK is decreasing, due to insufficient numbers of volunteers. As a result, some regions only have one branch, and other regions are no longer provided for. In 2010, CLAPA obtained funding from the Vocational Training Charitable Trust (VTCT) to pilot a full-time Regional Coordinator (RC) in the East of England for one year.

This project was piloted in 2011-2012 in the East of England and was evaluated by the Centre for Appearance Research (CAR) at the University of the West of England (UWE). With the support of this evaluation report, CLAPA was able to gain further funding from the Big Lottery Fund to employ three Regional Coordinators (East of England, East and West Midlands (known as Central), South East), using a staggered approach over four years.

### **Project Outcomes**

The CLAPA Regional Coordinators Project has three key outcomes which CAR is independently evaluating:

**Outcome 1:** Volunteers demonstrate useful and transferable new skills, feel more confident and better able to support others affected by cleft.

**Outcome 2:** Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental wellbeing, enabling to live fuller lives in which having a cleft is not an issue.

**Outcome 3:** Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.

All evidence obtained during this project will be evaluated against these three key outcomes.

## **This report**

This report describes the findings obtained from the evaluation during Year Two. Previous reports have been provided for the pilot year, and for the End of Year One. Supplementary reports are also being added throughout the project's duration.

Year Two of this project has seen an expansion in terms of activity in the East of England region, as well as the introduction of a Central Regional Coordinator in the Midlands. Data was predominantly collected using the measures provided by CAR, as well as through other methods where appropriate. This data is presented throughout this report along with findings from focus groups, case studies and other formal documents collected by both CLAPA and CAR throughout the year. Data is presented according to region, and in relation to each of the three key outcomes, along with summaries and future recommendations. Supplementary documentation, where relevant, is provided within the Appendices of this report.

Two interim reports are also included as an attachment to this report:

- Focus group studies in the Central UK region
- The psychosocial impact of cleft lip and/or palate on siblings

## East of England region

The East of England region is defined as: Bedfordshire, Cambridgeshire, Essex, Norfolk, Northamptonshire, Suffolk, parts of Hertfordshire and parts of Lincolnshire. Tansy Miller has been in post as the East of England Regional Coordinator since December 2013.

### **Outcome 1 (East of England)**

**“Volunteers demonstrate useful and transferrable new skills, feel more confident and better able to deliver support to others affected by cleft.”**

#### Overview

The Regional Coordinator for the East of England has recruited and trained several new volunteers, in addition to supporting existing volunteers to achieve the aims of their varying roles. The RC has also supported the restructuring of the East of England Branch, and has established a new Patient Voice volunteer consultation group.

#### Feedback from new volunteers

The RC has been involved in the delivery of six volunteer training days, including four Volunteer Induction Days and two Parent Contacts Training Days. Volunteers were asked to provide feedback of their experiences of training; the feedback collected is presented below.

Volunteers gave the following reasons for attending a training day:

- To meet other individuals and families affected by cleft
- To meet health professionals
- To learn more about cleft lip/palate
- To learn more about the support CLAPA offers
- To find out how to help others affected by cleft
- To share own experiences and offer advice to others

At the end of the training, all of the volunteers believed they had achieved these aims, and listed a number of reasons for why they had enjoyed the training:

- Meeting other trainees and getting to know everyone in the group
- Gaining insight into the work CLAPA does
- Learning from others and sharing experiences
- Gaining confidence in my knowledge and ability
- Small group activities
- Feeling my time would be valued and volunteering would be worthwhile

As a direct result of the training, volunteers reported feeling more confident in their role (n = 11/14), more able to support others (n = 12/14) and more able to address cleft-related issues in a positive way (n = 14/14). Volunteers also felt they had gained access to a local support network (n = 13/14) and gained new and transferrable new skills (n = 9/14). The remaining volunteers reported that the training had made ‘no

difference' to these outcomes, since they were already involved with CLAPA prior to training. Nonetheless, volunteers reported they had gained a great deal from the day:

*"Thank you for such an enjoyable and informative session."*

*"The course was run very well, it was enjoyable, informative and fun and I'm very glad that I took part."*

A few volunteers provided suggestions as to how future training days could be improved:

- The training could be more focused/more specific
- Improved timekeeping
- At times the discussions went a little off-track
- Holding the training more locally/encouraging more participants to attend

One new volunteer in the East of England provided a case study for this report:

*"I went on a volunteer day earlier in the year. [The RC] was so lovely and the day was very useful in helping me determine how I might be able to contribute to CLAPA. A few months later I organised a sponsored walk at [my son's] nursery... Everyone got to know each other as we walked round the local park... We raised some money and got some good coverage for CLAPA in the local press. [The RC] attended and supported the event, bringing CLAPA merchandise such as stickers and balloons... The volunteering I have been involved with so far has been very well supported and it felt appreciated."*

#### Feedback from existing volunteers

Existing volunteers within the region have also been very active over the last year, running a variety of events and activities with support from the RC. Throughout the year, volunteers were asked to provide feedback on how they felt they were progressing in their various volunteering roles. These roles included:

- Parent Contact
- Happy Faces Co-ordinator
- Clinic volunteer (a new role implemented in the East of England during Year 1)
- Fundraising
- Raising awareness
- Regularly contributing to the CLAPA Facebook pages

Existing volunteers indicated they were happy (n = 4/5), confident (n = 4/5) and supported (n = 4/5) in their roles. They also believed they were achieving their personal aims as a volunteer (n = 4/5) and felt able to actively support others affected by CL/P (n = 4/5). Volunteers also reported that their roles had provided them with access to a local support network (n = 5/5; indicating that volunteers are also beneficiaries of CLAPA's local services) and allowed them to develop useful and transferrable new skills (n = 4/5). One of the existing volunteers who provided this feedback reported feeling 'neutral' about these outcomes, since they had *"only done a small amount of volunteering"*.

Existing volunteers reported a number of reasons for enjoying their roles:

*"I enjoy being able to help others that are going through some of the challenges we faced as new parents both pre- and post-diagnosis. I really enjoy my work as a Parent Contact."*

*"I love being able to meet and support others when they need it most."*

*“The support I receive from CLAPA is excellent - there is nothing I don't enjoy.”*

Existing volunteers were also asked if there was anything which could improve their experience of volunteering for CLAPA:

*“It would be nice to meet up with the other Parent Contacts in the area, with our Regional Coordinator, and discuss how things are going.”*

*“Sometimes it is hard to keep momentum going... I think the RC might be able to help keep people interested and encourage new people to join.”*

One existing volunteer commented that their experience of volunteering had been disappointing:

*“I did the training ages ago, which was a big effort to get to. After the training there was no follow-up except one email saying [the RC] would be in touch. It felt like a total lack of commitment to volunteers and a waste of time doing the training. [The RC] also arranged a meeting with me and then forgot to come.”*

This volunteer completed the training prior to the current RC coming into post. The volunteer was encouraged to get back in touch with the new RC to discuss these difficulties and hopefully to find a way forward.

One existing volunteer provided a case study for this report:

*“I wanted to be able to help other parents of children with cleft and I've now gone on to do the Parent Contact and the Volunteer Training. CLAPA run these all around the country and I would highly recommend them – I personally got a lot out of them. [The RC] and I recently set up a new Happy Faces group. Our numbers are small at present but I'm hopeful that over time word will spread, people will join our Facebook page and with the RC's help more people will come along. Last year I helped a fellow mum to fundraise over £1,000 for CLAPA and I've also raised donations for CLAPA myself. I've met some lovely people both near and far and thank CLAPA for their amazing support.”*

#### Additional activities

Following a review of the way the CLAPA Branches are run during Year One, and in recognition of the increasing scope of the Branch's activities and membership, the Regional Coordinator has helped to reshape the 'Cambridge Branch', which subsequently became the 'East of England Branch'. It is hoped that this restructure will improve the function of the Branch and represent more of the region as a whole.

In response to the growing call for Patient and Public Involvement (PPI) in research and practice, the RC has helped to develop a Patient Voice volunteer consultation group in collaboration with the CleftNetEast network based in Cambridge. It is hoped that this collaboration will provide new and exciting volunteering opportunities for those interested in research and service development and strengthen the relationship between CLAPA and the local cleft team. A total of 10 volunteers from the East of England region are involved in this group. This group is one of the first of its kind and represents a great achievement. To date, the group has met only once, but the feedback from the Health Professionals involved has been positive:

*"[The meeting] was a hugely positive step forward in working together. Having a link person to consult with, and having the rest of the patient group behind him who can liaise locally and help to identify patient need is a really good model. We are looking forward to meeting again soon".*

In addition, the RC co-hosted a Patient Voice workshop at the Craniofacial Conference in April 2014. As the RC for the Central region led this workshop, the feedback collected is presented in the 'Central Region' section of this report.

The RC has also been in regular contact with the North Thames cleft team based at Great Ormond Street Hospital (GOSH). Although this hospital is based in the South East region, GOSH is twinned with Broomfield Hospital, which is based in Chelmsford, requiring the East of England RC to keep in touch with both sites.

The RC was recently involved in the design of a new Volunteer Handbook, which was introduced as a way of improving the volunteering experience. Every volunteer will receive a copy of the new handbook as part of their Volunteer Induction.

Since its realisation towards the end of Year One, the role of Clinic Volunteer has been implemented in the East of England region and expanded to other regions with the support of the East of England RC.

The RC has also been active in recruiting new adult volunteers, as recommended at the end of Year One.

Finally, this year has seen over 1,000 new CLAPA leaflets and posters distributed by volunteers in clinics, GP/dental surgeries and libraries across the region, facilitated by the RC.

## **Outcome 1: Summary (East of England)**

Building on the success of Year One, the RC has recruited and trained several new volunteers who continue to rate the training sessions highly. Some comments were made regarding the locality of the training sessions. Although the implementation of the RC role has allowed training days to be held more frequently and more locally than was the case prior to the RC being in post, the region covered by the RC is still a large area. The RC has recently begun to offer smaller training sessions in some of the more remote parts of the region, which may help to counteract this ongoing challenge.

Feedback from existing volunteers was also positive, indicating that they feel supported by the RC in achieving their aims. Existing volunteers felt there was a role for the RC in setting up meetings between volunteers to share problems and progress, and in relation to encouraging more people to attend local training days and events.

The RC has been involved in a number of important additional activities which have helped to expand the potential of the local CLAPA Branch, raise awareness of CL/P among Health Professionals and the general public and build upon relationships with members of the local NHS cleft team.

## **Outcome 1: Key recommendations (East of England)**

- Continue to recruit, train and support volunteers across the region, particularly in areas which may be remote or more difficult to access.

- Continue to trial smaller/one-to-one training sessions where necessary.
- Continue to engage with all volunteers regularly and incorporate their feedback into service delivery.
- Continue to develop and expand the Clinic Volunteer role.
- Continue to recruit more adult volunteers, e.g. through the new Peer Contacts training.
- Facilitate meetings between volunteers where possible.
- Continue to expand CLAPA's presence in the region and encourage more people to run and attend local training days and events.
- Continue to monitor the progress of the East of England Branch, particularly in light of recent restructuring.
- Continue to nourish relationships with local NHS cleft teams and expand this knowledge to working with other relevant organisations where beneficial.
- Continue to raise awareness of CL/P within the region.
- Continue to develop the RC role within the East of England and transfer this learning into other regions throughout the UK.
- Additional data would be valuable for the evaluation.

## **Outcome 2 (East of England)**

**“Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental health and wellbeing, enabling them to live fuller lives in which having a cleft is not an issue.”**

### Overview

The RC has assisted with the delivery of several events in the region, including a Residential Weekend for young people with cleft. The RC has also been involved in the CLAPA Children and Young People's Council (CYPC) and has kept in regular contact with the members who are based in the East of England. The RC has encouraged CYPC members to share their stories publicly and raise awareness of CLAPA, and of the issues which affect children and young people with cleft. The RC has also met with the CLAPA Adult Voices Council to gain a better understanding of how CLAPA can better support adults with cleft and has been involved in the development of the new 'Peer Contacts Training' for adults.

### Feedback from children and young people with CL/P

Over the last year, the RC has continued to support the delivery of events in and around the region aimed at increasing the wellbeing of children and young people with CL/P, although unfortunately little data is available. The RC helped to deliver a Residential Weekend for children and young people which was very successful; however since this event was held in the Central region, feedback from the weekend is provided in the Central region section of this report.

The RC has also encouraged children and young people to share their stories more publicly. One member of the Children and Young People's Council (CYPC) who is based in the East of England consequently wrote a piece for the CLAPA Annual Newsletter (see appendices). This year, the CYPC were also able to meet with the Adult Voices Council for the first time, to share experiences and to ask adults with CL/P questions. This was very successful and is to be repeated next year.

### Feedback from adults with CL/P

This year has been an important one for adults with CL/P. Following an external research study examining the experiences and support needs of adults with cleft (Stock et al., in press 2014), and an internal annual CLAPA survey (see [www.clapa.com](http://www.clapa.com) for further information), it was decided that adults with CL/P should be the focus of the 2014 Cleft Awareness Week (May 2014). The RC was involved in a variety of awareness raising activities across the week, and during the week itself CLAPA gained an additional 50 adult member (5% increase). The Facebook pages also saw an 18 percent increase in adult members. The RC supported adults to submit their photos and case stories, which formed a large part of the campaign.

With the support of the RC, adult volunteers have been successful in their application for funding to develop Peer Contacts Training. Much like the volunteer Parent Contacts already being recruited, Peer Contacts will be a source of semi-formal peer support for other adults, parents and young people affected by CL/P. Applications have already been received from several adults, with a further number expressing an interest in becoming a Peer Contact. The first Peer Contacts Training weekend took place in November 2014 and received feedback from 8 adult trainees.

Adults gave the following reasons for attending the training:

- To meet other individuals and families affected by cleft
- To meet health professionals
- To learn more about cleft lip/palate
- To learn more about the support CLAPA offers
- To find out how to help others affected by cleft
- Strategies for how to be a Peer Contact specifically

When asked which aspects of the training they enjoyed the most, adults responded:

- Group discussions and being able to ask questions
- Managing difficult conversations – very intense, but the most important part of Day 1
- Case scenarios
- Content related to psychological issues and support
- Socialising
- Understanding the services offered to adults by the cleft teams

When asked which aspects of the training they least enjoyed, adults responded:

- It is a personally affecting issue and can re-open old issues
- Sitting for long periods isn't always the best environment for learning
- Time constraints
- Some of the information was familiar already

When asked how future training days could be improved, adults responded:

- A little more time for questions/diversions
- Set agenda/expectations of Peer Contact before starting, e.g. how do Parent Contacts equivalent work?
- Consider revising the order of the agenda

As a direct result of the training, adults felt they had gained access to a local support network (n = 7/8) and gained transferrable new skills (n = 7/8). These new skills included: listening skills, answering questions, being more objective, the ability to analyse complex issues presented by a peer, understanding boundaries and knowledge of cleft teams (including the referral process and restrictions). One adult indicated the training had not made a difference to these aspects, but indicated this was because they had attended a Volunteer Training day previously. Adults also felt more confident as a result of the training (n = 7/7), more able to support others affected by cleft (n = 7/7) and able to address cleft-related issues in a positive way (n = 8/8). Adults also provided additional comments:

*“The weekend was quite intense, but necessarily so. It met and indeed exceeded my expectations and hopes. It will take me a while to digest everything. The weekend was very profitable – the accommodation and venue were very good. A refresher course / day in 6 months would be useful.”*

*“Handouts would be awesome. It was quite informative and we had amazing group. Email instructions to get to the place would help. Generally I am very happy I had chance to participate. Thank you so much.”*

*“Well rounded course with good opportunities for questions, answers, discussion and interaction. Thank you for the provision of excellent venue, hotel accommodation and Sat night meal which gave time to interact with colleagues and have some fun!”*

Since this was the first time the Peer Contacts Training weekend had been run, the facilitators were also asked to provide their feedback:

*“This is the first time we have delivered this training and although it has been based on the existing Parent Contacts course, the Peer Contacts service is totally new to CLAPA. The training went well and the group were excellent – very engaged, asking lots of questions, making sensible suggestions and sharing their own very personal stories and experiences. The dynamics of the group were very good and everyone seemed to bond well and feel comfortable with one another. As with any training course, there were some more vocal members of the group but I felt that everyone felt comfortable to voice their thoughts and for the quieter members of the group – the smaller group exercises enabled them to contribute more. There were some issues with time management for some of the sessions, particularly the one delivered by a Cleft Team representative and we have some ideas to improve the course for next time. There are also some mechanisms that need to be agreed in order for the Peer Contacts support service to begin.”*

The RC also supported one adult to join the Adult Voices Council, which has become much more active following a restructure of the membership and aims. The Co-Chairs of the Council provided a case study for this report (see appendices). A member of the Adult Voices Council also helped the RC to run one of the Residential Weekends.

## **Outcome 2 – Summary (East of England)**

The RC has continued to support the running of events around the region for children and young people, although data to evidence this is limited. This year has been very successful in terms of activity for adults

with CL/P and initial feedback has been favourable. The RC has a key role to play in supporting the CYP and Adult Voices Councils to achieve their aims and in relation to expanding the Peer Contacts Training on a local and National level.

## **Outcome 2 – Key recommendations (East of England)**

- Endeavour to host more events for children and young people across the region (and encourage volunteers to do to same).
- Continue to host activities for older children and teenagers (and encourage volunteers to do the same).
- Continue to encourage the development of informal groups/activities for adults with cleft across the region.
- Continue to raise the profile of events such as these in order to attract more participants.
- Continue to support the CYP and Adult Voices Councils, including joint meetings where appropriate.
- Continue to deliver Peer Contacts Training, involving existing adult volunteers where possible.
- Additional data would be valuable for the evaluation.

## **Outcome 3 (East of England)**

**“Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.”**

### Overview

Several family events have been held in the region, in addition to a number of fundraising events. Other services include Parent Contacts and Happy Faces groups. The RC has also been involved in other activities, including a regional newsletter and regional Facebook page.

### Feedback from parents/guardians

A range of events were held for families in the region this year, including the annual Winter and Summer parties in Cambridge. This year also saw the first Winter party to be hosted in Essex. Parents/guardians attending these events were asked to contribute feedback. The collected feedback is provided below.

Parents enjoyed the following aspects of the family events:

- The activities were fantastic
- Having a regional spread of parties is a great idea
- Really good organisation
- The children really enjoyed themselves
- Wonderful atmosphere

When asked about how the events could be improved, parents/guardians responded:

- There could be more for older children
- The venue was difficult to find

In addition to these events, three sponsored walks were held in the region this year in order to raise money for Cleft Awareness Week. These events were a huge success, raising a good sum of money, bringing families from around the region together and raising awareness of CL/P in the local media (see appendices).

There are three new Parent Contacts in the region. The new and existing Parent Contacts continue to be active in the region, receiving emails and phone calls from other families affected by CL/P. This contact tends to be from parents or prospective parents, although carers, friends and extended family members have also used the service this year. Enquiries include:

- The impact of future treatment
- Associated conditions, including speech, behaviour and hearing
- Diagnosis
- Feeding issues
- Pre- and post-operation concerns
- Emotional support
- How to support family members emotionally and practically
- Information about local groups
- Heritability of cleft

Those who had used the Parent Contacts service reported being 'satisfied' or 'very satisfied' with the support and information they received.

#### Additional activities

Four Happy Faces Groups are currently meeting regularly in the region. The RC has also supported volunteers to set up a new Happy Faces group for Norfolk and Suffolk, which has already attracted several members. Feedback from the group members would be helpful in monitoring the future progress of the groups.

A new East of England regional newsletter has been developed by the RC (see appendices) providing regular regional updates, patient case stories and advertisements for upcoming training days and events. Currently, 673 members in the region are subscribed to this newsletter.

The East of England regional Facebook page now has 172 active members, with this figure continuing to grow.

The RC also helped to write a Financial Help Factsheet in response to a growing number of queries regarding access to financial support after the birth of a child with CL/P.

Finally, the RC supported a number of families to contact the local press in order to raise awareness of CL/P and of the support CLAPA offers (see appendices).

### **Outcome 3 – Summary (East of England)**

The RC has supported a number of events for families affected by CL/P across the region, all of which have been rated highly by attendees. Fundraising activities have been successful for those involved and have contributed to awareness raising efforts by featuring in the local press. The Parent Contacts service is active within the region and receives calls on a range of topics. Additional activities by the RC, including the regional newsletter and the regional Facebook page have also helped to increase activity and communication between parents in the region. It would be useful to collect additional data about these activities next year in order to evaluate the progress made.

### **Outcome 3 – Key recommendations (East of England)**

- Endeavour to host more events across the region (and encourage volunteers to do to same).
- Endeavour to provide activities for children of all age groups at family events.
- Continue to raise the profile of events such as these in order to attract more families.
- Continue to build upon the success of the Happy Faces groups.
- Continue to support and promote Parent Contacts as a source of peer support.
- Continue to promote local activities within the local press.
- Continue to grow the regional audience of the newsletter and Facebook pages.
- Additional data would be valuable for the evaluation.

### **Follow-up from Year One (East of England)**

The End of Year One evaluation report provided a summary of the progress of the RC role in accordance with the three key outcomes, in addition to a number of suggestions for the future of the role. The RC for the East of England has been very responsive to these suggestions and has addressed many of the recommendations detailed in the previous report.

#### **Outcome 1: Volunteers**

Since the end of Year One, training days are being held more frequently and in varying locations across the region. These training days are now consistently well attended and highly rated by attendees. In response to challenges associated with travel to these events, the RC is now trialling smaller training days and one-to-one training in more remote locations. More adult volunteers have been recruited in the region and the Patient Voice Project is a promising new endeavour. The volunteer role profiles and volunteer training days have been altered slightly in accordance with participant feedback. The East of England Branch has been restructured and the RC for the East of England has been very supportive of the newly appointed RC in the Central Region by sharing experience and knowledge.

#### **Outcome 2: Children, young people and adults**

During Year One, CAR ran a focus group with members of the CLAPA CYPC in order to explore the kinds of challenges children and young people face in relation to their cleft and to discuss what type(s) of local support may help them to overcome these challenges. The group felt the RC had a key role to play in

helping the CYPC to achieve their aims. In response to the findings of the focus group (detailed in the end of Year One report), the RC has been involved in organising and delivering events for children and young people in the region, as well as monitoring and contributing to the children and young people's Facebook page. The RC has also been in touch with a number of schools and other key community organisations to raise awareness about CL/P and to strengthen the local support network. There are plans to organise a series of additional youth events next year, to include a regional section in the next National CYP newsletter and to support the topic of CL/P being discussed in school-based assemblies and fundraising events.

During Year One, CAR ran a similar focus group with members of the Adult Voices Council to discuss how the RC could support the development of services for adults. In response to the findings of the focus group (detailed in the end of Year One report), the RC has been involved in raising awareness of the issues that are important to adults, particularly during Cleft Awareness Week. The RC has also been involved in developing the Peer Contacts Training for adults with CL/P. The RC has continued to work with the local cleft team, and a recent Patient Voice initiative has been particularly successful. Although services for adults with CL/P are still behind those offered to parents and families, it is hoped that the RC will be able to build upon this success during Year Three.

In addition, events for older children and teenagers have been implemented and run very successfully with much positive feedback. The RC helped to develop a research study with siblings of children with CL/P, and assisted with the recruitment of eligible participants.

### Outcome 3: Parents/guardians

The RC has continued to support and promote Parent Contacts as a source of peer support for families. The number of events has increased and diversified, as has the attendance and local media attention. There are four Happy Faces groups which appear to be running well, and a new group has been established in an area with little previous activity.

## Central region

The Central region is defined as: Birmingham, Derbyshire, Herefordshire, Leicestershire, Nottinghamshire, Rutland, Shropshire, Staffordshire, Warwickshire, Worcestershire and parts of Lincolnshire. Becky Gowers came into post in December 2013 but left CLAPA in August 2014. A replacement RC for the region began in post in October 2014 and has provided additional data for this report.

Prior to the appointment of the RC for the Central region, few CLAPA services existed and any volunteers in the region were fairly isolated. A large part of the RC's role this year has been to set up a structure upon which regional activity can be based. As a result, data collection in the Central region has been limited. Nonetheless, the RC has made significant progress in establishing services and networks in the region, as evidenced by the increased level of activity. At the beginning of this year, CAR carried out focus groups in the Central region to explore gaps in support and to find out what regional services may be needed. The focus group findings were used to guide the RC's activities this year and a report is included in the appendices.

### **Outcome 1 (Central region)**

**“Volunteers demonstrate useful and transferrable new skills, feel more confident and better able to deliver support to others affected by cleft.”**

#### Overview

The RC has supported the delivery of three Volunteer Training days and helped to increase volunteer activity within the region. The RC also took the lead on a new Patient Voice project, aimed at increasing patient representation in cleft services, and has visited several cleft clinics to raise awareness of CLAPA's developing services in the region.

#### Feedback from new volunteers

The RC helped to deliver two Volunteer Induction days and one Parent Contact Training day. Unfortunately, feedback is only available from one volunteer. Although the volunteer *“enjoyed meeting other volunteers and finding out more about what CLAPA does”*, they also reported that the training day had not made a difference to their skills, confidence or ability to support others. The volunteer commented:

*“Although the day was very informative, I still have no idea whether I will be able to offer any useful skills as a volunteer other than having [experience of] cleft myself... However I feel sure that I will have good support.”*

One newly trained volunteer provided a case study for this report:

*“When [my daughter] was born we had so many questions and I really wanted to meet with other parents in a similar situation. I met the RC at my first volunteer training day. Since then I have set up a local Happy Faces group, several outings/meetings with families, fundraising events including a sponsored walk and I*

*also became a Parent Contact. I get lots of advice and support in our activities from the RC 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."*

This volunteer also commented that "regular regional surveys asking what people want" would be useful, instead of/as well as conducting this on a National level as is done currently.

#### Feedback from existing volunteers

The RC has been in contact with existing volunteers, including the active Happy Faces group in Sheffield. Unfortunately, no feedback was available from existing volunteers.

#### Additional activities

There is currently no CLAPA Branch in the Central region but the RC has made significant steps towards establishing one. Several volunteers have already expressed an interest in being involved in the Branch and this will be taking forward in Year Three.

The RC for the Central region led the development of the Patient Voice project and co-hosted a workshop at the Craniofacial Conference in April 2014. Twenty-four delegates attended the workshop, including a mix of Health Professionals working in cleft teams, researchers, CLAPA staff and CLAPA volunteers with experience of being a patient representative. Feedback was collected from 21 delegates and is presented below.

Overall, delegates found all aspects of the workshop to be either 'very useful' (48%) or 'useful' (52%), with only one delegate reporting that the 'action planning' session was 'not very useful'. All participants reported that they gathered information which would help them to address patient involvement, and that they would attend a similar event in the future.

When asked what they most enjoyed about the workshop, delegates responded:

- A good mix of delegates and perspectives
- Helpful group exercises and feedback sessions
- Hearing from others about their experience of being involved in PPI

When asked what could improve events like this in the future, delegates responded:

- More structured sessions and better timekeeping
- Have more definitive and actionable outcomes
- Hearing more about the patient perspective
- Allowing patient representatives to lead parts of the workshop
- Plans for follow-up

Delegates also provided additional comments:

*"This felt like a good starting point into discussing an area which can feel quite overwhelming."*

*"Thank you for organising it – it was very enjoyable and thought-provoking."*

*“Please keep us informed about how to move the Patient Voice project forward.”*

The RC has also been very active in attending regular cleft clinics delivered by the local cleft teams. The RC’s attendance at these clinics has helped with the recruitment of new volunteers and has been important in establishing a relationship with the cleft team. The RC delivered a presentation to the Birmingham cleft team in June 2014 to facilitate discussion around collaboration. One Health Professional provided a case study for this report:

*“I met the RC when they were first appointed. The experience of working with the RC is good. They are happy to come to meetings to meet the clinical team and discuss plans. We hope to start more formal patient/parent input to the cleft team by working with the RC – we don’t do this at the moment. I strongly hope we can help make the role a success and continue to develop it as a way of improving patient input to the Midlands cleft services and also to health commissioners and providers. A strong patient voice will help maintain and improve the quality of services provided by demonstrating from a patient point of view what is needed.”*

### **Outcome 1: Summary (Central Region)**

Although there is evidence of the RC’s substantial activity in building up a local volunteer network in the Central region, little data were available to evaluate the success of such activity. Nonetheless, it is clear from the data collected that there is a need for an increase in local volunteer-led services for families affected by cleft. Contact with the local cleft teams appears to be productive and the Patient Voice project in particular appears to have begun very successfully.

### **Outcome 1: Key recommendations (Central Region)**

- Continue to train new volunteers in the region and endeavour to host more Training Days across different areas of the region.
- Provide support for existing volunteers in the region where needed.
- Continue to engage with all volunteers regularly and incorporate their feedback into service delivery.
- Aim to recruit more adult volunteers, e.g. through the new Peer Contacts training.
- Consider how to set up a CLAPA Branch in the Central region.
- Continue to develop and be actively involved in the Patient Voice project.
- Maintain contact with the local cleft teams and encourage ongoing collaboration.
- Continue to attend cleft clinics and/or support local volunteers to adopt the Clinic Volunteer role.
- An increase in data collection is crucial to the ongoing evaluation of the RC project

## **Outcome 2 (Central region)**

**“Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental health and wellbeing, enabling them to live fuller lives in which having a cleft is not an issue.”**

### Overview

The RC hosted a family event and encouraged young people from the region to attend a Residential Weekend. The RC also attended an Adult Voices meeting, two Adult Cleft Clinics at a local hospital and supported the annual Cleft Awareness Week which focused on support for adults with CL/P.

### Feedback from children and young people with CL/P

The RC helped to host a ‘Family Fun Day’ in Birmingham in July 2014. This event was primarily aimed at children born with a cleft aged 4-12 years and their families, based in the Central region. Twenty-two children and sixteen parents booked to attend the day, but eleven were later unable to attend. Feedback about the event was collected from a number of children and their parents. The data collected is incomplete, but is presented below.

Children gave the following reasons for attending the event:

- To meet other children/young people with a cleft
- To meet adults with a cleft
- To learn more about the support CLAPA offers
- To offer help and advice to other children/young people with a cleft
- To have fun/make friends

As a direct result of the event, 7 children felt they had made friends who they could talk to about having a cleft, 5 felt they could support others with cleft, 4 felt they had learned new and positive ways of coping, 7 felt more confident and all children reported that they would like to attend a similar event in the future.

When asked about which aspects of the event they most enjoyed, children responded:

- The drama workshop
- Playing games

When asked how future events could be improved, children responded:

- A bit more time
- More games
- More breaks

Parents also provided feedback about the event. Parents were asked whether they felt the event had any positive or negative effects on their children:

*“Seeing [my son] integrate and play with other children and adults was fantastic.”*

*“Exposure to kids in the same position as [my son] was positive.”*

*“It was a great way to fire the imagination and encouraged confidence and speaking out.”*

Two young people from the Central region attended a CLAPA Residential Weekend in April in Wales, which the Central RC helped to deliver. Two parents provided comments:

*“[My son] gained more confidence and independence.”*

*“Thank you for the opportunity for [my son] to meet new people with a cleft.”*

The RC also organised another Residential Weekend which was held in the Central region and attended by a number of local young people. Feedback from this event is provided below.

Children and young people gave the following reasons for attending an event:

- To meet other children/young people who have a cleft
- To meet adults who have a cleft
- To learn more about the support they can get from CLAPA
- To offer help and advice to other children/young people who have a cleft
- To have fun and make friends

All of the children and young people believed they had achieved these aims, and listed a number of reasons for why they had enjoyed the events:

- Being self-confident
- Meeting new friends
- Learning about other people’s experiences
- Meeting other people with cleft and knowing I’m not alone
- Playing games and having fun

When asked what they had enjoyed least, children and young people responded:

- Nothing, it’s been great!
- Having to go home!
- The weekend was too short!

When asked what could improve the events, children and young people responded:

- More outdoor games
- Being able to use more equipment, e.g. zipwire, canoeing

As a direct result of attending the events, children and young people stated they had made friends who they could talk to about having a cleft (n = 13/13) and had learned new ways of coping with cleft in a positive way (n = 13/13). They also reported that they felt more confident about themselves (n = 13/13) and felt able to offer help to other children and young people with CL/P (n = 11/13). All of the children and young people stated they would like to attend another event in the future.

Parents also provided feedback following these events:

*“Please pass on our thanks for a fantastic weekend. [Our daughter] didn’t want to leave and is now looking forward to the next event that she can attend. This weekend was the first time she has met anyone else with a cleft and it was a huge boost for her. Thank you so much.”*

*“We picked up [our son] yesterday afternoon and to say that he thoroughly enjoyed the weekend is an under-statement – he met new friends, was able to speak with others about cleft and to relate to their experiences while having a great time. This morning he is to tell his school assembly about the weekend. He is already asking if there will be more events and similar weekends that he can attend. The guys at the centre were absolutely first class and I commend and thank them for making our son feel special. Our sincere thanks to you for enabling this to happen.”*

#### Feedback from adults with CL/P

Very little feedback from adults with CL/P is available for the Central region. However, two testimonials from adult volunteers were provided:

*“As far as I know, little was done in terms of Adults - I suppose the RC’s first priority was getting to know people, systems etc. and to facilitate support for families. I was asked to go to an adult cleft clinic once, but to man a stand in the foyer which I felt was redundant as I was competing with several other stands.”*

*“I have been involved with CLAPA for almost 2 and a half years e.g. before the 1st Central Regional Coordinator was appointed. I was on the interview panel for both the 1st and 2nd – current – Regional Coordinators for the Central Region. I subsequently worked closely with the 1st Coordinator and have met the 2nd Regional Coordinator twice – once at the National Conference and only a few weeks ago for a meeting re the West Midlands. I was born with a cleft palate. I took early retirement over three years ago and one of the first decisions I made was to become involved in volunteering work. It, therefore, made sense to become involved with a charity engaged with cleft. I simply wanted and want to help. I want to support others living with a cleft to help them become the people they are destined to be and in line with CLAPA’s vision to become people where having a cleft is in no way a barrier to doing what you want to do or being the person you want to be. I consider myself to be a “doer”, someone who is actively engaged. Since becoming involved with the RC I have been involved with several activities:*

- Giving presentations on “Adult Voices Council” at Volunteer Induction Days
- Representing CLAPA at a Disability Awareness Day
- Representing CLAPA at a Cranio Facial Symposium held in Birmingham last year
- Representing CLAPA at a local “Baby Shower”
- Talking with an adult with a cleft and lending support
- Giving a Presentation on CLAPA’s work to a local Singing Group which raised money for CLAPA
- Representing CLAPA at a Family Day at the Rep Theatre in Birmingham
- Representing CLAPA at an Adult Cleft Clinic in a local hospital

*My experiences with the 1st Regional Coordinator were excellent. I felt that my experience was respected and taken on board. We met initially for a long meeting to discuss what had gone on in the West Midlands and thereafter liaised closely with each other, sometimes attending events together, and sometimes I “filled in” for the Regional Coordinator when she could not attend an event due to extenuating circumstances. We kept in touch via phone calls, texts and emails .I felt appreciated, respected and “kept in the loop”. Her*

*successor has only been in situ just over a month. Again, we have had an initial meeting re my engagement with CLAPA on a local level and I look forward to a close working relationship.*

*The benefits of a Regional Coordinator cannot be underestimated:*

- *(S)he is the local representative of CLAPA bring the vision of the Charity to the institutions within that region.*
- *(S)he recruits, trains and supports volunteers thereby increasing user involvement, CLAPA membership and donor potential*
- *(S)he builds and maintains relationships with volunteers and generic health professionals*
- *(S)he establishes and maintains links with NHS Cleft Teams and represents CLAPA on regional governing bodies*
- *(S)he raises awareness in the local community by proactively approaching individuals, businesses, local media and ethnic communities*
- *(S)he supports Parent Contacts, Adult Contacts, sets up a Branch where one is not in existence, supports existing Branches, helps set up Happy Face Groups where these do not exist and supports those already in existence*
- *(S)he works with CLAPA's Community Fundraising Manager to maximise opportunities for awareness raising and income generation*
- *In short, (s)he is a catalyst for all these things. A Regional Coordinator is CLAPA's link to those on the ground. I believe that, whilst being accountable to CLAPA a Regional Coordinator should feel (s)he can take the initiative and experiment with ideas.*

*Adults can be a neglected part of the cleft community. More engagement with schools, colleges, institutions of higher and further education is needed. Here is a ready "pool" of young people, some of whom would be eager to raise awareness and fundraise for CLAPA. Freshers Weeks are ideal opportunities for this kind of awareness raising. More Contact is needed with the local Dental Hospital. I would like to see a West Midlands Branch set up. I have indicated my willingness to be a part of this. I would like to be introduced to the local Cleft Team so that they know who I am. I have trained as a Peer Contact and if I am to have referrals it would be good for the Cleft Team to know who I am. I would like an organised structure for the Adult Cleft Clinic so that we can contact more people there."*

#### Additional activities

The RC attended a 'Transition Day', which is run by a local cleft team and is aimed at helping young people to make the transition to secondary school.

The RC has maintained close contact with the Co-Chair of the Adult Voices Council, who is based in the Central region. The RC also contributed to an Adult Voices meeting in May 2014.

As described in the 'East of England' section of this report, this year has been an important one for adults with CL/P. Following an external research study examining the experiences and support needs of adults with cleft (Stock et al., in press 2014), and an internal annual CLAPA survey (see [www.clapa.com](http://www.clapa.com) for further information), it was decided that adults with CL/P should be the focus of the 2014 Cleft Awareness Week (May 2014). The RC was involved in a variety of awareness raising activities across the week, and during the week itself CLAPA gained an additional 50 adult member (5% increase). The Facebook pages also saw an 18 percent increase in adult members. The RC supported adults to submit their photos and case stories, which formed a large part of the campaign.

The RC also attended the Adult Cleft Clinic at the Queen Elizabeth Hospital on two occasions.

Two adult volunteers attended and helped to facilitate the 'Family Fun Day' alongside the RC.

## **Outcome 2: Summary (Central Region)**

The family event was rated highly by those who attended, although attendance on the day was much less than expected. The two Residential Weekends which the RC was involved with appears to have been a success. Although the RC had some involvement with adults with CL/P, such as contributing to the Adult Voices Council meeting and supporting activities held during Awareness Week, it appears as though the RC was unable to do more than this during their first year in post. However, the relationship and importance of the RC was strongly advocated by one adult volunteer who worked closely with the RC.

The new RC for the Central region may wish to look at the End of Year One report, which included a number of recommendations based on focus groups held with the CYP and Adult Voices Councils.

## **Outcome 2: Key recommendations (Central region)**

- Endeavour to host more events for children and young people across the region (and encourage volunteers to do to same), building on the success of the Residential Weekends.
- Endeavour to host activities for older children and teenagers (and encourage volunteers to do the same).
- Continue to raise the profile of events such as these in order to attract more participants.
- Endeavour to link local families up to share travel to increase attendance.
- Continue to support the CYP and Adult Voices Councils, including joint meetings where appropriate.
- Encourage the development of informal groups/activities for adults with cleft across the region.
- Support the delivery of Peer Contacts Training, involving existing adult volunteers where possible.
- Additional data for the evaluation would be valuable.

## **Outcome 3 (Central region)**

**“Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.”**

### Overview

The RC supported the facilitation of a local family event, the set-up of a new Happy Faces group and the organisation of a sponsored walk.

### Feedback from parents/guardians

Following the 'Family Fun Day' held in Birmingham in July 2014, parents were invited to provide feedback about the event. The feedback collected is incomplete but is presented below.

Parents gave the following reasons for attending the event:

- To meet other families and individuals affected by cleft
- To learn about the support CLAPA offers

Most of the parents felt they had achieved these aims. As a direct result of the event, 3 parents reported they had gained access to a local support network, 4 parents reported they felt more able to support others affected by cleft, 3 parents reported they had gathered information which would help them address cleft-related issues in a positive way and all parents stated they would like to attend a similar event in the future. Parents reported that having better organisation and more information about the day ahead of the event would have been helpful. In addition, parents requested more activities for older children where possible.

Feedback was also collected from four parents who attended the Redditch Happy Faces group, which is a newly established group in the region. This feedback is presented below.

Parents attended the group for a variety of reasons:

- To meet other individuals and families affected by cleft
- To learn more about cleft lip and/or palate
- To learn more about the support CLAPA offers
- To find out how I can help others affected by cleft

When asked which aspects of the group they enjoyed the most, parents responded:

- Talking to others affected by cleft
- Sharing experiences
- Meeting others for advice
- Seeing other children after their operation

When asked how the group could be improved in the future, parents responded:

- It would be good to meet expectant parents
- A hospital cleft nurse could attend

All of the parents who provided feedback agreed that the group had given them access to a local support network, provided them with information to help them address cleft-related issues in a positive way and helped them to feel more able to support others affected by cleft. Parents also stated that their son/daughter had also enjoyed attending the group and indicated they would like to attend a similar event in the future. Some additional comments were provided by parents:

*"I enjoyed meeting other people in the same position. It also gives my older daughter (who wasn't affected by cleft) a chance to see that there are other children who have cleft lip."*

*"Playing with other children has helped [my child] to socialise."*

All of the parents who provided feedback had heard about the event through the regional Facebook page, which provides another example of the usefulness of this regional tool.

Since December 2013, four parents have used the Parent Contacts service in the region. Enquiries included issues related to treatment and access to local support and were made via email and in person at a cleft clinic. All four parents reported being 'satisfied' with the support they received from this service.

#### Additional activities

The RC has supported the set-up of a new Happy Faces group in Redditch which had their first meeting in May 2014. The group was successfully established following a small grant from the local Council and received some local media attention. One Health Professional commented on the set up of the new Happy Faces group:

*"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".*

Feedback from some of the group members would be useful in evaluating the progress of the group in the future.

The RC has also been in contact with the Happy Faces group in Sheffield and two awareness raising events involving local families. The RC also supported the organisation of a sponsored walk which attracted more than 70 people and interest from the local press (see appendices). Unfortunately, no feedback is available for these events.

The RC's attendance at the local cleft clinics also helped to introduce families to one another and raise awareness of the growing regional presence.

One Health Professional provided a case study for this report:

*"As I had hoped, having a Central RC has started more patient-run activities. The clinical team believe there is a need/wish for this sort of opportunity for families to get together but they have not been able to coordinate this themselves. Having someone from CLAPA at our paediatric clinics, even though only for a short time, proved really useful. It helped connect the patients and families in the waiting area and seemed to facilitate them being able to speak to each other. It has also improved the quality of the waiting time."*

Finally, the RC has set up a regional Facebook group which currently has 116 members, and started a regional newsletter (see appendices).

### **Outcome 3: Summary (Central Region)**

The parents who attended a local family event rated the day highly, although indicated that better organisation may have been helpful. Existing and new services for parents/guardians appear to be valued. The Happy Faces groups in particular appear to be appreciated. Fundraising activities have been successful for those involved and have contributed to awareness raising efforts by featuring in the local press. The Parent Contacts service is starting to become more active within the region. Additional activities by the RC,

including the regional newsletter and the regional Facebook page have also helped to increase activity and communication between parents in the region.

### **Outcome 3: Key recommendations (Central Region)**

- Endeavour to host more events across the region (and encourage volunteers to do to same).
- Endeavour to provide activities for children of all age groups at family events.
- Continue to raise the profile of events such as these in order to attract more families.
- Continue to build upon the success of the existing and new Happy Faces groups.
- Aim to recruit more Parent Contacts in the region.
- Continue to support and promote Parent Contacts as a source of peer support.
- Continue to attend cleft clinics and/or support local volunteers to adopt the Clinic Volunteer role.
- Continue to promote local activities within the local press.
- Continue to grow the regional audience of the newsletter and Facebook pages.
- An increase in data collection is crucial to the ongoing evaluation of the RC project.

### **Follow-up from Central region focus groups**

At the beginning of this year, CAR carried out focus groups in the Central region to explore gaps in support and to find out what regional services may be needed. The focus group findings provided recommendations for the RC's activities this year and a report is included in the appendices. Specifically, there was a clear need to introduce many of CLAPA's existing services to the Central region and to address a number of region-specific needs.

#### Peer support

The findings of the focus groups indicated that one-to-one and group peer support is valuable but lacking in the region. During the year, the RC has contributed significantly to the growth of a sustainable peer support network and the new RC is encouraged to build upon this progress.

#### Barriers to treatment and support

Barriers included limited resources and the logistics of travelling across a large area to attend social events and medical appointments. The RC has supported the development of local activities and events across the region. The new RC is encouraged to increase the frequency and locality of these events and to endeavour to improve accessibility and attendance. The RC has also made progress in acting as an intermediary between beneficiaries of CLAPA's services and HPs and the new RC is encouraged to maintain and build upon these newly established relationships.

#### Education and awareness

The focus groups indicated that knowledge of CL/P is lacking among the general public and non-specialist Health Professionals. The RC has contributed to awareness-raising via a fundraising event and interest from the local press. These efforts could now be increased, for example by holding more events like these, and making links with schools and community services, as well as other relevant organisations. Distributing

posters and leaflets in local GP/dentist surgeries and libraries has also been successful in the East of England region, and may be a useful model for the Central region.

### Neglected groups

The Central region is a large and culturally diverse area. The focus groups suggested that some sub-groups may be particularly lacking in support, including Black and Minority Ethnic (BME) groups; low Social Economic Status (SES) communities; children with additional difficulties; fathers and siblings of children with cleft; and older children, teenagers and adults with cleft. Discussing ways to reach these groups and implement appropriate support may be useful. Concurrently, engaging in research activity (e.g. with CAR) which can help to identify the specific support needs of these groups may be valuable. One such group (siblings) has already been investigated via a research study led by CAR during Year Two. A copy of this report is included as an attachment to this report.

## **Additional activities (East and Central regions)**

The RCs from both regions have been involved in a number of additional activities during Year Two.

Collaboratively, both RCs designed the new CLAPA Volunteers Awards ceremony, which was held as part of the National Volunteer Day in October 2014. Awards were handed out to 5 key volunteers, as well as 5 runners-up. Awards included:

- 'Outstanding contribution to supporting others'
- 'Super star fundraiser'
- 'Outstanding contribution to awareness raising'
- 'Patient Voice of the year'
- 'Extra mile award'

Further information about the CLAPA Volunteer Awards can be found here: <http://www.clapa.com/news/article/1970/>

Both RCs also contributed to the preparation for the annual CLAPA conference, which was held in London this year. 98 delegates (parents, adults with cleft, health professionals, researchers, friends/family members and under 18s) attended on the day, with a further 258 people watching the live stream via Facebook, and 262 watching the live stream from the website. Of the feedback collected, 93% indicated that every measured aspect (location, time of year, venue, food, delegate bag, programme) of the conference was either 'good' or 'great'.

The East of England RC was also involved in the running of a workshop, facilitated by an East of England volunteer.

Both RCs helped to prepare for the National Branch Day, which was held the day after the annual conference in London. The East of England RC helped to run a second workshop on the day. Feedback was collected from attendees and is presented below.

When asked about the most enjoyable aspect of the day, attendees responded:

- It was nice to learn so much about CLAPA, really good introduction
- It was really welcoming
- Meeting members of the Head Office and the Trustees
- The workshops
- Being able to chat and network with the other CLAPA Branches

When asked what could be improved about future events, attendees responded:

- Handouts of the workshops
- The weekend as a whole was very tiring
- Better regional representation
- The workshops could have been longer

As a direct result of the day, attendees generally felt they had gained access to a local support network (n = 3/5), felt more able to support others with cleft (n = 4/5) and had gathered information which would help them address cleft-related issues in a positive way (n = 3/5). All attendees said they would like to attend a similar event in future.

Attendees also provided some additional comments:

*“The next Branch day should solely be an opportunity for the Branches to raise topics that require Branch discussion and any issues that they may be experiencing difficulties with. I wanted to discuss event charging and I know that another Branch wanted to discuss branding.”*

The facilitators of the National Branch Day also provided some feedback on their experiences. This is presented below:

#### **What worked well?**

- Good range of topics covered and I feel more knowledgeable if I get asked any questions by Branch. Wasn't as formal as I expected but that's not a bad thing! Loved seeing what Branches were doing and was a great way to network with those not already spoken to.
- Stands were fab and made Branches feel involved.
- It was really useful to have an insight into how the relationship between CLAPA and the Branches work.
- I was only there for half the day but it seemed well organised and full of useful and practical information.
- I found the day really useful and interesting and I think most of the Branches really enjoyed it looking at the Facebook posts!

#### **What didn't work so well?**

- Seemed to be sitting a while – back really sore (may be coincidence!), possibly too rushed and feel there was so much more than could be discussed had there been time.
- When talking about our Strategy, I felt it would have been better to talk more about how following our strategy will benefit the Branches e.g. Regional Coordinators providing support, taking on some of their workload, etc.
- I wasn't sure that showing the difference in income and expenditure between the different Branches was wise – I know a carrot and stick approach is often effective, but this seemed like a very large stick to me!
- I think the day was pretty intense with the amount of presentations and sessions, I think it would

be helpful to reduce these so there was a more leisurely pace to the day.

#### **What should we do differently next time?**

- Longer (but realise difficult due to travel) or less topics to discuss. Maybe have 2 a year with a theme to focus on for each. Otherwise not really sure just yet.
- More opportunity for volunteers to speak.
- Use someone more inspiring to open.
- Perhaps a few handouts would have been helpful. Some of the presentations e.g. Anna's, had a lot of really useful information in them but there was a lot to take in, in a short space of time.
- I think it would have been lovely for the day to feel like a celebration of Branches work – maybe if there was just half an hour out of the sessions where we recorded a thank you video (with interviews of people benefitting from the Branches, etc.)

Finally, the RC Project as a whole is guided by the Regional Coordinators Project Advisory Group (RCPAG), which meets once per year and provides ad-hoc support throughout the duration of the project. The RCPAG consists of CLAPA staff, CAR staff, patient representatives (including two parents, a member of the CYP Council and a member of the Adult Voices Council), members of the local cleft teams and representatives from two related charities (ChildLine and the National Deaf Children's Society). The group met in February 2014 to discuss the progress of the project and its evaluation. The RCPAG also provided guidance in relation to the siblings study, which is included as an attachment to this report.

### **Final summary (East and Central regions)**

The evaluation of the Regional Coordinator's Project throughout Year Two has allowed for the continued monitoring of progress within the East of England region. In addition, the evaluation has allowed for a better understanding of the issues that are important to those affected by CL/P living in the Central region, and of the support that individuals and families would like to see implemented in the future.

Following on from the lessons learned from the pilot year and Year One, a range of suitable measures which allow for the collection of feedback from new and existing volunteers, children, young people, adults and parents/guardians have now been implemented and are being used successfully, particularly in the East of England region. Despite this, there are clear gaps in the data being collected, most notably from the Central region. The RC for the Central region was new in post this year and was immediately responsible for a very large region where CLAPA services were scarce. It is clear that much groundwork has been laid during this first year, and it is hoped that data collection will naturally increase over the next year. It will also be important to carry this knowledge through to Year Three, particularly in regard to the South East region, where a new RC has recently been introduced. It is likely that some changes to the protocol regarding data collection will be made to increase the volume, quality and diversity of the data being collected in all three regions.

Many positive 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. A number of specific recommendations have been set, including the development and expansion of existing activities across the two regions, as well as the development of new services for a

range of sub-groups who appear to be more difficult to reach. A number of topics for future research in this area have also been identified. The key aims for Year Three are to build on the successes of Years One and Two and to implement the recommendations laid out in this report.

## Appendix 1: Young Person's piece for the CLAPA Annual Newsletter

### **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, I didn't realise it was that long until I just really thought about it. In any case, I just thought it'd be nice to write a little something about my experience in the CYPC and tell everyone where I'm going next.

I actually joined as a result of a huge amount of persuasion from a former council member, Rebecca Loveday. We happened to meet around eight years ago at a dance school, and have been friends ever since. 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 CLAPAKidz and CLAPAEEdge 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 at Addenbrookes 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 kickstart 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 for a condition that is becoming more and more common! If anyone would like access to the project, please feel free to email me on [danielle\\_901@hotmail.co.uk](mailto:danielle_901@hotmail.co.uk) – I'd love feedback from anyone that's interested!

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!

## Appendix 2: Adult Voices Council testimonial for 2014

“CLAPA, historically, may have given a perception that it focuses purely on parents and children and that adults do not have any issues either physically or psychologically. In 2010 they established Adult Voices (AV) with aims to:

- To take an active part in shaping the future of the services available to them.
- To proactively generate ideas and form action plans for the Council.
- To be the voice of adults born with cleft lip and/or palate and inform CLAPA of issues they should be addressing.
- To help provide a regional presence to deliver CLAPA’s services effectively.

An Adult Council was formed to help fulfil these aims and since then there has been a positive change to how CLAPA is perceived. The website has an improved to include a section on Adult Voices and their activities. CLAPA’s recent introduction of Regional Coordinators (RC) and Peer Contacts (PC) has and will make a huge difference. CLAPA has created a specific and structured training programme for volunteers, wishing to be PC’s. It will mean the RC’s can support the volunteers acting as PC’s in their region. It is hoped that this will encourage more CLAPA volunteers to consider AV. This year with two co AV chairs, a new structure has been put into place where volunteers can either be a PC or an AV Council Member or both. Each role has a role profile that can help volunteers understand what the role entails, so to ensure that individuals are in roles that best fit their skills and desires. It is fair to say that some will prefer being a PC and engaging with those adults that need support either physically or psychologically or both. Whereas the Council Member may prefer to involve themselves in meetings to discuss current and future progress of AV while others would like to do both. The RCs can support and coordinate in both roles and help with local events, helping individuals to engage regionally with the 11 Cleft teams around the UK. The objective is to have one council member for each Cleft Team/Region and Branch. The support from the RCs and CLAPA HQ can make a huge difference to increasing the number of individual's with clefts that need support. This after all is what AV exists to achieve!

This year, so far, AV has also achieved a number of things:

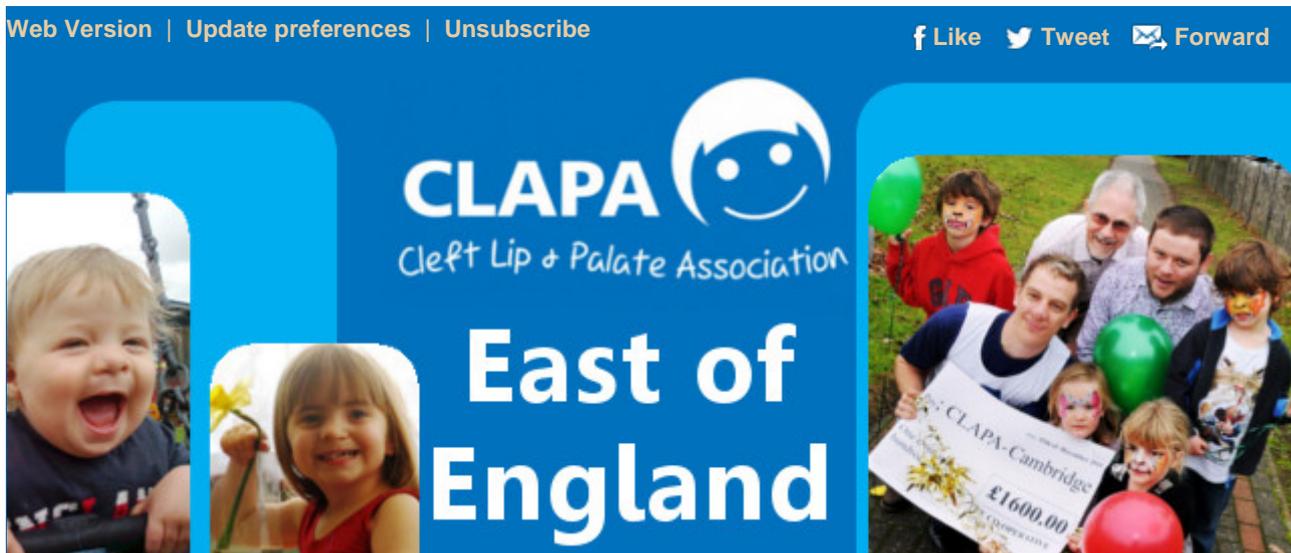
- Adults with clefts was the theme for CLAPA’s 2014 Awareness Week in May.
- The Co Chairs presented AV at the Appearance Matters Conference in Bristol
- Council members manned stands at a number of regional events
- Volunteer Induction Days have showcased AV to encourage new members, with introductory presentations by AV council members
- Made presentations to cleft teams
- Co chairs will be presenting at this year’s CLAPA conference in October in London.

I think it is safe to say that AV is well and truly on the CLAPA map and radar!”

## Appendix 3: Record of articles in local and national media

Date	Publication	Region	Subject of article	Link to article
07.12.2013	Nottingham Post	Central	It's Big Smiles all round for Santa!	<a href="http://www.nottinghampost.com/s-Big-Smiles-round-Santa/story-20273848-detail/story.html">http://www.nottinghampost.com/s-Big-Smiles-round-Santa/story-20273848-detail/story.html</a>
27.01.2014	Worcester News	Central	Couple raise over £1,000 in memory of their stillborn son	<a href="http://www.worcesternews.co.uk/news/10965461.Couple_raise_over_pound_1_000_in_memory_of_their_stillborn_son/">http://www.worcesternews.co.uk/news/10965461.Couple_raise_over_pound_1_000_in_memory_of_their_stillborn_son/</a>
19.02.2014	Worcester News	Central	Lucy Blunt's Paris Marathon	<a href="http://edition.pagesuite-professional.co.uk/launch.aspx?eid=18d7fb4a-3256-47c8-9c65-1896bf7d7e3">http://edition.pagesuite-professional.co.uk/launch.aspx?eid=18d7fb4a-3256-47c8-9c65-1896bf7d7e3</a>
22.04.2014	Sheffield Telegraph	Central	Awareness Week Treasure Hunt	<a href="http://www.sheffieldtelegraph.co.uk/news/health/sheffield-treasure-hunt-to-help-clapa-charity-1-6573220">http://www.sheffieldtelegraph.co.uk/news/health/sheffield-treasure-hunt-to-help-clapa-charity-1-6573220</a>
23.04.2014	Leicester Mercury	Central	GB miniature golf captain opens course	<a href="http://www.leicestermercury.co.uk/GB-miniature-golf-captain-opens-course/story-20997368-detail/story.html">http://www.leicestermercury.co.uk/GB-miniature-golf-captain-opens-course/story-20997368-detail/story.html</a>
25.04.2014	The Star	National (Central)	Sheffield Treasure Hunt to help CLAPA Charity	<a href="http://www.thestar.co.uk/news/health/local-health/sheffield-treasure-hunt-to-help-clapa-charity-1-6573220">http://www.thestar.co.uk/news/health/local-health/sheffield-treasure-hunt-to-help-clapa-charity-1-6573220</a>
25.04.2014	Redditch Advertiser	Central	NHS Cleft Lip and Palate Service delighted with creation of Redditch group	<a href="http://www.redditchadvertiser.co.uk/news/11170140.NHS_Cleft_Lip_and_Palate_Service_delighted_with_creation_of_Redditch_group/">http://www.redditchadvertiser.co.uk/news/11170140.NHS_Cleft_Lip_and_Palate_Service_delighted_with_creation_of_Redditch_group/</a>
13.05.2014	Redditch Advertiser	Central	Sponsored walk for cleft lip charity	<a href="http://www.redditchadvertiser.co.uk/news/11208690.Sponsored_walk_for_cleft_lip_charity/">http://www.redditchadvertiser.co.uk/news/11208690.Sponsored_walk_for_cleft_lip_charity/</a>
20.05.2014	ITV News (includes video)	East	Ely family raises awareness of cleft surgery	<a href="http://www.itv.com/news/anglia/story/2014-05-20/families-raise-awareness-of-cleft-lip-and-palate-surgery/">http://www.itv.com/news/anglia/story/2014-05-20/families-raise-awareness-of-cleft-lip-and-palate-surgery/</a>
24.05.2014	EDP24	East	Toddlers in North Walsham put best foot forward	<a href="http://www.edp24.co.uk/news/toddlers_in_north_walsham_put_best_foot_forward_1_3614966">http://www.edp24.co.uk/news/toddlers_in_north_walsham_put_best_foot_forward_1_3614966</a>
20.07.2014	Cambridge News	East	How Little Eva Fulton is living life to the full in spite of her health problems	<a href="http://www.cambridge-news.co.uk/News/In-spite-of-her-health-problems-little-Eva-Fulton-from-St-Neots-is-living-life-to-the-full-20140720070251.htm">http://www.cambridge-news.co.uk/News/In-spite-of-her-health-problems-little-Eva-Fulton-from-St-Neots-is-living-life-to-the-full-20140720070251.htm</a>
01.10.2014	Newark Advertiser (online)	Central	Team from Bird & Co Solicitors to tackle extreme obstacle course	<a href="http://newarkadvertiser.co.uk/articles/news/Team-from-Bird-and-Co-Solicitors-to-tackle-ex">http://newarkadvertiser.co.uk/articles/news/Team-from-Bird-and-Co-Solicitors-to-tackle-ex</a>
20.10.2014	Solihull News (online)	Central	Solihull author Michael Lancashire backed by Carol Vorderman	<a href="http://www.solihullnews.net/news/local-news/solihull-author-michael-lancashire-backed-7966295">http://www.solihullnews.net/news/local-news/solihull-author-michael-lancashire-backed-7966295</a>

## Appendix 4: East of England regional newsletter (Summer 2014)



### Summer Newsletter 2014

Welcome to our summer newsletter! Our volunteers across the region have been busier than ever and we're already starting to celebrate our 35th anniversary. In this edition we've got news on exciting developments for the local Branch, a new Patient Involvement scheme and an update on our Conference, 35th birthday and our first ever volunteer awards!

Plus we'd like to extend a very warm welcome to new Lead Clinical Nurse Specialist in the Cleft team at Addenbrookes, Jenny Williams, and to all our new volunteers, James, Anita, Nathalie, Paul, Suzy, Rhiannon, Haider, Dennis, Suzi, Claire, Lesley, and Kate!

### Patients Involvement

Would you be interested in joining a patients' consultation group and help shape local cleft services? We are absolutely delighted to be supporting one of our Cleft teams, CleftNetEast, at Addenbrookes with bringing together a user group of parents and individuals affected by cleft to inform, consult and provide feedback on cleft care in the region. You don't need to be an expert, and we need people who are happy either to simply respond to consultations or actively gather feedback, represent users' views and raise issues at Cleft team meetings. If you are interested in either role please email or call for an application form or to find out more! [tansy.miller@clapa.com](mailto:tansy.miller@clapa.com) 0777 268 4398 Deadline for applications is Wednesday 20th August!

## East of England Branch and Summer party!



Most of us in the region at some point will have enjoyed one of the wonderful Winter or Summer parties organised by our Cambridge Branch. And every parent will have received a welcome pack, which the branch delivers via the cleft team, from CLAPA. But not everyone realises all the work behind the scenes that the Cambridge Branch does, or quite how tirelessly they've worked over the years to support local cleft services and link up with the cleft team.

So we would like to take the opportunity to say some 'thankyous' to Branch Committee members Sam & Fiona Sanders-Hewett, Zara Napier & Hilary Tate who have helped us so much, and who've stepped down after completing their time on the Committee- you've all done an amazing job and we are extraordinarily grateful. Thank you so much for all your hard work over the years everyone!

However, the AGM also saw some exciting new developments for the Branch! In recognition of the wider scope of the Branch's activities and membership, the Branch Committee voted to re-launch as the East of England Branch. We're also absolutely delighted to welcome our new Committee: Chair, Leanda Cable, plus CleftNetEast representative James Kiff and new members James and Anita Palmer. We're hoping to hold more events out and about in the region, to support local activities and most importantly of all, to involve you all in activities, events and decision making.

To celebrate the Branch's re-launch we are hosting a thankyou meal for new members in September! Its our way of helping you get to know your fellow CLAPA Branch members, and saying thankyou for getting involved!

Want to know more? Being a member isn't the same as being on Committee but it does mean you can vote, have say in Branch activities and generally be much more informed and involved. Plus of course we'd be delighted if you'd like to help with events and parties! To find out more please get in touch: [eastofenglandclapabrand@outlook.com](mailto:eastofenglandclapabrand@outlook.com)

### Volunteer Awards

To celebrate the contributions of our Volunteers, we're excited to launch our first annual Volunteer Awards! We're a small charity and we couldn't exist without the hard work done by the people around the UK who work so tirelessly to help us support all those

### Conference & dates for your diary

And speaking of our conference, please don't forget that bookings are now open! It's an extra special conference this year, as we are also celebrating our 35th birthday with a tea-party. Everyone is welcome, we've got some

affected by cleft lip and/or palate.

In honour of this week and our 35th anniversary year, we are delighted to be launching our first ever Volunteer Awards to formally recognise the contribution made by our volunteers. Nominations will be accepted until 31st August, after which our panel of judges will have their work cut out deciding who should receive each of these awards at the ceremony which will take place during our Tea Party directly after the CLAPA Conference. Nominations are now OPEN! You can nominate yourself, your Branch/group or someone else, and you can enter as many categories as you like.

To be nominated, you must be an official CLAPA Volunteer, an official Branch or Happy Faces Group, or (for the Super Star Fundraiser category) be a fundraiser who is known to our fundraising team. We will be accepting nominations in the following categories:

- Outstanding Contribution to Supporting Others
- Super Star Fundraiser
- Outstanding Contribution to Awareness Raising
- Patient Voice of the Year
- The Extra Mile Award (for health professionals and teams)

To nominate someone, please visit [www.clapa.com](http://www.clapa.com)

great speakers and workshops and it's a lovely opportunity for health professionals, patients, volunteers and everyone involved in cleft to get together! So please do come if you can- Saturday 18th October, London. See [www.clapa.com](http://www.clapa.com) for details.

More dates for your diary:

East of England Branch Launch event for new members – Saturday 13th September, Newmarket

Parent Contact Training, 25th & 26th October, Cambridge

Peer Contacts Training, 22nd and 23rd November, London

Volunteer Induction Day, Sat 6th December, Colchester

East of England Branch Winter Party, Sunday 7th December, Cambridge

## How my cleft experiences inspired me to apply for medicine (Haider Ali Sheikh)

Finally, we're always inspired by your cleft experiences and the different reasons you get into volunteering. Here Haider Sheikh, who completed our Volunteer training in January this year, shares his story. Thank you Haider!

'How did my cleft experiences led to me becoming obsessively devoted, somewhat fanatical, about studying a prestigious career like medicine? Personally, becoming a doctor is something I had always wanted/dreamt my life to revolve around; the hectic mornings, the patients, the staff, the everyday-challenging shifts, the carefully planned patient-specific cases, suit me like a tailor-fitted glove. Every aspect of the career, from my first day at university to my last ever day before retirement, makes me fall into love with it each and every time I dare to dream. Regardless to say, the day I get a place in medicine course would be the happiest day of my life and the definitely my greatest achievement. Some might wonder; why study medicine when you have a cleft, haven't you had enough of doctors? Well, simply put, I would say that having a cleft further strengthened

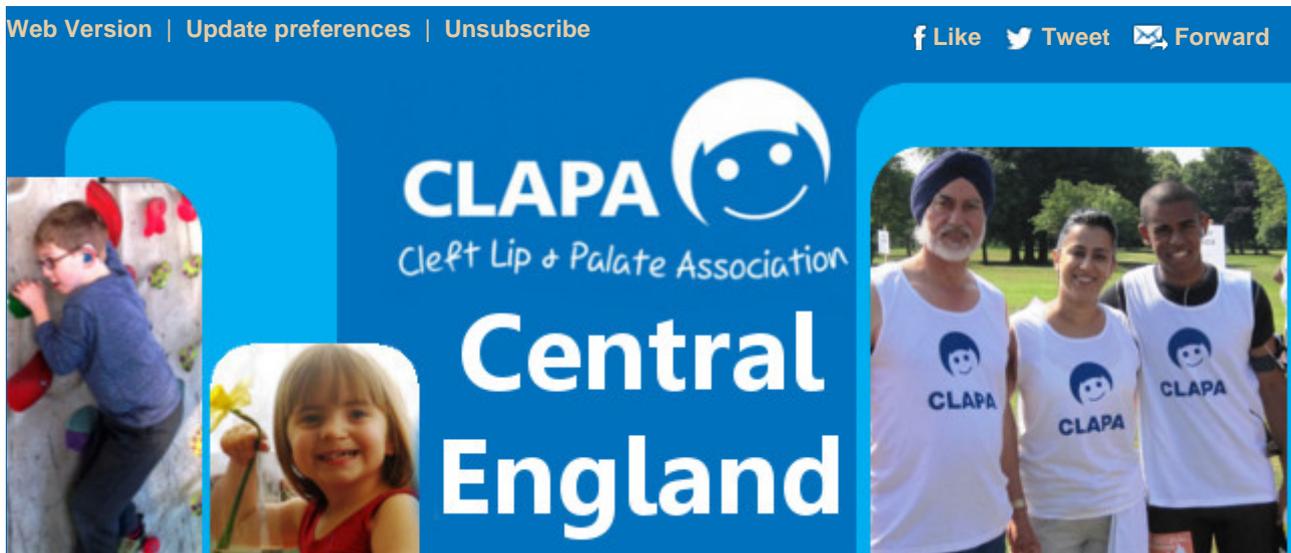
my ambitions to become a doctor. Why? Because having a cleft meant I saw little blessings in life with greater gratitude and learnt to value and appreciate the smaller things in life. My cleft experiences have made me extremely determined to achieve, making me want to excel at everything and anything that I put my head towards, because I was not willing to sit down and become despondent at my cleft and dejectedly 'accept my fate'. I used my cleft as a motivation, as I became tired of hearing the 'no' word, I refuse to be discounted to do tasks merely because I have a cleft. My cleft experiences directed my inner grit and refusal to 'being put-down' to blossom as outward determination and perseverance. I no longer looked to others for inspiration, nor needed quotes or music to become a confident, high achieving man I have become today. My advice to all the cleft community out there, no matter what the age group, is to not take pity nor slack from anyone and expect more from yourself. The key is to build yourself from within, strong enough to show the world what indeed you can do'.

### **Next newsletter out Autumn 2014**

Don't forget, if you've got an article, story or something to share in the next newsletter, please get in touch. We love to hear from you!

Thanks  
The CLAPA team

## Appendix 5: Central region newsletter (2014)



### Welcome to the first ever CLAPA Central Region e-newsletter!

I joined CLAPA in December 2013 as the first ever member of CLAPA staff based in the Central region – I cover the areas covered by the Trent Cleft Service and the West Midlands Regional Cleft Service...so it's a big region! My role is funded by the Big Lottery for 3 years and my focus is to increase CLAPA's presence and activities in the East & West Midlands through working with new and existing volunteers and with the Cleft Teams.

There has always been very limited CLAPA activity in the central region – those of you who are active volunteers, be it as parent contacts, Happy Faces groups, Adult Voices, fundraisers or anything else have been doing a fantastic job, but the aim is to have many more volunteers, groups and events.

We are fortunate to have the support of both Cleft Teams in the region, and I've already been meeting with them and discussing how we can work together to increase the support available for people affected by cleft.

This newsletter will keep you updated on developments in the region and will let you know about forthcoming events. If you'd like me to include something in this newsletter just let me know – I'd love to include your photos and updates about what you've been getting involved in for CLAPA!

*Becky Gowers - Central England Regional Coordinator*

### First regional Volunteer Induction Day

The first Volunteer Induction Day in the central region took place on Saturday 22nd March. 7 new volunteers were joined by existing volunteers, CLAPA staff and the West Midlands Cleft Service Manager to find out about the wide range of volunteer roles available with CLAPA. The day was a

great success, with a lovely mix of adults with a cleft and parents of young children who were not only able to learn about volunteering for CLAPA, but also share their experiences and support each other.

If you are interested in volunteering for CLAPA, please get in touch by emailing me on [becky.gowers@clapa.com](mailto:becky.gowers@clapa.com) – I'd love to hear from you!

We are currently in the process of planning a Lincolnshire Volunteer Induction Day for summer 2014...watch this space!

## Spreading the word about CLAPA at clinics

We are keen to increase awareness about the support CLAPA provides, and a really great place to do this is in clinic waiting rooms where we have a (literally) captive audience! In the West Midlands, I have been attending clinics at Birmingham Children's Hospital, where I am stationed in the waiting room of the main outpatients' department with CLAPA leaflets and stickers. I have also arranged a CLAPA stand for adult cleft clinic days at the QE Hospital in Birmingham. Look out for me if you're attending a clinic – I'll be easy to spot in my CLAPA T shirt! I'm currently talking to the Trent Cleft Service about the best days/clinics for me to come to so you may see me there soon too.

## Happy Faces comes to Redditch!

We are absolutely delighted to announce the launch of a new Happy Faces group in Redditch! The group, which is being organised by CLAPA volunteer Selena Foster, whose daughter Lorena was born with a bilateral cleft lip and palate, will offer support to families affected by cleft lip and/or palate. Holly Trees Children's Centre have provided a room for the group so there's plenty of room for little ones to play, and everyone is welcome, including expectant parents. This will be a friendly, informal group and meetings will take place on the first Friday of every month, 10am – 11.30am.

The first meet will take place on Friday 2nd May 2014, 10am – 11.30am, at Holly Trees Children's Centre, Mabey Avenue, Redditch, B98 8HW. You're welcome to just turn up on the day – there's no need to book a place.

For more information contact Becky Gowers on 07792 772362 or [becky.gowers@clapa.com](mailto:becky.gowers@clapa.com)

## Walk a mile for CLAPA!

The West Midlands Sponsored Walk takes place on Saturday 17th May 2014 at Arrow Valley Country Park in Redditch.

We will be walking 1 mile along surfaced paths along the Lakeside Trail. This is a fun and social event to which friends, family and of course the family dog are all invited. The

## Awareness Week is coming...

CLAPA's annual awareness week runs from 10 – 17 May. We will be campaigning to raise awareness of adults with a cleft – more information is available on our website <http://www.clapa.com/news/article/1806/>

Have you got an event planned during

route is suitable for wheelchair users, pushchairs, the elderly and young children, and we hope to get everyone together for a picnic afterwards. (Please be aware that there is access to the lake along some parts of the route, so children will need to be closely supervised.)

Come and join us!

More information and the link to sign up for the walk is on the CLAPA website here

<http://www.clapa.com/news/event/1840/>

awareness week? Please let us know and make sure you send us your photos!

It's not too late to plan something – perhaps you could organise a cake sale at work or at your child's school? Perhaps you'd like to share your story with the media? Maybe you could take some CLAPA posters to your local clinic, GP surgery or dentist?

## Get involved with the Trent Patient Forum

The Trent Cleft Lip & Palate Service is keen to gather the views and feedback of the patients and families they look after, and as part of this they are working with CLAPA to set up a Patient Forum where patients (including parents of children with a cleft) will have the opportunity to have their say on the service.

This is a great opportunity to help ensure the team can provide the best possible care to people in the local cleft community. The first Patient Forum will take place on Saturday 28 June 2014 in Nottingham. If you are interested in attending please email [becky.gowers@clapa.com](mailto:becky.gowers@clapa.com)

***We hope this email is of interest to you. Please feel free to pass it on to friends, family or colleagues who might be interested in CLAPA's work in the Central Region. If you'd prefer not to receive these regional e-newsletters in future, please email [becky.gowers@clapa.com](mailto:becky.gowers@clapa.com)***

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