



# **CLAPA Regional Coordinators Project**

## **Evaluation Interim Report**

End of Year Three

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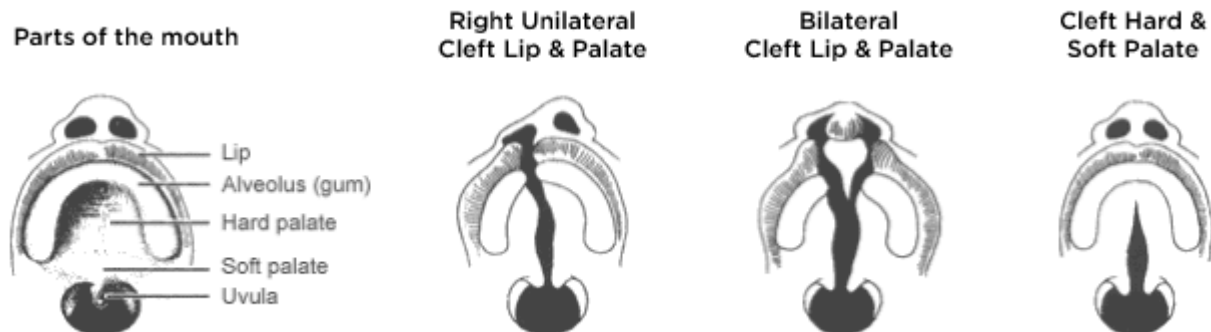
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## Glossary of terms

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.

**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.

**Multidisciplinary Team (MDT)** – Cleft care is offered as part of the National Health Service (NHS) and is provided by a multidisciplinary cleft team, offering specialist treatment and support to affected individuals and their families from birth through to adulthood. Cleft teams usually involve Cleft Nurse Specialists, Plastic and Maxillofacial Surgeons, Speech and Language Therapists, Orthodontists, ENT (ear, nose and throat)/Audiology Specialists, Paediatricians and Psychologists. There are 17 cleft teams in the UK.

**Cleft.Net.East** - this network provides treatment for all cleft lip and palate patients in the East of England, and is based at Addenbrookes Hospital (Cambridge).

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

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

**North Thames Cleft Service** – this service covers parts of the South East region and is based across two surgical sites; Great Ormond Street Hospital (London) and Broomfield Hospital (Chelmsford).

**South Thames Cleft Service** – this service covers parts of the South East region and is based at St Thomas' Hospital (London).

**Spires Cleft Service** – this service covers parts of the South East region and is based across two surgical sites; Salisbury District Hospital (Wiltshire) and John Radcliffe Hospital (Oxford).

**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 Three, Nov 2015)

### 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 Three (Dec 2014-Nov 2015) are summarised below.

In all three regions, new volunteers are being trained and continue to rate the training sessions highly. On the whole, existing volunteers appear to be active and satisfied with the support they receive to carry out their role. There has been an impressive number and range of events aimed at young people of all ages, as well as parents/guardians and families. Adult volunteers are engaged and enthusiastic, although to date there is much less evidence for the impact of the new adult services on beneficiaries. These services are still being developed and it is hoped that the RCs can play a key role in making them a success in the next year.

In the East of England, highlights for Year Three include the work of the Patient Partnership group, the role of the Clinic Volunteer and the introduction of an antenatal support group. Key achievements in the Central region include the establishment of the new West Midlands Branch, the Residential Weekends and the CLAPA Birthday Party in the Park. Although there was already some existing activity in the South East region, the RC has engaged with many different stakeholders and attended a wide range of events since starting in post, with the aim of developing support in the region further. The focus groups conducted at the beginning of the year provided several recommendations and the RC has made significant progress toward meeting these.

Aims for the final year of the current funding stream for the CLAPA Regional Coordinators Project include:

- Continue to expand the volunteer network across each of the regions, establishing new Branches and regular support groups where needed.
- Continue to host training days and events as frequently and locally as possible, establishing links between attendees prior to the event and advertising more widely in order to increase attendance.
- Continue to support the Children and Young People's Council, and to host events and activities for young people of all ages across the regions.
- Continue to support the Adult Voices Council and the development of the Peer Contacts service.
- Endeavour to host events involving adults with CL/P, and raise awareness of the issues important to adults.
- Continue to support and develop the Parent Contacts service, the new Clinic Volunteer role and the Happy Faces groups.
- Build upon the success of the Patient Partnership groups and endeavour to increase patient representation within regional cleft services.
- Continue to work collaboratively with cleft teams, non-specialists HPs, other organisations and researchers.
- Continue to share knowledge and progress across all regions and support applications for matched and additional funding.
- Continue to collect and incorporate feedback from volunteers, parents, young people and adults.

**A huge thank you** to everyone who contributed to the evaluation report. For more information about the Regional Coordinators 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 often 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) and 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 Three. Previous reports have been provided for the pilot year, for the End of Year One and for the End of Year Two. Supplementary reports are also being added throughout the project's duration.

Year Three of this project has seen an expansion in terms of activity in the East of England and Central regions, as well as the introduction of a third Regional Coordinator in the South East. 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.

An interim report is also included as an attachment to this report, along with a recent joint publication between CAR and CLAPA in the world's leading academic journal for cleft and craniofacial research which was developed out of the Regional Coordinators Project:

- 1) Focus group studies in the South East region
- 2) Stock, N.M., Stoneman, K., Cuniffe, C. and Rumsey, N. (e-pub ahead of print, 2015). The psychological impact of cleft lip and/or palate on unaffected siblings. *The Cleft Palate-Craniofacial Journal*.

## 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 continued to support the newly restructured East of England Branch and the Patient Partnership volunteer consultation group.

#### Feedback from new volunteers

The RC delivered six volunteer training days, including four Volunteer Induction Days and two Parent Contacts Training Days in the East of England region. In response to the feedback gathered in previous years, a new approach to volunteer training in Year Three was to offer one-to-one training for those volunteers living in more remote areas, and those less able to travel long distances. Two volunteers who were trained using this new one-to-one approach provided feedback, which is presented below.

Volunteers gave the following reasons for attending a training day:

- 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

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

- I enjoyed learning more about CLAPA
- I enjoyed learning about the Happy Faces groups

As a direct result of the training, both volunteers reported feeling more confident in their role, more able to support others and more able to address cleft-related issues in a positive way. Volunteers also felt they had gained new and transferrable new skills. However, volunteers were less positive about gaining access to a local support network, possibly because of the one-to-one nature of the training. One volunteer commented that *“it was good to meet locally but I would also like to meet others with cleft”*. It would be interesting to monitor the one-to-one training approach more closely and to compare the impact of these sessions with the larger group sessions.

Two new volunteers in the East of England provided case studies for this report:

*"I was not involved with CLAPA until I met the Regional Coordinator. I have an adult son with a cleft lip and palate and wanted to give something back. Since my initial contact with the RC I have run stalls to raise funds, helped with the Christmas Party and joined the Branch Committee. My experience has been very good. As we are in a large region it helps to have knowledge of what is happening in other parts of the region and back at Head Office."*

*"As a person born with cleft lip and palate who has gone onto having two children both with cleft lip and palate, I wanted to be able to share my experience and help and support new parents. Since meeting the RC and signing up to the Parent Contacts Training I now run the local Happy Faces Group. Our local RC has helped me organise local meet-ups and organise a charity event. The RC is always so full of energy and very helpful. It's nice to be able to phone her and bounce around new ideas for fundraising etc. I have a great relationship with her and at times she has attended our Happy Faces meet-ups and it's great for the other parents to meet her too. She is always very positive which makes us feel our work is worthwhile."*

Unfortunately, no other training feedback was collected during Year Three. However, the East of England region is the longest running region engaged in the Project, and there may therefore have been a lesser focus on training new volunteers, and more of a focus on supporting those volunteers who are already active. Feedback was provided by six existing volunteers who are currently active in the region. This feedback is provided below.

#### 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 Year Three, 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
- Member of the local Branch

On average, the six volunteers who provided feedback had been volunteering for approximately two years. Existing volunteers indicated they were happy (n = 5/6), confident (n = 5/6) and supported (n = 5/6) in their roles. Volunteers also felt able to actively support others affected by CL/P (n = 5/6).

Half of the volunteers believed they were achieving their personal aims as a volunteer (n = 3/6). Two volunteers reported that their roles had provided them with access to a local support network, and two indicated that they had gained useful and transferrable new skills.

Those existing volunteers who responded 'neutrally' or more negatively left the following comments:

*"It can be lonely sometimes when organising events."*

*"Often it's lack of commitment from other parents which lets things down."*

*"Clefts in our local area are rare so creating a group wouldn't be as beneficial, and I don't have regular access to a car or time to visit hospitals."*

*"The RC is lovely but I don't always hear back. I completed my volunteer training a while ago but my profile still hasn't been added to the website. I did enquire about this but nothing has changed. As a parent I find certain activities, such as putting materials together for speech and language therapy, to be time consuming and often expensive. I raised this with my RC and I think she made enquiries but I never heard much back. Everyone seems interested but nothing happens. I am still happy to volunteer and in particular to set up some new activities, but I need support to do this."*

*"If CLAPA could update the website with future local events, as not everyone is on Facebook and I'm desperately trying to spread the word."*

Existing volunteers reported a number of reasons for enjoying their roles. Some of these comments also indicate that volunteers are also beneficiaries of the regional support which CLAPA is now able to offer:

*"I enjoy meeting other families."*

*"Being able to raise funds for CLAPA and raise awareness."*

*"Being able to support and offer advice to others affected by cleft."*

*"I enjoy running the Happy Faces groups and planning outings. Also being a great support to new parents as a Parent Contact."*

One existing volunteer provided a case study for this report:

*"I was already a Parent Contact when the current RC came into post, but I've found my experience of working with her to be very good. I wanted to help other children with Pierre Robin Sequence as I received excellent support myself when my daughter was born and I wanted to give something back. I currently attend the local Happy Faces group regularly and events associated with the group. The RC brings everybody together and I have had a very good experience with all CLAPA staff and events."*

Year Three also saw the establishment of the first Happy Faces group in Cambridge. The volunteer who ran the group provided the following feedback:

*"Our Happy Faces group went fine, though we only had one mum and her baby come in. I know to advertise more widely next time, in particular using the Addenbrookes networks. The family worker who was at the children's centre that day has also given me some good contacts, were very supportive and happy for us to have future meet-ups there."*

#### 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 helped to reshape the 'Cambridge Branch', which subsequently became the 'East of England Branch' in Year Two. Throughout Year Three the Branch has been much more active, and it is hoped that this restructure will continue to improve the function of the Branch and represent more of the region as a whole. Further evidence of the Branch's activities and impact would be useful for the evaluation.

In response to the growing call for Patient and Public Involvement (PPI) in research and practice, the RC has helped to develop a Patient Partnership Group in collaboration with the CleftNetEast network based in Cambridge. This initiative began in Year Two and the group has since grown in number, with parent, health

professional and adult representatives. The group has devised a 'terms of reference' document and a 'how to' guide, outlining the aims of the group, what is expected from group members, and the benefits of the group for all stakeholders. The group now meets quarterly and regularly engages with cleft teams and other organisations in need of patient representation. One Health Professional provided feedback in relation to the Patient Partnership Group:

*"It's really great to have help with all these things, just not doable in our clinical schedules. But it should really help improve the engagement/voice of people within the service."*

The CleftNetEast Patient Partnership group:



In addition, the RC attended a number of AGMs and forums held at local hospitals, and gave a joint presentation with a patient representative to a multidisciplinary audience at the annual conference of the Craniofacial Society of Great Britain and Ireland. This presentation was well received and one of the only examples of Patient Involvement at the conference.

The RC has led the development of a number of factsheets, including the 'Benefits of Being a Branch', and has helped to distribute information about volunteering opportunities to local NHS cleft clinics.

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

Building on the success of Years One and Two, the RC has recruited and trained several new volunteers. Unfortunately, little data was available for the evaluation, but the case studies which were provided were very positive. A new one-to-one approach to training appeared to be appreciated by those who provided feedback, and demonstrates the RC's responsiveness to the feedback obtained in Years One and Two. This approach also seems to have some limitations in relation to the volunteer accessing the wider community and should be monitored.

Feedback from existing volunteers was generally very positive, indicating they felt confident in their roles and in their ability to support others. However, a number of challenges were also raised, and volunteers felt that certain aspects of the RC's role could be improved to enhance the support offered to them and to beneficiaries.

The RC has been involved in a number of important additional activities, which have begun to instil the patient voice into clinical services and build upon relationships with members of the local NHS cleft team. It would be helpful to generate feedback from those who are volunteering for and benefitting from these activities in order gain a better understanding of the types of activities being carried out and of the impact these are having on the CL/P community.

### **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 and monitor the impact of these sessions.
- Continue to engage with all volunteers regularly and incorporate their feedback into service delivery.
- Continue to expand CLAPA's presence in the region and encourage more people to run and attend local training days and events.
- Endeavour to bring volunteers together, particularly those in more remote areas where the potential for volunteers to feel isolated is higher.
- Support the development of the new CLAPA website, ensuring the region is well represented and consider creative ways of advertising local events and services online.
- Continue to monitor the progress of the East of England Branch, particularly in light of the restructuring.
- Continue to nourish relationships with local NHS cleft teams and expand this knowledge to working with other relevant organisations where beneficial.
- Continue to build on the success of the Patient Partnership group and negotiate different ways of incorporating the patient voice into clinical services.
- Continue to raise awareness of CL/P and of the volunteering opportunities which CLAPA provides 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 is crucial for the evaluation, particularly going into the final year of the current funding stream.

### **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 delivered several events in the region aimed at children and young people, including a boat trip, the Christmas parties, designing a Confidence-Building Day and a Transition Day. The RC has also been involved in the CLAPA Children and Young People's Council and the CLAPA Adult Voices Council, and has been involved in the development and running of the new Peer Contacts Training for adults.

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

During Year Three, 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, as evidenced by monthly reports. Unfortunately little data is available for the evaluation. Data was collected from three regional Christmas parties, which the RC facilitated alongside parents and adults affected by cleft, and which attracted a combined total of more than 80 families. Feedback was collected from 12 of these families, and although the forms were completed by parents/guardians, the data which relates to CYPs is presented below:

Parents/guardians reported that their children enjoyed the event and that the children wanted to go to a similar event in the future (12/12). They also reported that their children had made friends who they could talk to about having a cleft (12/12), were in a better position to offer help to other children affected by CL/P (10/12) and had learned new ways of coping with cleft-related problems in a positive way (10/12). All other responses were neutral, rather than negative. The majority of parents/guardians also responded that their children felt more confident about themselves as a result of attending the event (7/12), with five parents indicating that they felt 'neutral' about this.

As part of Cleft Awareness Week, the RC was involved in a number of awareness-raising and fundraising activities, including a Sponsored Walk. Although feedback was completed by parents, both respondents indicated that their children had enjoyed the event (2/2).

One parent/guardian provided feedback about the impact which she feels her local Happy Faces group is having on her son:

*"We love to attend and both of us benefit from not only getting out of the house an meeting new people but from regularly seeing those who are in a similar situation (or who have been in a similar situation) to us. As my son grows older these events will be more than just good fun for him, as he too will be able to relate. He may even have his own questions to ask, experiences to share or worries to discuss."*

Another event which was planned in response to feedback from previous years, but that ultimately had to be postponed due to late cancellations, was a Youth Event hosted in collaboration with another charitable organisation, Changing Faces ([www.changingfaces.org.uk](http://www.changingfaces.org.uk)). This event has now been reorganised and should take place in December. The RC has also promoted youth events which are hosted by the NHS Cleft Teams (e.g. a 'self-confidence workshop' and a 'transition day') to CLAPA CYP members.

The RC has led the development of a number of factsheets aimed at young people and families, including 'Bullying Support'.

#### Feedback from adults with CL/P

Following an external research study examining the experiences and support needs of adults with cleft (Stock et al., 2015), and an internal annual CLAPA survey (see [www.clapa.com](http://www.clapa.com) for further information)



conducted during Year Two, it was concluded that more focus should be placed on creating support for adults born with CL/P across all regions. Support for adults is still in its infancy, but the RC for the East of England has been instrumental in designing and delivering the first series of Peer Contacts Training. Feedback from a 'refresher' course is provided below:

Adults gave the following reasons for attending the training:

- To meet other individuals and families affected by cleft
- To learn more about the support CLAPA offers
- To find out how to help others affected by cleft

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

- Open group discussions
- Thinking about ways we can help others
- Having this information refreshed
- Seeing other adults with cleft

As a result of the training, adults reported they had access to a local support network (n = 4/4) and had gained transferrable new skills (n = 4/4). Adults also felt more confident (n = 4/4) and more able to support others affected by cleft (n = 4/4) and able to address cleft-related issues in a positive way (n = 4/4). Adults also provided additional comments:

*"The event was well organised and informative. In a bittersweet way having a smaller group also helped."*

*"The refresher course was extremely useful. Monitoring the outcomes is essential and to see what progress is made in the future."*

Several adults with CL/P have also taken part in regional activities, such as fundraising events, family days and the Patient Partnership group.

## **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 seemingly been successful in terms of activity for adults with CL/P and the feedback gathered, although limited, has been favourable. It would now be helpful to collect further information regarding how other adults may have benefitted from this increase in service delivery.

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

- Continue to host events for children and young people of all ages across the region (and encourage volunteers to do to same).
- Continue to partner with other charitable organisations to increase the scope of these events and to build upon relationships.
- 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.
- Continue to engage adults with cleft in regional activities and endeavour to collect evidence of the impact and growth of adult services in the region.
- Additional data is crucial for the evaluation, particularly going into the final year of the current funding stream. Collecting data at large events is challenging, but the correct forms need to be used with key beneficiaries in order to get the most out of the data.

## **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

As mentioned above, several family events have been held in the region, in addition to a number of fundraising events. Events aimed at parents/guardians included an Open Day, a social evening, the Christmas Parties, a Sponsored Walk an antenatal group and Parent Contacts tele-conferences. Other services include Parent Contacts and Happy Faces groups. The RC has also been involved in other activities aimed at supporting and informing parents/guardians and families, including a regional newsletter and regional Facebook page.

### Feedback from parents/guardians

A range of events were held for parents/guardians in the region this year, including a new antenatal support group. Seven attendees of this antenatal group provided feedback, most of whom had not attended a CLAPA event before:

Parents/guardians gave the following reasons for attending the antenatal event:

- To meet other individuals and families affected by cleft
- To meet Health Professionals
- To learn about cleft lip/palate
- To learn about the support that CLAPA offers
- To find out how to help others affected by cleft

All parents/guardians indicated that they had achieved these aims. In addition, parents commented on the aspects of the event which they most enjoyed:

- Hearing different perspectives
- Ways of thinking about/processing the news of the diagnosis
- Meeting other parents and hearing about their experiences
- Providing support to other parents
- Meeting the Clinical Psychologist

Parents/guardians gave the following suggestions for how to improve similar events in the future:

- Advertise more
- Consider two sessions instead of one
- Reduce the amount of time spent sitting down

Parents/guardians indicated that as a result of the event they felt they had gained access to a local support network (4/7), felt more able to support others affected by cleft (6/7) and had gathered information which would help them to address cleft-related issues in a positive way (7/7). Six out of the seven respondents indicated they would attend a similar event in the future, with one parent responding neutrally, but commenting *"I found this event very useful, thank you"*. All other responses were neutral, rather than negative.

One of the Health Professionals who attended the event also provided feedback:

*"I recently saw one of the mums who attended the last antenatal group. Baby and parents are doing brilliantly. She was so grateful for the support she received as a result of the group and was very complimentary as everyone made her feel so welcome and supported. Thank you to the RC for sitting with her, it made such a difference."*

Attendees at the antenatal group:



Feedback from parents/guardians was also collected from three Christmas parties and a Sponsored Walk, which were previously mentioned above. This feedback is provided below.

Parents/guardians attended the events for the following reasons:

- To meet others affected by cleft
- To learn more about the support I can get from CLAPA
- To offer help and advice to others affected by cleft
- To have fun and to make friends

Parents/guardians indicated they had achieved these aims and had particularly enjoyed the following aspects of the events:

- Meeting other parents and children
- Talking and giving advice
- Meeting an expectant cleft mum
- Two children finding out their surgeries would be on the same day

- Seeing the children enjoy themselves
- The event was very well organised
- Great venue
- The children seeing Santa arrive
- Meeting people I'd previously only spoken to through Facebook
- The event was very relaxed

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

- The distance from home/travel
- To have the event slightly earlier in the day
- To have more people join in the event
- To arrange the event in good time

As a result of the events, 12 parents/guardians commented on the impact the events had had on their children (see Outcome 2 above). Three parents/guardians also commented on how the event had impacted them, indicating that they had access to a local support network (2/3), were more able to support others affected by cleft (2/3), were more able to cope with cleft-related issues in a positive way (2/3) and that they would attend a similar event in the future (3/3). All other responses were neutral, rather than negative.

Additional comments from all of the parents/guardians included the following:

*"We had a fantastic time – thank you!"*

*"Same again next year please!"*

*"The whole event was a success. Would certainly do it again."*

The Sponsored Walk in Norwich:



One parent/guardian provided a case study for this report, specifically in relation to one of the Happy Faces groups:

*"Myself and my son have been involved in activities and events organised by our local Happy Faces group and Regional Coordinator. I always have questions and love to hear about other people's experiences. Reading from a textbook is in no way as informative or reliable – honest discussions really do help. It's so*

*reassuring to know you are not alone – you are part of a wonderful family with no judgements made. I always feel welcome and at ease.”*

A number of Parent Contacts also provided information regarding the nature of the enquiries they have been contacted about during the year. This information indicates that this service, which is predominantly aimed at parents/guardians, is used to address a range of concerns, and that it benefits a number of different patient groups, including expectant parents/guardians, parents/guardians of older children, and grandparents. Furthermore, in several cases these beneficiaries were referred to the Parent Contacts by the NHS Cleft Teams, suggesting that the RC and local volunteers have built up a positive relationship with local Health Professionals, and that the regional service offered by CLAPA compliments the service offered by the NHS. However, one parent/guardian also commented that *“there should be more cleft material in the clinic area of my local hospital. At the moment there is none.”* This is an issue which the RC has also noted and has increased efforts to distribute appropriate literature to relevant hospitals in recent months.

#### Additional activities

A new East of England regional newsletter has been developed by the RC, 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 228 active members, with this figure continuing to grow.

The RC has also begun to work on a strategy to approach families from Black and Minority Ethnic (BME) backgrounds, to increase the representativeness of these groups within CLAPA.

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

The RC has supported a number of events for families affected by CL/P across the region, which have been rated highly by attendees. Of particular note was the establishment of a regional antenatal group. 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 in the region.

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

- Continue to host events across the region (and encourage volunteers to do to same), including regional antenatal groups.
- 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.
- Increase the distribution of information leaflets to regional hospitals and other relevant locations.
- Promote regional activities to the local press in order to raise funds and awareness.
- Continue to grow the regional audience of the newsletter and Facebook pages.
- Additional data is crucial for the evaluation, particularly going into the final year of the current funding stream.

## **Follow-up from Years One and Two (East of England)**

The End of Year One and End of Year Two evaluation reports provided summaries of the progress of the RC role in accordance with the three outcomes, in addition to a number of suggestions for the future of the role. The RC for the East of England has been responsive to these suggestions and has addressed several of the recommendations detailed in the previous report. Unfortunately, a key difficulty this year has been the collection of relevant data to evidence the impact of the significant work being carried out in the region. This may be due in part to the East of England RC's work in supporting developments in other regions, and to the role expanding and developing as time goes on.

### **Outcome 1: Volunteers**

At the end of Years One and Two, training days were being held more frequently and in varying locations across the region. At the end of Year Three, it is clear from the RC's monthly reports that this success has continued, although there is little evidence to support the impact of these training sessions. In response to challenges associated with travel, the RC is now trialling smaller training days and one-to-one training in more remote locations. Since this is still a relatively new approach, the RCs are encouraged to monitor the successes and challenges of these smaller sessions. A number of existing volunteers provided follow-up feedback, and indicated a high level of overall satisfaction and willingness to continue as a CLAPA volunteer. They also highlighted a number of ongoing challenges, some of which were also apparent in previous reports. At the end of Year Two, one of the key successes was the implementation of the Clinic Volunteer role, which was led by the East of England RC. During this year little evidence was collected to this effect, although it is apparent from other sources that this role is still in place and has been successfully implemented in other regions. It is unclear whether new adult volunteers have been recruited; however those who remain as CLAPA volunteers appear to be highly active. The work of the Patient Partnership group is particularly commendable and more evidence of the work and impact this is having on the clinical service and in other relevant areas would be beneficial. Relationships with NHS Cleft Teams also appear to be strong, and there is some indication that the RC has begun to build upon relationships with other charitable organisations as well. This year there was little evidence of awareness-raising activities and media interest, where in previous years this had been a particular strength in the East region. The restructuring of the East of England Branch appears to have been successful, although again additional data would be valuable.

### **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 RCs had a key role to play in helping the CYPC to achieve their aims, particularly in regard to organising and delivering events for children and young people in the region, monitoring and contributing to the children and young people's Facebook page and engaging with schools and other key community organisations. Although there was evidence of these activities taking place in the East of England during Year Two, the evidence for Year Three has been much less. In addition, it seems that events for older children and teenagers have been difficult to organise this year. This is partly true for the services for adults, which appear to have been quieter this year, although it is clear that adults have been involved in a number of key regional activities in a

volunteering capacity. The RC has also led the Peer Contacts Training for a second year. Although services for older children and adults with CL/P are still behind those offered to parents and families as a whole, it is hoped that the RC will continue to build upon this opportunity during Year Four.

### Outcome 3: Parents/guardians

The RC has continued to support and promote Parent Contacts as a source of peer support for families. Several events have been hosted in the region, and the RC has contributed to events which have taken place in other regions as well. Where data has been collected, feedback has been positive overall. The new Happy Faces group appears to be gathering speed, and the establishment of a new antenatal group is commendable.

On a wider scale, and as the longest standing RC in post, the RC for the East of England plays a key role in lending support to the other RCs and the services which are delivered within other regions.

## Central region

The Central region is defined as: Birmingham, Derbyshire, Herefordshire, Leicestershire, Nottinghamshire, Rutland, Shropshire, Staffordshire, Warwickshire, Worcestershire and parts of Lincolnshire. Claire Evans has been in post since October 2014.

During Year Two, a large part of the RC's role was to set up a structure upon which regional activity could be based. In Year Three, it is clear that these efforts have generated a significant growth in activity throughout the region.

### **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 delivered a number of group-based and one-to-one volunteer training sessions throughout the year, as well as supporting existing volunteers to develop and expand regional support and activity. The RC has also developed the new Patient Voice project in the region, aimed at increasing patient representation in cleft services.

#### Feedback from new volunteers

The RC delivered two Parent Contact Training weekends in the Central region. In addition, the RC has trained six new volunteers through one-to-one sessions. Fourteen volunteers provided feedback following a training session. This feedback 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

At the end of the training, volunteers generally believed they had achieved these aims. Three indicated that they had not learned any more about cleft lip/palate, but did not comment further. It is possible that this was because the focus of the training is on providing support to others, rather than gaining knowledge about CL/P itself.

Volunteers listed a number of reasons for why they had enjoyed the training:

- Meeting the RC, other parents, volunteers and health professionals
- Hearing other people's views and experiences
- The honesty of everyone was invaluable
- Learning about how to really listen to others and think about the impact of what I say



- Looking at case studies
- The information provided, especially the guest speakers
- Enjoyed all aspects. Very encouraging with a variety of interventions.

Some volunteers commented that the *“safeguarding aspect was heavy going”*, that *“sitting down for prolonged periods”* wasn’t enjoyable, and that *“discussions often went off topic”* and *“lacked adherence to timekeeping”*. When asked about how training could be improved in the future, volunteers gave the following responses:

- More of a focus on real case studies
- Facilitated by people with more experience in cleft support and/or more input from specialists such as members of the cleft team
- Inviting a psychologist to the training sessions
- More details of other support CLAPA can provide

As a direct result of the training, volunteers reported that they had gained access to a local support network (11/14), felt more confident in their volunteering role (13/14), more able to support others (12/14) and more able to address cleft-related issues in a positive way (12/14). All other responses were neutral, rather than negative.

All volunteers felt they had gained new and transferrable new skills (14/14), including *“how to support others”*, *“more awareness of the diversity of parent experiences”* and *“listening skills”*.

Volunteers left a number of additional comments, including the following:

*“There were too many conversations about Happy Faces group, which is not relevant to everyone wanting to be a Parent Contact.”*

*“An excellent two days with very inspiring parents and useful tools to help us provide the best support.”*

*“It was great to meet the surgeon and get real in-depth knowledge. Felt free to ask questions.”*

*“The two day training sessions have been outstanding and I would definitely recommend it to others.”*

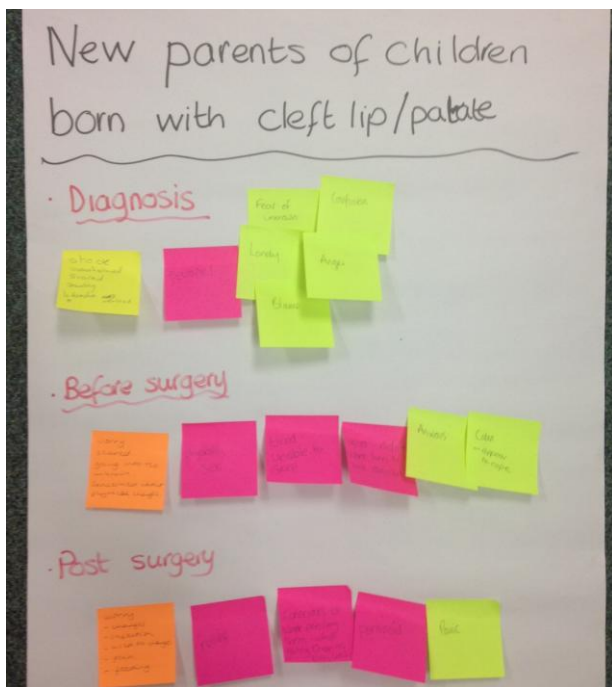
The RC provided her own reflections on these training sessions, and it is clear from her comments that she incorporated what she had learned from the first sessions into subsequent sessions. Some illustrative extracts are provided below.

*“Timekeeping was an issue – I am much more experienced in delivering training to young people and professionals. Both of these groups need different boundaries and parameters to parents, who want to talk about their individual experiences much more. I found it challenging to intervene when conversations were going off topic...and need to develop these skills for next time.”*

*“I think it would be better if the facilitator had more experience in cleft support – however that was the reason we had two facilitators... I do think we should have psychologist involvement in the training weekend.”*

In response to this feedback, the RC subsequently met with a Psychologist to go through the content of the Parent Contact weekends.

Activities at one of the Parent Contact Weekends:



Three volunteers who were trained during a one-to-one session also provided feedback for this report. They indicated that they had achieved all of their aims, besides meeting Health Professionals. Volunteers indicated they had gained access to a local support network (2/3), felt more confident in their volunteering role (3/3), more able to support others (3/3) and more able to address cleft-related issues in a positive way (3/3). Volunteers also felt they had gained new and transferrable new skills (2/3), including “communication, empathy and general supportive skills” and “confidence in what I want to do in my role.” All other responses were neutral, rather than negative.

Volunteers provided the following additional comments:

*“I most enjoyed the learning aspect of the training and the relaxed, friendly atmosphere. I feel the training was delivered well and see no improvements which need to be made. I am looking forward to becoming part of the team.”*

*“It has been useful because I’ve got more information about my role and what CLAPA is about.”*

The RC has played a key role in forming and supporting the new West Midlands Branch. To date the Branch has met three times and hosted a launch event (see Outcomes 2 and 3 for beneficiary feedback). The RC provided a statement outlining her role in the Branch:

*“The Branch work closely with me and receive relevant support and information to link with CLAPA National, advice on finances and localised funding applications, and how to link with the West Midlands NHS Cleft Service. I provide support and supervision to all volunteers... I have also supported both Branch meetings and chaired one meeting where the Co-Chairs couldn’t attend.”*

One of the Co-Chairs of the newly formed Branch provided a case study for this report:

*“Having been a very active volunteer in the West Midlands for over two years I was very eager to hear about the possibility of setting up a Branch here. After attending an initial meeting I was extremely happy that we had enough interest to start a Branch and I was elected Co-Chair. I am really excited to be part of a unique and wonderful bunch of people as passionate as I am to help families and adults affected by cleft in*

*the region, as being a large region there hasn't been much in the past. I am really looking forward to our upcoming launch party and arranging many more fantastic events in the future."*

A social event was also held for members of the new Branch in September 2015.

Years One and Two saw the launch of the new Clinic Volunteer role. The first Clinic Volunteer in the Central region began attending cleft clinics at local hospitals this year. According to the records available from two cleft clinics (both in July 2015), the Clinic Volunteer made contact with 12 parents and 12 children, who were particularly interested in learning more about the Happy Faces groups. The Clinic Volunteer commented that *"five out of the 12 families had never heard of CLAPA, even though the children were between the ages of 5-10."*

The Clinic Volunteer wrote a case study for this report, which was also featured in a publication by the Volunteers Service of Birmingham Children's Hospital. This case study is provided in the Appendices.

A Health Professional also provided a testimonial in relation to the Clinic Volunteer:

*"I just wanted to let you know what a star the Clinic Volunteer was in a very busy clinic with me yesterday. I was running clinic on my own, and she was so helpful with patients, walking them up to Photography etc. She's a credit to CLAPA and is invaluable."*

The Clinic Volunteer has since begun to support a second Clinic Volunteer, and has also attended a number of events hosted by the local Cleft Team, including a 'Transition Day' for children and young people. As a result of the volunteers' presence in the clinics, several people have signed up to the regional Facebook page and attended local events.

#### Feedback from existing volunteers

In her monthly reports, the RC indicated that communication with volunteers was an ongoing barrier to working with existing volunteers effectively. Nonetheless, the evidence collected suggests that the RC has formed good relationships with a number of existing volunteers in the region, such as the Co-Chair of the newly formed West Midlands Branch. In addition to the case study presented above, one other existing volunteer provided feedback. This volunteer indicated that they were an active Parent Contact, fundraiser and now an active member of the new Branch Committee. The volunteer reported that they were happy in their role, felt confident and supported in their role and were achieving their aims as a volunteer. They also indicated they had access to a local support network, felt able to actively support others, and were developing useful and transferrable new skills.

#### Additional activities

The RC has attended a number of additional networking and training events, including a volunteer networking event which was *"really useful for ideas on creating a more structured framework for support and supervision of volunteers"*. This has also included attending events hosted by the regional NHS Cleft Teams, such as the Big Smiles meeting in Nottingham and the Trent Cleft Team Away Day.

The RC supported a parent volunteer to attend an event for Sonographers and to host a CL/P information stand. The RC also facilitated an adult volunteer to attend Safeguarding Training and a number of Health Professionals to offer their expertise at the Parent Contact Training.

The RC for the Central region led the development of the Patient Voice project in the region, and the first meeting was held in Birmingham in July 2015. The RC also met with the Trent team to discuss how best to communicate the 'below average Speech and Language Therapy results' detailed in a national report ([www.cranedatabase.org.uk](http://www.cranedatabase.org.uk)) to parents, and to help integrate Patient and Public Involvement into the Craniofacial conference in April 2016.

This year the RC produced a new guide for Happy Faces group volunteers. The RC also attended a family networking event *"to meet with other charities in the area and discuss partnership/linking up opportunities"*.

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

A significant number of new and existing volunteers have received training throughout the region. Those who provided feedback rated this training highly; although some comments indicated that conversation tended to go off topic, and that input from a Psychologist and/or other specialists would be valued. Although being able to share experiences is a key part of the training, training sessions are not intended to replace other opportunities to give and receive peer support. It is clear that the RC has acted upon this feedback in order to improve future training sessions and supervisions.

Some volunteers were trained using a one-to-one approach. It would be helpful for all RCs to monitor this new approach to training to determine its impact and to ensure trainees are offered opportunities to achieve all of their aims.

The new Branch in the West Midlands has been established and is already highly active. The addition of the Clinic Volunteer role, although challenging initially, seems to be beneficial.

Little additional data from existing volunteers was collected for this report; however this feedback was very positive and indicated that the RC is working hard to build relationships with all volunteers across the region.

The efforts of the RC to attend other training and networking events, as well as encouraging volunteers to do the same, is commendable, as is the work carried out with the new Patient Voice group to date. It would be helpful to have more information on the progress of this group next year.

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

- Continue to train new volunteers in the region, including one-to-one sessions where needed
- Continue to include input from cleft specialists, including Psychologists, in the Parent Contact training sessions
- Have knowledge on how to refer volunteers/patients to the clinical team where appropriate
- Continue to engage with all volunteers regularly and incorporate their feedback into service delivery
- Continue to monitor the progress of the new West Midlands Branch
- Continue to develop and be actively involved in the Patient Voice project
- Maintain contact with the local cleft teams and continue to encourage ongoing collaboration

- Continue to support local volunteers to adopt the Clinic Volunteer role
- Continue to attend relevant training and networking events in order to build relationships and links with other organisations
- Additional data collection would be valuable for the evaluation

## **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 has delivered several events in the region aimed at children and young people, including two Residential Weekends and the West Midlands Branch Launch event. The RC has also been involved with the CYP and Adult Voices Councils, as well as attending an adult cleft clinic.

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

The RC helped to organise and run two Residential Weekends this year. Twenty-seven children and young people provided feedback from these two events, as outlined below.

CYPs gave the following reasons for attending the events:

- 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

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

- Seeing my friends
- Playing games
- Having fun with other people with cleft and getting to know them better
- The fun activities (archery, wacky races, zip wire, quad biking, climbing, Halloween disco, tag rugby)
- Having free ‘chill’ time in the evenings, including the campfire

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

- Having more time – making it a whole week! Could we have it in summer holidays?
- More activities/extend how long the activities are
- Less tightly scheduled activities - having more time to socialise/more chill time
- Smaller dorms – less people in each dorm

- Invite more people
- Better location
- Nothing – it's already amazing!
- I didn't like having to go home!

As a direct result of these events, CYPs felt they had made friends who they could talk to about having a cleft (24/27), felt they could support others with cleft (25/27), felt they had learned new and positive ways of coping with cleft-related problems (21/27) and felt more confident about themselves (22/27). All other responses were neutral rather than negative. Of the 27 respondents, only two CYPs indicated they would not attend a similar event in future. CYPs left the following additional comments:

*"I think these weekends are so important for children with clefts. I have made so many friends and the support I've had is amazing!"*

*"The staff are really nice."*

*"Residential is a very good way of getting to know everybody outside of the more formal meetings. I had so much fun!"*

*"I would definitely want to come again as I am having fun with friends."*

The RC also commented on one of the Residential Weekends:

*"The weekend was brilliant! Everyone was so supportive of each other, staff were great, the centre and instructors were fantastic."*

Following one of the Residential Weekends, a parent of a CYP emailed some comments to the RC, as outlined below. It would be helpful to collect feedback from other parents in future as well.

*"The photographs are fantastic... Everybody should see and know about the fun that these young people have at the Residential. My son is already talking about next year and meeting up again with his friends! What was clear when we picked our son up was that everybody had packed a great deal into the weekend...they all had a smile on their face! A job very well done by you guys, and one for which you should be recognised and be proud."*

The RC also helped to facilitate a Residential Weekend in the South East region in July. Feedback is provided in the South East section of this report.

The RC was involved in a number of other events aimed at families, including the West Midlands Branch Launch party, a Cleft Awareness Week Sponsored Walk in Redditch and a Birthday Party in the Park. Feedback was given predominantly by parents/guardians, but some of the comments relating to CYPs are reported below:

*"My daughter really enjoyed the soft play and interacting with the other children. I feel it is important for her to grow up around other children affected by clefts."*

*"I enjoyed seeing the children enjoy themselves; my grandson enjoys it because he is not singled out."*

*"There was a good range of activities for all my children (10 months, 4 and 6)."*

*"My son met his friend previously known from another CLAPA event."*

*"A massive thank you to all the team for all your hard work in looking after our children on their journeys."*

All parents/guardians who completed feedback indicated that their son/daughter had enjoyed the events and would attend again in the future.

The RC also attended a CYP Council meeting, which are held quarterly. Although the CYPC is not restricted to the Central region, feedback was collected to demonstrate the RC's involvement with CYPs on a wider scale. Nine CYPs attended the meeting, and eight provided feedback, as presented below.

In addition to the reasons given above for attending regional and national CLAPA events, two CYPs commented that they attended the meetings to *"make a difference to the future of cleft care"*, demonstrating the different but equally important aims of the Council in comparison to that of less formal events.

Following the meeting, CYPs felt they had made friends who they could talk to about having a cleft (8/8), felt they could support others with cleft (7/8), felt they had learned new and positive ways of coping with cleft-related problems (7/8) and felt more confident about themselves (8/8). All other responses were neutral rather than negative. All of the eight attendees indicated they would attend a similar event in future. Members of the CYP Council left the following additional comments:

*"I love the CYPC! I am so lucky to be part of it and it has made a huge difference to my life and how I feel about myself."*

*"CLAPA events are the best things ever and I'm so glad I joined!"*

*"CLAPA is the best charity – give us more money please!"*

Feedback was also collected by the RC in the form of flipchart discussions. A summary of this feedback is included in the Appendices of this report. The RC commented that collecting feedback *"seems to have worked well... This is something I recommend we now include as part of every future meeting."*

During Year Two of the RC Project, an additional study was carried out on the impact of cleft lip/palate on the unaffected siblings of children born with a cleft. The original siblings report was submitted alongside the End of Year Two Report, and a copy of the academic paper which was accepted for publication in August 2015 is attached to this report. In response to the siblings report, it is apparent that some work has begun in the Central region, as evidenced by the quotes obtained below:

*"The event had a lovely relaxed atmosphere, with plenty for older siblings to be involved in as well."*

*"It is nice for my children who don't have a cleft to see other children like their brother."*

#### Feedback from adults with CL/P

Three adults born with CL/P provided a case study for this report. All four of these adults are also CLAPA volunteers. Illustrative extracts are provided below:

*"There is a close and vibrant relationship with the RC. The role of the RC is vital to the success of activities within a region and at long last the West Midlands has received the support that it needs. I believe that the new West Midlands Branch can also be a role model for other Branches in the UK. The RC is doing a fantastic job in being a catalyst for the individual volunteers within the region... I would like to see more contact with the cleft team RE: promoting the Peer Contacts and services for adults with cleft."*

*“CLAPA Regional Coordinators provide a valuable service, tying together the various volunteers and activities, ensuring we all stay informed and are provided support. To improve local services - the addition of RCs where there are currently none.”*

*“As someone born with a cleft lip and palate myself I thought it would be good to volunteer with an organisation that I could identify with and have experience of. It’s great to have a RC so you have someone to ask for guidance and help where needed. They can also keep us up to date on what’s new. My RC is very supportive and approachable, and very good at her job.”*

Adult volunteers have also been active within the Central Region and have contributed to a number of events and activities with the support of the RC. One such event was the ‘Transition Day’ hosted by the cleft team based at Birmingham Children’s Hospital.

*“I was invited to a Cleft Transition Day... The children transitioning from primary to secondary school participated in their own workshop which concentrated on imbuing them with confidence and equipping them to cope with the changes they are facing. I delivered a presentation on who CLAPA is and what CLAPA can offer those affected. We went on to promote the newly formed West Midlands Branch and upcoming events. There was certainly great interest shown in everything that was said and hopefully this will lead to increased membership in the Branch as well as those attending the events.”*

One Health Professional provided the following comment:

*“The day went really well...they were a keen group of [parents and] children and were really interested in CLAPA and the events you have to offer.”*

The RC also attended an adult clinic at the Birmingham Children’s Hospital in July, to look at options for supporting the adult patients there.

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

The activities for children and young people within the Central Region this year has been extensive and widely praised by parents and young people themselves. It is encouraging to see evidence for the inclusion of unaffected siblings in events as well. Adult volunteers seem to be active, enthusiastic and supported. It would now be beneficial to collect feedback from adults with CL/P who are beneficiaries of CLAPA’s recently re-established services for adults, rather than volunteers alone.

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

- Continue to host events for children and young people of all ages across the region (and encourage volunteers to do to same), building particularly on the success of the Residential Weekends.
- 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 develop links with cleft teams and other organisations.
- Encourage the development of activities for adults born with cleft across the region.
- Additional data for the evaluation, particularly from adult beneficiaries 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 was involved in a number of events aimed at families, including the West Midlands Branch Launch party, a Cleft Awareness Week Sponsored Walk in Redditch, an Easter Fun Day and a Birthday Party in the Park.

### Feedback from parents/guardians

Feedback from a number of parents/guardians who attended events in the Central Region is provided below.

Parents/guardians attended the events for the following reasons:

- To meet others affected by cleft
- To meet health professionals
- To learn more about the support CLAPA offers
- To offer help and advice to others affected by cleft

Overall, parents/guardians indicated they had achieved these aims and had particularly enjoyed the following aspects of the events:

- The community getting together
- Everyone gets involved and is ready to support
- Meeting friendly children, parents and volunteers
- All events were well organised and for the benefit of both children and parents

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

- More families in attendance

As a result of the event, parents/guardians commented on how the event had impacted them, indicating that they had access to a local support network (10/14), were more able to support others affected by cleft (7/14), were more able to cope with cleft-related issues in a positive way (8/14) and that they would attend a similar event in the future (12/14). All other responses were neutral, rather than negative, with some parents/guardians suggesting that they already had access to a local support network and felt able to support others prior to the event. Parents/guardians also indicated they had heard about the event through a variety of sources, including the RC, a local volunteer, another parent, the regional Facebook page, the local Happy Faces group and a regional e-newsletter.

Additional comments from all of the parents/guardians included the following:

*"We thoroughly enjoyed the Easter party and loved meeting fellow cleft families both old and new. We are always made to feel welcome and it is clear how much hard work is put in to make it a success. There was an impressive range of activities which we found very entertaining. We look forward to future events."*

*"The whole afternoon was lovely. I personally enjoyed meeting other people and talking about our experiences. It was the first time I'd spoken to others with children with clefts. Looking forward to the next event!"*

*"It was our first cleft event that we've been to. It was lovely to see so many children and to see the cleft team in a more relaxed atmosphere...unlike when we have our routine appointments. We find we don't go to many things due to locations but couldn't miss this one. I met two ladies who I originally met through social media, so it was amazing to finally meet in person."*

Photographs from the Awareness Week Sponsored Walk:



The Easter Fun Day and Sponsored Walk attracted some media attention, which is included in the Appendices.

#### Additional activities

This year the RC has produced 3 regional e-newsletters, containing information about upcoming events and opportunities within the region. Approximately 3,378 regional CLAPA members are signed up to receive this e-newsletter. An example copy is included in the Appendices.

The regional Facebook pages are also active, with 126 members currently signed up.

Moving forward, there is the possibility of three new Happy Faces groups in Wolverhampton, Scunthorpe and Rotherham.

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

A range of regional events were held in various locations during Year Three, all of which were well attended and highly praised by those parents/guardians who provided feedback. Fundraising activities have been successful for those involved and have contributed to awareness raising efforts by featuring in the local press. Little data in regard to how the regional Parent Contacts service is functioning was available this year. This was also the case for the regional Happy Faces groups, although there is evidence to suggest that several new Happy Faces groups hold promise. 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)**

- Continue to host events across the region (and encourage volunteers to do to same).
- Continue to provide a wide range of 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 and share stories with the local media.
- Continue to encourage the running of Happy Faces groups and the collection of data from volunteers and beneficiaries.
- Collect data on the activities carried out by regional Parent Contacts.
- Continue to have a presence in local cleft clinics.
- Continue to grow the regional audience of the e-newsletter and Facebook pages.

### **Follow-up from Year Two (Central region)**

The End of Year Two evaluation report provided summaries of the progress of the RC role in accordance with the three outcomes, in addition to a number of suggestions for the future of the role. The RC for the Central region has been responsive to these suggestions and has addressed several of the recommendations detailed in the previous report.

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

At the end of Year Three, many more volunteers have been trained within the region and relationships with some existing volunteers appear to be strong. Particular highlights for this year include the establishment of the new West Midlands Branch, the development of the Patient Voice Project and the success of the Clinic Volunteer role. Relationships with Health Professionals also appear to be productive and mutually beneficial.

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

The number and range of activities for children and young people has increased in the Central region this year, and have received considerable praise. Activities for older children, teenagers and siblings have been incorporated into events as suggested and have been appreciated by beneficiaries. The RC has also contributed further to the CYPC and AVC meetings. Although there is evidence to suggest the RC has a good relationship with adult volunteers, there is little data to describe the activities being carried out for adult beneficiaries and the impact of these activities. Adults with CL/P are more difficult to make contact with as they are no longer engaged in routine treatment. Working further with the AVC to develop measurable goals for the year ahead, as well as engaging further with cleft teams and adult clinics, could prove helpful.

#### **Outcome 3: Parents/guardians**

As also evidenced in last year's report, local events have been well-received and popular in the Central region. Activities for people of all ages have been provided at these events, in response to the

recommendations laid out in the End of Year Two report. Events have also been promoted in the local press, in regional e-newsletters and on social media. Compared to Year Two, little data has been collected in relation to Happy Faces groups or Parent Contacts, and would be beneficial for the final year.

In general, the RC should also be commended on her efforts to increase and diversify the evidence gathered for this evaluation, in accordance with last year's recommendations, and is encouraged to continue to build on this for the final year of this funding stream.

## South East region

The South East region is defined as: Berkshire, Buckinghamshire, East Sussex, parts of Hertfordshire, Kent, London, Oxfordshire, Surrey and West Sussex.

The South East region is the third and final region to be introduced during the current funding stream, and was launched in December 2014. The original RC for this region left the post in February 2015, and little data was available for this period. The data presented below has therefore been collected since the current RC, Cherry LeRoy, began in post in June 2015.

### **Outcome 1 (South East region)**

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

#### Overview

During her time in post, the RC has delivered a number of training days for volunteers, including two Volunteer Induction Days and one Parent Contacts Training weekends. She has also made links with existing volunteers around the region.

#### Feedback from new volunteers

Ten volunteers provided feedback following a training session. This feedback 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 support my daughter who is thinking of becoming a CLAPA volunteer

At the end of the training, volunteers believed they had achieved these aims. Three indicated that they had not learned any more about cleft lip/palate, but did not comment further. It is possible that this was because the focus of the training is on providing support to others, rather than gaining knowledge about CL/P itself.

Volunteers listed a number of reasons for why they had enjoyed the training:

- Meeting the RC, other parents, volunteers and health professionals
- Hearing other people's views and experiences
- Learning about what CLAPA does
- Finding out why other people were here/their backgrounds

Some volunteers commented that the *“going through the policies wasn’t very enjoyable, although I understand why it is compulsory”*. When asked about how training could be improved in the future, volunteers gave the following responses:

- Someone to explain each volunteering role in detail, who has already taken on the role
- Some more guidance on what happens next
- More illustrations/case studies
- Could be a shorter session, maybe 3-4 hours

As a direct result of the training, volunteers reported that they had gained access to a local support network (9/10), felt more confident in their volunteering role (8/10), more able to support others (9/10) and more able to address cleft-related issues in a positive way (9/10). All other responses were neutral, rather than negative.

Most volunteers felt they had gained new and transferrable new skills (8/10), including *“Safeguarding”, “CLAPA aims and ethos”, “awareness and ability to share information about CLAPA”* and *“understanding the barriers people face and awareness of the issues affecting them”*. One volunteer indicated that they had not learned any new or transferrable new skills, but it was unclear as to why this was.

Volunteers left a number of additional comments, including the following:

*“I feel that my confidence will grow once I have participated in my new volunteering role.”*

*“I have really enjoyed today and am looking forward to getting more involved.”*

The RC provided her own reflections on one of these training sessions:

*“Although low in numbers this was a really positive day and we had a really useful discussion about what younger adults and teenagers need who are affected by cleft. There were three suggestions in particular:*

- 1) Volunteers said there is very little information, either from the cleft teams or CLAPA, written directly for teenagers themselves who are facing cleft surgery – i.e. about operations, going into hospital, bullying, etc.*
- 2) They would like some more ‘before and after’ photos from teenagers and adults so they are more reassured about the surgery and how they might look.*
- 3) They would like more opportunities for teenage/young adult meet-ups, get-togethers, a chance to talk to adults affected by cleft without their parents around.”*

Unlike the other two regions, no data from one-to-one training sessions is available yet. It would be interesting to see if there is a need for this in the region and what the impact of this approach to training might be.

#### Feedback from existing volunteers

The RC has attended several meetings of the GOSH Branch, and has been engaged with the Sussex and South London and Surrey Branches. As well as supporting the Branches to organise a range of regional events, the RC has helped to promote the Branches’ activity by attending local events and by raising awareness via social media. Two Branch members commented:

*“Thank you for spreading the word about our branch, it’s great that we have you on board helping us out.”*

*“Thanks so much for all you’re doing, it’s a great help.”*

The GOSH Branch has also been actively planning a number of future events, including the Branch Christmas Party for December 2015. Similar events are also being planned around the region by existing volunteers with the support of the RC.

The RC has also provided one-to-one supervision to a number of existing volunteers, and has met with the new Trustee for the region.

#### Additional activities

The RC has made contact with a number of Health Professionals working in the region, including all three of the cleft teams, and attended a TriCentre audit day, involving cleft clinicians and researchers.

The RC attended a Parent Partnership event in October, and invited several volunteers to attend as well. The RC also attended a Sonographers Day to support a CLAPA volunteer.

### **Outcome 1: Summary (South East Region)**

Despite only being in post for a short while, the RC has delivered a number of training days for volunteers. The RC has also established a good relationship with the Great Ormond Street (GOSH), Sussex, and South London and Surrey Branches, and has made good links with the three cleft teams in the region.

### **Outcome 1: Key recommendations (South East Region)**

- Continue to train new volunteers in the region, including one-to-one sessions if needed
- Engage with all volunteers regularly and incorporate their feedback into service delivery
- Consider the establishment of a new Branch if needed, and continue to monitor the progress of existing Branches
- Continue to develop relationships with the local cleft teams and encourage ongoing collaboration
- Consider ways of increasing Patient and Public Involvement in the region
- Consider encouraging local volunteers to adopt the Clinic Volunteer role
- Continue to attend relevant training and networking events in order to build relationships and links with other organisations

### **Outcome 2 (South East 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 helped to facilitate several events in the South East region aimed at children, young people and families. The RC also contributed to the organisation of a Residential Weekend and delivered a talk to a school assembly of approximately 300 pupils. The RC has also made initial links with adult volunteers in the region.

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

Events included a Sussex Branch Summer Event, a South London and Surrey Branch Family Day, a South East Family Fun Day, two GOSH Branch forums and a Happy Faces Picnic. Although the majority of feedback was provided by parents/guardians and not by the CYPs themselves, extracts which relate to the impact of the events on CYPs is provided below:

*"It was hugely positive for my daughter to interact with other young children also affected by cleft."*

*"It's great for children who have had similar experiences to socialise and have fun together."*

*"My daughter enjoys being part of the [Happy Faces] group and knows that the other children have the same thing as her. Especially with her recent surgery she is able to explain and share experiences."*

*"I think this has helped my children learn about up and coming operations."*

*"Today has been great for my daughter to increase how she feels about herself and her confidence."*

*"My daughter made friends and discussed experiences. She gave our phone number to some other children in order to help them in case they need advice about their alveolar bone graft."*

Two children provided feedback themselves:

*"I really enjoyed today because I got to make new friends that have got cleft lips/palates and have gone through the same thing as me."*

*"It makes me feel not alone."*

Some parents/guardians also commented briefly on the positive impact the events have on unaffected siblings:

*"Although my son affected by cleft is only 18 months old, I feel events run by CLAPA to meet other children with a cleft are good for him, and also for his older brother."*

*"My older son (without a cleft) enjoys the events as it helps him feel included. It also helps him understand his brother better and enables him to talk to his friends about his brother."*

The RC also commented:

*"One family with a four-week-old baby with cleft and two older children arrived [at the South East Family Fun Day]... The new family were very grateful for their introduction to the CLAPA community, to help and support them with their new born baby, but also to support their older children (aged 3 and 7) and to allow them to enjoy some play experiences with other siblings of children with cleft."*

Parents/guardians also provided feedback regarding the impact a Residential Weekend had on their children (aged 9-15 years). Although this event was facilitated by the RC for the Central region, the weekend took place in the South East and is the feedback is therefore presented below.



Parents/guardians gave the following reasons for their children attending the events:

- 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

When asked about which aspects of the event their children most enjoyed, parents/guardians responded:

- The companionship of others with clefts to discuss problems and solutions
- Playing games
- Being with friends and talking
- Chill time

When asked how future events could be improved for their children, parents/guardians responded:

- More challenging activities
- Being able to decide who they share a room with
- Ensure CLAPA staff attending have established a good rapport with attendees

Parents/guardians also left the following comments:

*"I think the weekend has improved my son's confidence."*

*"It is disappointing that our son didn't have the confidence to say he wasn't happy on occasions. However, we feel assured by you that this would not reoccur. On the whole our son had a marvellous time and has benefitted from spending time with other young people with a cleft. In his own words, 'even though I've known my friends at school for a long time, I feel a stronger connection with the CYPC members.'"*

*"My daughter met people who have had the treatment which she will have in the future."*

#### Feedback from adults with CL/P

Two adults born with CL/P provided a case study for this report. Both of these adults are also CLAPA volunteers. Illustrative extracts are provided below:

*"Working with the RC is a good way to progress local activity. The benefits of having an RC are to enhance regional activity and to provide a good link between local volunteers and CLAPA National. To improve the RC could form a strong bond with cleft teams in order to promote CLAPA services."*

*"The benefits of having an RC are being able to link to events and other local people. I don't know yet who the new RC is for my region. It would be good to send updates on what's happening in the region and any changes."*

#### Additional activities

Upon the request of a young person with a cleft, the RC delivered a talk to a school assembly of approximately 300 pupils aged 14-15 years in July, with the aim of raising awareness of CL/P. Little

feedback was available from the pupils or the teachers; however the RC wrote a reflective piece on her experience of delivering the talk. This is provided in the Appendices.

The RC also supported a member of the CYPC to interview a group of cleft clinicians using questions posed by young people with CL/P.

## **Outcome 2: Summary (South East Region)**

Many of the above activities were already planned prior to the RC starting in post; however, it is clear that the RC has made considerable effort to attend and support these events. The activities offered to CYPs have been appreciated by parents/guardians and young people themselves, and appear to have a positive impact on CYPs and their unaffected siblings. According to the RC's own reflection, delivering a talk at a local school and collecting feedback from this event was challenging. The RC had several ideas of how to improve school events in the future, and may also wish to refer to the focus group conducted with CYPs during Year One. Little data was available from adults this year, although the adult volunteers who provided feedback seem to be enthusiastic. It would now be beneficial to collect feedback from adults with CL/P who are beneficiaries of CLAPA's recently re-established services for adults where possible.

## **Outcome 2: Key recommendations (South East region)**

- Continue to host events for children and young people of all ages across the region (and encourage volunteers to do to same)
- Endeavour to host more Residential Weekends in the region.
- Consider how to best to engage with local schools and to evaluate the impact of this work stream.
- Engage further with the CYP and Adult Voices Councils, including joint meetings where appropriate.
- Continue to develop links with cleft teams and other organisations.
- Encourage the development of activities for adults born with cleft across the region.
- Additional data for the evaluation from CYPs and adult beneficiaries would be valuable.

## **Outcome 3 (South East 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**

As mentioned above in Outcome 2, several events aimed at families were held across the South East region during Year Three. Feedback collected in regard to the impact of these events on parents/guardians is provided below.

### Feedback from parents/guardians

Parents/guardians gave the following reasons for attending an event:

- To meet others affected by cleft
- To meet health professionals
- To learn more about cleft lip and palate
- To learn more about the support CLAPA offers
- To offer help and advice to others affected by cleft

Overall, parents/guardians indicated they had achieved these aims and had particularly enjoyed the following aspects of the events:

- Sharing experiences with parents who have dealt with similar challenges
- Raising money for CLAPA
- Enjoyed seeing people we see regularly at events and catching up, and seeing how the children are progressing
- Meeting CLAPA volunteers and being inspired to do more
- Watching my children enjoying the activities
- Informal and relaxed environment
- Opportunity for Q&A sessions with Health Professionals and teenagers with cleft
- Being able to talk to parents with children a little further on in the treatment process and feeling reassured about the future
- The friendliness of everyone, very welcoming to a newcomer

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

- More advertising
- A donation tin
- Leaflets to hand out on the day
- More tickets for family members
- It would be good to highlight PRS issues more
- Some of the presentations were great for kids but less informative for the parents
- Perhaps we could exchange parent emails
- It would be great to find a way of contacting other grandparents

As a result of the events, parents/guardians commented on how the event had impacted them, indicating that they had access to a local support network (33/35), were more able to support others affected by cleft (29/35), were more able to cope with cleft-related issues in a positive way (29/35) and that they would attend a similar event in the future (35/35). All other responses were neutral, rather than negative, with some parents/guardians suggesting that they already had access to a local support network and cleft-related information, and felt able to support others, prior to the event.

Additional comments from all of the parents/guardians included the following:

*"I travelled from Maidstone as I believe there is no Branch in this area. It would be lovely if there was but I have met lovely people and had a great time at this event run by the Sussex Branch."*

*"The support and the Branches are a huge lifeline to us as a family."*

*"This was brilliantly organised and delivered."*

Parents/guardians also indicated that they had heard about the events through a variety of sources, including the RC, the regional Facebook pages, the CLAPA website, the national CLAPA e-newsletter, via a CLAPA volunteer and at previous events.

There are active Parent Contacts in the region, although little data was available for the evaluation.

### **Outcome 3: Summary (South East Region)**

A high number of events were held across the region during Year Three. The majority were well attended and all were highly praised by parents/guardians who provided feedback. Going forward in to Year Four, an expansion of regional activity in line with that now provided in the East and Central regions is recommended. This could include the establishment of additional Happy Faces groups where needed, as well as further online activity, including the development of regional Facebook pages and a regional e-newsletter. Additional evidence of how the Parent Contacts service is used and rated by beneficiaries would be useful.

### **Outcome 3: Key recommendations (South East Region)**

- Continue to host events across the region (and encourage volunteers to do to same).
- Continue to raise the profile of events such as these in order to attract more families and share stories with the local media.
- Consider the addition of new Happy Faces groups where needed, and continue to monitor the progress of existing groups.
- Aim to develop relationships with existing Parent Contacts and to collect data on the activities they carry out.
- Develop the regional Facebook pages and e-newsletter.

### **Follow-up from the South East region focus groups**

At the beginning of this year, CAR carried out three focus groups in the South East region (Oxford, central London and Kent) to explore gaps in support and to find out what regional services may be needed. A focus group report is attached to the End of Year Three report.

The focus group findings provided recommendations for the RC's activities for the project going forward. Specifically, recommendations were made in relation to four key areas. The progress made towards these recommendations during the year is outlined below.

#### **Barriers to accessing and sustaining support**

Some of the main barriers identified in the focus groups were locality/attendance, information sharing and funding. The RC has been working alongside volunteers and cleft teams to identify particularly isolated areas, and to discuss ways of tackling non-attendance and reaching patients and their families via regional online support and through the establishment of new Happy Faces groups. The RC has attended all regional events where possible, in order to actively promote her role and the support which CLAPA can

offer. The RC has also been promoting the use of the CLAPA Regional Fund to assist volunteers and cleft teams in setting up groups, running events and providing resources. One other barrier identified in the focus groups was that of access to CLAPA services for BME communities. The RC has been in discussion with the GOSH cleft team in relation to translating some of CLAPA's materials into relevant languages, and has spoken to BME volunteers about the various cultural issues which may impact how support is accessed and utilised.

#### Diversity of support

One of the key points identified in this theme was the relative lack of support for adolescents and adults. It is clear from this evaluation report that the majority of activities are currently aimed at younger children. Nonetheless, the RC has made contact with the AVC and a number of other adult volunteers about how to work together to develop the services for adults and young people, and to encourage more young people and adults to volunteer. The focus groups also identified a need for support to be matched to an individual's needs, giving the example of a 'specialised' Parent Contact with experience of Pierre Robin Sequence. The RC has noted that Parent Contacts service is not currently being used very much, and is therefore planning a development day to discuss ways of further utilising Parent Contacts' skills.

#### Availability and quality of information

The perceived gaps in information provision identified in the focus groups stemmed predominantly from, and could be overcome by improvements on, the CLAPA website. Funding to redesign the website was given earlier in the year and the new website will be unveiled at the CLAPA conference in November. Additional information provision, including an FAQ document for Parent Contacts and an information sheet for parents taking their child into surgery, have been designed in collaboration with volunteers and Health Professionals. Additional information, including a leaflet about Peer Contact services for adults with CL/P, is currently being designed. In addition, the RC has ensured that patients' information needs are represented at a patient engagement forum at Guy's and St Thomas' Hospital. The RC has also supported volunteers to give presentations to non-specialist Health Professionals, such as midwives and health visitors, to raise awareness of CL/P and CLAPA amongst these groups.

#### Coordination of local care

As indicated in the focus groups, there is a clear need for an RC role to provide a level of support that the NHS cleft teams are less able to offer, and therefore relationships with cleft teams are essential in order to provide a comprehensive level of care. It is clear from this evaluation report that the RC has made progress toward building links with cleft teams and other relevant organisations. In addition, the RC has compiled an event calendar to avoid any event clashes and to ensure her attendance at all events where possible. Events will be advertised widely, including at NHS cleft clinics.

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

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

The RCs have contributed to the preparation for the annual CLAPA conference, which will be held in London in November 2015. The theme for this year's conference is "My Cleft, My Voice!" with a focus on patient empowerment. 90 delegates (including parents, adults with cleft, health professionals, researchers, friends/family members and under 18s) are expected to attend on the day, with a further 250 people expected to watch the conference via a live online stream. Feedback from the conference will be collected on the day. The RCs have also contributed to the preparation for the National Branch Day, which will be held the day after the conference.

All RCs have contributed to this year's CLAPA Volunteers Awards ceremony, which is due to be held as part of the National Volunteer Day in November 2015. Awards will be handed out to key volunteers, as well as runners-up. Awards include:

- '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/>.

CLAPA have also been active in following up on the recommendations made in the Siblings Report, which was submitted alongside the main End of Year Two report. In particular, they have been in touch with another organisation based at the Serennu Children's Centre in Wales, which aims to support those affected by health conditions *"in a holistic and family-centred way, thereby offering health and social activities for the family as a whole, rather than just the needs of the disabled child."* The organisation runs a younger sibling group and an older sibling group, and has offered a range of information which will be useful to CLAPA moving forward.

The RCs also offer support to one another, meeting regularly to discuss the project as a whole, and to share achievements and challenges. The RCs will occasionally facilitate/help to facilitate an event in a region which is not their own in order to learn from one another, and to ensure the events go ahead and are delivered to a high standard.

All RCs have played a role in securing matched funding to support the continuation and expansion of the RC Project as a whole.

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 former member of the CYP Council and a member of the Adult Voices Council), members of two of the local cleft teams and representatives from two related charities (ChildLine and Transplant Sport). The group met in February 2015 to discuss the progress of the project and its evaluation.

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

This evaluation report has outlined the considerable progress made in all three regions toward the three main outcomes of the RC Project. The East of England role continues to develop, while activity in the Central region has increased significantly. The South East region already had some existing activity, but the RC has clearly engaged with as many stakeholders as possible and attended a wide range of events.

The RC project continues to grow in strength and numbers, delivering a local service which many families, individuals and Health Professionals value highly. A number of specific recommendations have been set; although recommendations given throughout this report are region-specific and based on the evidence collected, most recommendations apply to all of the RCs. Therefore, RCs are reminded to address the overall aims of the project, as well as the more specific suggestions laid out in this report.

In some areas, data collection for the evaluation remains a challenging process. CAR meets with the RCs and CLAPA's Director of Development regularly, in order to collaboratively tackle these inherent difficulties. CAR will continue to do so into the final year of this current funding stream, with a particular focus on collecting a higher quantity and quality of data and using more creative methods of data collection. CAR will also meet with the RCs at the beginning of Year Four, in order to formulate a plan for maximising the opportunities for data collection during the final year.

## Appendix 1: Clinic Volunteer case study (Central region)

Volunteers Service

Birmingham Children's Hospital  
NHS Foundation Trust



### Volunteer Story – Kathy Parker

I was introduced to volunteering at Birmingham Children's Hospital through the Cleft Lip and Palate Association (CLAPA), and I have volunteered in the cleft clinic for six months. My role involves explaining to patients and parents what CLAPA is and how it can support them.



When I first started I found it quite difficult to approach people and speak to them as I'm not a very confident person, although after a few weeks I felt more confident in what I was doing. The staff in clinic are lovely and supportive and helped me feel part of the team.

I am trying to encourage people to join our CLAPA West Midlands Branch so that they can find out what is happening in the local area, and I also help advertise any events that the Cleft team is organizing.

I chat with parents about their experience, most parents seem very happy how their child is developing, and some ask how they can fundraise for CLAPA to thank them and raise awareness of the condition. I have even spoken to a couple of people about how they can volunteer too.

Overall my experience has been very beneficial to me as a volunteer as it has helped me become more confident with having a cleft lip and palate around others. Clinics are sometimes quiet but then I meet a mom, dad or child who really wants to know all about CLAPA and wants to share their experience with me and then it feels so worthwhile being there to help 😊





## Appendix 2: Summary of flipchart feedback collected at CYPC meeting (facilitated by Central RC)

### Comments gathered from CYPC Meeting 27<sup>th</sup> June 2015.

#### **1. They feel less isolated**

- *"Don't feel isolated anymore as I can ask other people who know the answer"*
- *"This has changed my life because it's made me not be afraid of anything."*
- *"It provides an outlet for me to talk about cleft related problems & other problems in general. I've met great friends."*
- *"Seeing other people like me. Being able to talk about experiences. Sharing with other people"*
- *"Allowed me to meet new people"*
- *"Being in CYPC make me feel like I am not the only person with a cleft lip and palate and can share your problems with people who have gone through the same things"*
- *"I feel more confident about myself"*
- *"I feel better!"*
- *"I feel more confident"*

#### **2. They feel as though they have helped someone else**

- *"At the very beginning when I joined CYPC I was a bit nervous about saying and sharing my views but I have been in CYPC for about year and I fully contribute and feel a lot more confident about saying what I feel and think and therefore being able to support others in their feelings"*
- *These meeting have increased my ability to share experiences & support others by letting me meet the most wonderful people who also have clefts & giving me an outlet to express my feelings about clefts"*
- *"Being able to share our experiences together and not being scared"*
- *"A way to share my thoughts"*
- *"Tell people more about this charity"*
- *"A way for people to listen to my questions"*
- *A way to voice opinions"*

#### **3. They have a sense of relief – a cathartic experience (Improved Self Esteem)**

- *"Coming to CYPC has helped me become proud of having a cleft lip and palate. This is because others at CYPC have helped me to get to this feeling"*
- *"Be proud of having a cleft"*
- *"Feeling more confident around people"*
- *"Made me more confident"*
- *"I feel more confident with talking about my cleft lip"*
- *"I feel more confident with answering questions"*
- *"I don't feel alone anymore – There are people like me"*
- *"More exposure to people like me"*
- *Become more involved with our condition. More confident in the acceptance of my speech. Learn different coping methods"*
- *"I've met people with clefts who are so confident in their skin it inspires me to be like them 😊"*

## Appendix 3: Articles in the local press (Central region)

### Easter fun day for families affected by facial impairment



Event organiser Selena Foster's daughter Lorena (pictured) was born with a cleft lip and palate.

First published Wednesday 25 March 2015 in [News](#)

Last updated 16:48 Wednesday 25 March 2015 by [Liz Sharpe](#), Reporter

FAMILIES affected by cleft lip and/or palate are being invited to attend an Easter fun day at the Redi Centre in Redditch.

The event has been put on by Redditch Borough Council and is supported by the Cleft Lip and Palate Association (CLAPA).

On Saturday, March 28 between 1.30 and 3.30pm a range of activities will be taking place including an Easter egg hunt, face painting and a bouncy castle.

Local CLAPA volunteer Selena Foster, who has organised the event and set up the local support group Redditch Happy Faces after her daughter was born with a cleft lip and palate, said: "When Lorena was born we had so many questions and I really wanted to meet with other parents in a similar situation.

"I am delighted to have organised the fun day which will provide an opportunity for families affected by cleft of all ages in Redditch and surrounding areas to get together.

"I'm really excited that Redditch Borough Council have so generously donated the funds to make it happen."

For more information visit [www.clapa.com](http://www.clapa.com).

# Sponsored walk to raise vital cash for charity



Baby Lorena, diagnosed with a cleft lip and palate.  
Lorena now, after a number of surgeries and hospital appointments

Ben Russell / Thursday 14 May 2015 / News

Thursday 14 May 2015

WHEN baby Lorena was diagnosed with a cleft lip and palate, her parents were launched into a world of surgeries and hospital appointments.

Two years on and hoping to raise vital money and awareness a sponsored walk is being held.

The event, organised by Selena Foster who lives in Redditch and whose daughter Lorena was born with a cleft lip and palate in October 2012, takes place in Arrow Valley Country Park and is raising cash for the Cleft Lip and Palate Association (CLAPA).

The charity supports people affected by cleft lip and palate, a condition that affects one in every 700 babies worldwide.

Mum Selena said: "CLAPA has been an invaluable service for us since Lorena's diagnosis at our 20 week scan to the present day.

"The information is accurate and up to date and the Facebook support group has led me to meet many other families affected by cleft, which has helped with the many questions I had. I was never judged and was welcomed with open arms."

She added: "I wanted to give something back to the charity that had helped us so much so I started volunteering for CLAPA about a year ago. Following a really successful sponsored walk last year I am hoping to see as many families, if not more at this year's sponsored walk."

The event, where people are being encouraged to come dressed as their favourite book character, will take place in Arrow Valley Country Park on May 24 at 11am.

It is part of CLAPA's annual awareness week, held last week.

For more information on the walk, visit [clapa.com](http://clapa.com).

## Appendix 4: Example of the e-newsletter (Central region)



### CLAPA West Midlands Branch is launched!



The West Midlands Branch was launched at a party at the MAC, in Cannon Hill Park, Birmingham on Saturday 29th August. Over fifty people enjoyed a variety of activities on the day and lots are looking forward to supporting more Branch events in the future!

A Branch member told us 'It was a fantastic day with lots of new faces and lots of regulars from all backgrounds mixing with each other. Very positive start to the branch which is only going to grow with lots more events for all ages.'

One mum shared what her son told her about the party 'He looks forward to your events

because he meets other kids like him and can just be himself'

***A huge thank you to the Committee members for organising such a great event and thank you to all families who came out to support. Watch this space for more events happening soon!***

For more information contact the Branch on [clapawestmids@yahoo.com](mailto:clapawestmids@yahoo.com)

## Patient Voices

Are you passionate about healthcare for people affected by cleft?

Want the opportunity to express your views?

Want to make positive changes in your local cleft service?

This group have met once so far and it brings together a range of people of all ages who can use their experiences of cleft services to highlight good practice and suggest improvement.

There are going to be lots of opportunities to work on projects alongside the cleft team and we would welcome more members to the group who would like to get involved. Please email [claire.evans@clapa.com](mailto:claire.evans@clapa.com) if you would like to know more!

## Birthday Party in the Park!



Come along to a great big party celebrating 15 years of the West Midlands Cleft Lip and Palate Service!

Featuring bouncy castles, music and bands, magicians, face painting, games and more, this is an event not to be missed!

Date: Sunday 20th September

Time: 12-4pm

Location: Town Gate, Sutton Park, B74 2YT

You are welcome to bring your own picnic to enjoy in the park. Some refreshments will be provided.

Get your free tickets by emailing [cleft.services@bch.nhs.uk](mailto:cleft.services@bch.nhs.uk) or call on 0121 333 8235!

Tickets are required for entry, so make sure you get yours before Sunday 13th September.



## Big Smiles

Bringing together local families of children born with a cleft lip and/or palate in the area served by the Trent Cleft Lip and Palate Service.

Big Smiles is an independant charity ran by Rachel and Ian Smith (who also happen to be brilliant CLAPA volunteers!). The group meets monthly and also once every quarter on a weekend too.

The groups are a great support network for families in the area. For more details check out [www.big-smiles.co.uk](http://www.big-smiles.co.uk) or contact Rachel and Ian on [info@big-smiles.co.uk](mailto:info@big-smiles.co.uk).

## Residential weekend for 9-15 year olds!

A FREE weekend getaway for 9-15 year olds in Central England who were born with a cleft lip and/or palate.

It's all about having fun, becoming more confident and meeting others like you in a safe and supportive environment.

WHERE: The Kingswood Centre,  
Staffordshire, WV7 3AW

WHEN: 16th -18th October 2015

Places are limited and need to be booked by **Friday 18th September**. For more information or to book a place contact Claire Evans on 07792 772362 or email [claire.evans@clapa.com](mailto:claire.evans@clapa.com)

## New volunteers for the region!

A huge CLAPA welcome and THANK YOU to all of the new volunteers who have joined this Summer and who will be fundraising, attending Branch meetings and helping at residential weekends...we couldn't do it without you.

Welcome to the team :)

## Interested in volunteering??

We particularly need more volunteers doing brilliant work for us in the East Midlands. If you live in the Lincolnshire, Leicestershire and North Yorkshire area and would like to get involved in our work, we would love to hear from you!

Get in touch with Claire at [claire.evans@clapa.com](mailto:claire.evans@clapa.com) or 07792 772362.

## **Appendix 5: RC reflection on delivering a school assembly (South East region)**

### Cherry LeRoy -CLAPA Regional Coordinator South East

I was asked to attend a school assembly of approximately 300 pupils aged 14 & 15 on 2.7.15. The request came from a young person, who was a pupil at the school and had previously completed a sponsored piano recital to raise money for CLAPA. The purpose of the assembly was to raise awareness about cleft lip and palate.

I had only been in post for 4 weeks, so had background knowledge, but needed notes to prompt me to ensure I delivered the right message and covered the key points. The presentation was by power point, with the idea being to ask questions of the young people and to have a quiz at the end. The assembly was in a large sports hall with poor acoustics and the young people seated on the floor, with teaching staff around the outside. Therefore there was no opportunity to gather feedback from the young people, who had no bags with them and logistically would have taken too long.

I had hoped that I could evaluate their understanding of the presentation by the feedback from the quiz at the end, but only one person answered one of the 8 questions, so this didn't work at all.

Originally I had been told I had 20 minutes, but this was cut down to 15 due to the head of year needing to give a speech at the beginning of my session.

What went well was that they all listened, although I was unable to assess their understanding and the impact of the session.

I also gained positive feedback from the teacher that showed me out, so feel that if the presentation had given the teaching staff a better understanding of Cleft Lip and Palate and the effect, physically, emotionally and practically for young people then it had been worthwhile.

The challenges were the environment, lack of interaction from the young people, not enough time for the session, no feedback. The head of year had said he would follow up the session with form groups, but I have not received any feedback.

If I were asked to deliver such a session again. I would have a telephone conversation with the person who asked for the presentation to ascertain their involvement with the school. (To begin with I was unsure whether the person was a teacher or pupil and didn't know whether she had a cleft). If it was a pupil I would ask to contact the teacher and arrange to do a workshop type event, with a smaller group of pupils in an interactive session. I would also arrange to build some sort of evaluation into this, probably to gather at the time as asking for feedback retrospectively from any event has proved very difficult.

